A Study of the Relationships between Perceived Pain, Social Support, Coping and Quality of Life in Patients with Advanced Cancer

by

Shelagh Wright, BA (Mod), RGN, RM.

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Director of Research: Professor Martin McHugh
Supervisor: Mr. James McLoone

The Department of Psychology,
National University of Ireland,
Galway.

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ABSTRACT

The aim of the study was to assess the implications of perceived pain and social support for coping ability, levels of distress and quality of life in a group of patients with advanced cancer. A total of 98 patients who were undergoing palliative treatment and/or care and were aware of their cancer diagnosis, but not necessarily of their prognosis, consented verbally to participate. A questionnaire was administered to each participant comprised of scales to measure perceived pain intensity and to evaluate overall pain experience, to measure perceived and actual support given by each participant's family, friends and health care professionals and to measure participants' present coping attitudes and their perceived loss. Measures of anxiety, depression and quality of life were also included. A qualitative aspect to the study was included which asked participants which type of support they most appreciated and to describe what changes having cancer had made to their lives.

Although perceived pain was significantly and positively associated with received and perceived support from health care professionals and tangible support from the family, results showed significant negative associations between the perception of pain and perceived appropriate social support from family and friends. Results also showed a deficit in perceived support from health care professionals for older participants. Overall evaluated pain experience was significantly and positively associated with items measuring psychological distress, loss and helplessness/hopelessness and was significantly and negatively associated with fighting spirit. Perceived satisfactory support given by family and health care professionals was significantly and negatively associated with overall perceived loss as well as with 'negative' coping attitudes. Perceived satisfactory family support was also significantly and positively associated with fighting spirit. These results and their implications are discussed.

FOREWORD

The idea for the research project being reported here was prompted in the early 1990s by my personal experience of the benefits of Autogenic Training (AT) which led me to consider how the technique, widely available to patients in Europe and the US (e.g. Linden 1990; Sloman, 1995), could help Irish people with cancer. The cognitive-behavioural technique of AT consists of learning a series of simple mental exercises designed to turn off the stressful 'fight-flight' mechanism in the body and turn on the restorative rhythms associated with profound psychophysical relaxation. Developed by Schultz, a German neuropsychologist, in the 1920s, the method was perfected and expanded by Luthe in Canada in the 1950s, where it was used extensively by stress expert, Hans Selye, before being brought to Britain by Carruthers and Diamond. In general, the physiological and psychophysiological oriented effects of AT may be considered as being diametrically opposed to changes elicited by stress (Luthe & Schultz, 1969). AT has been shown to be effective with prevention and control of stress (e.g. Carruthers, 1979). AT may also help to increase self control and self-efficacy (Rosenbaum, 1993) and to enhance drug-based methods of anxiety and pain control for patients with cancer (Sloman, 1995). AT has also been shown to be effective in reducing anticipatory nausea and anxiety in cancer patients receiving chemotherapy (Palekar, 1995).

People with cancer pain and related emotional distress may be able to increase their coping ability and sense of control through the use of relaxation and imagery techniques (Sloman 1995; Golden, Gersh & Robbins, 1992). These techniques, which people can initiate for themselves, help to reduce feelings of helplessness and hopelessness and provide a calming diversion from the experience of pain and emotional reactions associated with the diagnosis of cancer. In this way the pain-anxiety-tension cycle is broken, thereby facilitating pain relief through a calming effect. The techniques can be taught by nurses and readily learned by patients and provide a self-care strategy, in line with Orem's nursing theory, that, to a limited extent, shifts the locus of control from clinician to patient (Sloman, 1995).

It became necessary to think of developing back-up services in Ireland before implementing an AT programme for people with cancer, as people who go through such a programme are likely to experience an increased sense of self-efficacy (Bandura, 1992) and may therefore seek to implement their needs more effectively across all spheres of life, including requesting optimal health care services. More pro-active consultation and information-seeking behaviours on the part of patients would require an increased provision of specialist care. These issues relate not only to improved patient care and quality of life but also to patient expectation, satisfaction and compliance (Ley & Llewelyn, 1995). Therefore, it became important to understand where, within their social networks, patients with cancer might perceive support deficits and what could be done to implement a care programme that might help to offset any negative support experiences.

Macmillan nursing posts were first developed in Britain in the 1970s with the aim of improving care for people dying with cancer and their families, thereby enhancing the quality of their lives. Their role is primarily that of clinical nurse specialist and today they contribute to improving the quality of life for people with cancer and their families from the time of diagnosis, or before, through treatment to when the disease is no longer responsive to treatment. Clinical nurse specialists are described as having several components to their role, namely clinical practice, consultancy, teaching, research and leadership (Ryan-Merritt, Mitchell & Pagel, 1988). The Macmillan nurse has a role in empowering and enabling professionals to deliver high quality care to patients and families and also in helping patients and families to achieve the best possible quality of life while living with cancer (Bullen, 1997). To find out whether an emotional and information support intervention, similar to that offered by the Macmillan nurse service in Britain (Bullen, 1997), might be a useful back-up facility within the health service in Ireland for patients from the time they are diagnosed with cancer, a research project was devised to look at the way in which people with advanced cancer consider they are supported by others and to discover what elements of the experience of support of people with advanced cancer might impact negatively or positively upon their quality of life.

The onset of cancer. A normal tissue develops to a point when cell proliferation is balanced by cell loss and the tissue remains static in size, unless subjected to a changing environment, for example the normal breast ductular tissue during the menstrual cycle or in pregnancy. In cancer, the regulatory mechanisms appear to be defective and the tumour gradually increases in size (Souhami & Tobias, 1998). Cancer is believed to arise when one of 5 x 10^{13} cells in the human body escapes normal growth control mechanisms, (although these are not well understood), with division occurring even when it is not necessary to replace dead cells (Barr, Cowan & Nicolson, 1997; Souhami & Tobias, 1998). Most tumours are much larger than the initially detectable size 10^{9} (1g) when they are diagnosed and there may have been spread of the primary tumour to produce metastatic (secondary) lesions in the body. The rapid division of cells may produce varying types of cells, some of which may demonstrate different capacities for survival. However, sustained tumour growth is not necessarily rapid (Barr, Cowan & Nicolson, 1997; Souhami & Tobias, 1998). Some cells may thrive in a relatively hypoxic environment while others may have varying sensitivities to a particular chemotherapeutic agent. Tumour cells may be lost by exfoliation, especially common in gastro-intestinal tumours or by outgrowing their blood supply, rendering the centre of the tumour necrotic and non-viable (Barr, Cowan & Nicolson, 1997; Souhami & Tobias, 1998). Some tumour cells will be fatally flawed because of a genetic defect and will die. Others may travel via the lymphatic or blood vessels and implant elsewhere, resulting in metastatic disease if the secondary tumour can stimulate synthesis of its own blood system (Barr, Cowan & Nicolson, 1997). A few cancers tend to predominate, with lung, prostate, colorectal, breast and stomach cancers accounting for a substantial proportion of the cases diagnosed each year.

The best estimate of prognosis is offered by staging the extent of a patient's disease. For many tumours a useful staging notation is the TNM system developed by the American Joint Committee on Cancer Staging and End Result Reporting which utilises the prognostic relevance of the size or local invasiveness of the primary tumour (T), lymph node spread (N) and the presence of distant metastases (M) (Sobin & Wittekind, 1997). The system is widely accepted for staging most solid tumours but is less practical for tumours that are generalised. For many gynecological tumours the FIGO system (International Federation of Gynaecology and Obstetrics) is often preferred (Souhami & Tobias, 1998). In some cancers the size of the tumour relates to prognosis, such as in tumours of the head and neck, whereas, in other tumours, depth of invasion, such as in melanoma, colon and bladder cancer, is of greater prognostic significance. Nodal involvement is probably the most important determinant of survival in many solid tumours and, with very few exceptions (notably testicular tumours), distant metastatic disease has considerable implications for prognosis (Souhami & Tobias, 1998). The term 'advanced cancer' generally refers to cancer tumours that have spread outside their area of local origin. Over the past 30 years there has been little change in the 5-year survival rate for some common cancers, especially lung and pancreatic cancer. While improvements have been made in the surgical and radiotherapeutic control of the primary tumour during this period, failure to improve survival is due to the fact that the major cause of death is lymphatic and blood-borne metastasis (Souhami & Tobias, 1998).

Palliative care is an active approach to the care of those whose disease is not responsive to curative treatment; that care should encompass physical, psychological, social and spiritual problems (Sheldon, 1997). Major disease such as cancer brings worry and dread. Cancer is most common in the elderly (Yancik & Ries, 1994) and many elderly patients will have had friends or relatives who have been ill with or who have died of the disease. These experiences will have an important influence on a patient's outlook and experience (Souhami & Tobias, 1998). Until recently, it was widely believed that since emotional distress was an understandable and perhaps inevitable reaction to the diagnosis of cancer, psychological intervention was not feasible. However, in an increasing number of oncology centres health care professionals across a spectrum of disciplines are contributing directly to the care of patients and their families (Greer, 1991).

Incidence of cancer in Ireland. Cancer poses major challenges for the health services in Ireland and ranks second only to cardiovascular disease as the most common cause of death. Furthermore, cancer is a cause of premature death. As a result, cancer presents a formidable physical, psychological and socio-economic burden on patients, their families and on health providers. In Ireland the National Cancer Registry recorded 19,833 cancer cases as incident in 1995. The overall risk of developing cancer before age 75 was 37%, a little more than one in three for the entire population: 39% for men and 35% for women. In the same period, the mortality rate was roughly 2 per 1,000 persons per year and was 20% higher for men than for women. The risk of dying of cancer before age 75 was 17% for men, 13% for women and 15% for both sexes combined. By far the most common site of cancer recorded by the National Cancer Registry (NCR) was skin (excluding melanoma). Colorectal (large bowel) cancers, comprising cancers of the colon, rectosigmoid, rectum and anus were the second most common category for both sexes combined, female breast cancer numbers being almost twice those of colorectal cancer. Prostate cancer was slightly more common than colorectal cancer in men. The five sites mentioned: skin, colorectal, breast, cervix and prostate, accounted for more than two-thirds of all the cancers registered. In the same period, the largest number of cases for both women and men, with or without the inclusion of non-malignant skin cancers, was in the 70-74 year age group. Patients over 65 accounted for more than half of the cases in men and slightly less than half of the cases in women (National Cancer Registry, 1998).

The largest number of cancers (6,089) in 1995 was diagnosed in residents of Co. Dublin. However, when allowance was made for population size, the highest crude incidence rate was found in Co. Leitrim (696 cases per 100,000 persons). The highest rate for men alone was also in Leitrim (741 cases per 100,000 population) but the highest rate for women was in Co. Kerry (652 cases per 100,000). However, as the incidence of cancer is age-dependent, the high rates in these counties may be due to a more elderly age profile. If the incidence rates are corrected for the different age structures of populations, a quite different pattern of cancer incidence emerges. In 1995, corrected incidence rates were significantly above average for both sexes in Dublin. Other areas with a significantly above average incidence for both sexes were Cork and Louth. According to the National Cancer Registry, the rates of cancer incidence in Dublin and Cork remain significantly above those expected, while those in Clare, Galway, Kilkenny, Mayo, Offaly and Roscommon are significantly lower than expected for both men and women (National Cancer Registry, 1998).

Breast cancer was the commonest cancer in women after non-melanoma skin cancer. One in every six cancers in women was a breast cancer. The risk to a woman of developing breast cancer before age 75 was 7.3% and the risk of dying of breast cancer before age 75 was 2.8%. The largest number of cases (215, 14% of the total) was in women aged 50-54. The age-specific incidence rate peaked at age 55-59 and rose again after 70 to a second maximum in the oldest age group. One third of cases was in the age group 50-64. Deaths from colorectal cancer were second only to those from lung cancer; 9% of all cancer cases and 13% of deaths were due to colorectal cancer. The overall incidence of colorectal cancer was higher in men than in women. The median age at diagnosis of colorectal cancer was 70 for women and 69 for men. The largest number of female cases was in the 75-79 year age group and the largest number of male cases in the 70-74 year age group. The age-specific incidence rate was highest for men and women from age 85 years. Lung cancer was the third most frequent cancer in men and the fifth most common in women (excluding skin cancer). The median age of male cases was 69 years and of female cases 71 years. The largest number of male cases was in the 65-69 year age group and the largest number of female cases in the 70-74 year olds. The age specific incidence rate for men was highest in those aged 80-84, while for women the highest rate was in patients aged 75-79. Male incidence was low by European standards. Ireland had the third lowest incidence of the twenty three countries studied. However, female incidence was third highest in Europe, lower only than that in Denmark and the United Kingdom (NCR, 1998).

INTRODUCTION

Psychological reactions to the diagnosis of cancer

The impact on quality of life. Like everyone, people with cancer worry about their health, self-appraisal, work and finances, family and significant relationships, religion, friends and associates and existential concerns. However, people with cancer also have to tolerate the uncertainty that the illness of cancer imposes on them (Weisman, 1979). The experience of cancer frequently imposes limitations on self sufficiency and the effects of cancer on the family and on family relationships can have psychological repercussions for the person with cancer. Cancer also alters the dynamics of relationships between friends (Weisman, 1979).

It is likely that, in addition to the loss of self esteem already incurred as a result of the diagnosis and advancement of the disease, along with the activity restriction and reduced social contact cancer is known to impose, the person with cancer is further threatened with more possible perceived loss due to changes in the dynamics of the relationships with family and friends. The perception of loss is incurred through loss of intimacy and happiness, loneliness, isolation, hopelessness, fear and dissatisfaction, all of which further reduce the quality of life of the person with cancer, with implications for anxiety and depression levels, which may impact on pain perception (Mermelstein & Lesko, 1992; Barraclough, 1994). Thus, changes in family and social relationships may have very serious implications for patients with advanced cancer, who are likely to experience an increase in a number of negative events: more pain, activity restriction, financial burden, social isolation and family strain.

Half of all cancers are curable, and, as treatments improve, cancer is considered more as a chronic rather than a terminal illness (Spiegel, 1993). Psychosocial support may have an influence on the rate of disease progression, because patients who feel less isolated, frightened and depressed may eat, sleep and exercise better than those with similar disease who feel demoralised and unsupported. Also, patients who perceive their psychosocial support as adequate may be more assertive in getting their doctors to detect disease progression earlier and to respond to it more quickly. They may comply better with treatments administered and possibly elicit more vigorous intervention from their doctors because they feel more like partners and more in control of their health care (Spiegel, 1993).

The experience of cancer pain

Pain is present in some 70% of cancer patients. In advanced cancer, pain is moderate or severe in 40-50% of patients and very severe or excruciating in 25-30% of patients. When translated into global terms, the problem is one of massive proportions (World Health Organisation [WHO], 1990): (a) in developed countries, 25% of the population dies from cancer; (b) everyday, at least 4 million people globally are suffering from cancer pain and (c) many of these do not obtain adequate relief (Twycross, 1994). In the United States, the under-treatment of pain constitutes a serious public health problem (Breitbart, 1994). The 'new public health' integrates primary prevention (life style and environmental changes to prevent disease), secondary prevention (detection of early signs of disease and action to contain problems at this stage) and tertiary prevention (action to treat existing disorder and limit handicap where disorders are chronic) (Richards, 1996; Ashton & Seymour, 1988). Reasons for the continued poor management of cancer include inadequate knowledge about its pathogenesis and the under-treatment of cancer pain (WHO, 1990). Cancer pain syndromes have characteristic clinical features by virtue of their invasion of contiguous structures and by the pathophysiological complications of that tissue invasion. The invasion of the contiguous structures produces specific signs and symptoms that may compound the original pain problem. For example, many of the symptoms associated with cancer, including anorexia, dyspnoea, constipation, vomiting and xerostomia, may aggravate pain. Mood and morale may have a circular effect on the intensity of symptoms. In a study of 30 outpatients at a cancer centre, patients and physicians acknowledged an appreciable influence of emotional state on pain and a somewhat greater influence of pain on emotional state. Thus, all aspects of discomfort and distress need to be considered if pain is to be relieved (Peteet, Tay, Choen, & MacIntyre, 1986).

The etiology and treatment of pain. In general, pain related to cancer is caused by a tumour pressing on or invading contiguous structures such as a nerve, or the membrane covering a bone or the liver or some other organ. A tumour can irritate a nearby nerve in the same way as an inflamed disc ('slipped disc') in the back can irritate the sciatic nerve and result in sciatica. Pain caused by irritation of a nerve may be perceived as coming from the area that the nerve is responsible for, just as the pain from a slipped disc may be felt as if it had started in the back of the thigh. In the same way a tumour in the vertebral spine may cause pain that apparently begins in the thigh, a tumour in the upper back may cause pain that feels as if it is coming from the chest, and a tumour in the diaphragm may cause shoulder pain. A tumour might cause pain by stretching the covering of a bone or by inducing a bone fracture. The same situation applies to a tumour stretching the covering of the liver or the brain (Buckman, 1996).

Pain perception and thresholds vary between individuals and with varying physical factors such as heat or cold and may be modulated by the patient's emotional state. Many people have experienced trauma while playing sport which they hardly noticed at the time. The same degree of trauma when sad or not pleasurably distracted would have been extremely painful. The gate control theory of pain (GCT) (Melzack & Wall, 1965) attempts to explain this. Neural mechanisms in the spinal cord act like a gate opening or closing, influencing the level of pain impulse which is transmitted to the brain. This effect occurs at the synapses between the peripheral and ascending nerves in the spinal cord. The ascending nerve fibres then cross the cord to join the contralateral tract carrying the pain sensation to the brain. The perception of pain within the synapses in the spinal cord is thought to be modified by inhibitory and excitatory impulses influenced from higher centres (e.g. Sofaer, 1998; Adams, 1997; Hull, Ellis & Sargent, 1989).

Fundamentals of palliative care

Concerns at the point of diagnosis may be very different from those in the last few weeks of someone's life, even for those who are sadly found to be incurable at the time of first presenting themselves for investigation (Sheldon, 1997). The National Council for Hospice and Specialist Palliative Care Services (1995) has distinguished between the palliative approach and specialist palliative care services, describing the palliative approach to care as a 'vital and integral part of all clinical practice, whatever the illness or its stage.' All professionals, whatever their setting of health care, should practise the principles of palliative care, described as (1) an emphasis on quality of life including good symptom control, (2) autonomy and choice, (3) a holistic approach, (4) focused care for the person who is dying and those who matter to that person and (6) open and sensitive communication with patients, their informal carers and professional colleagues (Sheldon, 1997). The aim should be the maximisation of the patient's quality of life. However, with such an infinitely variable disease as cancer, palliative care may be required for anything from a few days to several years. Good palliative care depends on two principles: communication and symptom control (Hull *et al.*, 1989).

Good communication depends on listening and talking. In the context of cancer, a two-way exchange of verbal and nonverbal communication by health care professionals aims to accurately perceive the attitudes, preconceptions and fears of the person with cancer. Health care professionals need to take adequate time to listen to patients, combined with attitudes of honesty and kindness and discussion in terms the patient can understand. Situations are unique and sometimes difficult; doctors and nurses vary in their personalities and skills and patients vary even more (Hull *et al.*, 1989). Persons 65 and older bear the brunt of cancer (Yancik & Ries, 1994). At a time of life when long accustomed skills are changing, the ability to communicate effectively becomes both a resource and a need for elderly people. An environment that enhances communication can be one of the most powerful tools for enabling elderly people to live maximally independent, secure and fulfilling lives (Lubinski & Welland,1997). However, despite the emphasis on teaching communication skills over the past two decades, good communication is often curtailed by structural factors. These include the nature of ward organisation, remote management styles and an overwhelming emphasis on increasing the number of patients cared for in hospital at any one time. Increased day surgery and the greater use of bank and agency staff impose further limitations on nurses' ability to develop a meaningful rapport with patients (Spiegel, 1993). A study by Wilkinson (1991) showed that nurses tend not to use facilitating behaviours with patients unless their work environment is conducive to good communication. Each situation is different, so it is important that health care professionals understand the theory and principles behind taught communication skills in order that they can be adapted and applied to any situation (Fielding & Llewelyn, 1987). A major drawback in encouraging patient-centered attitudes on the part of medical and nursing personnel is the time required to really listen effectively. It is probably true that current medical workloads in outpatients' departments make it virtually impossible for consultants to devote the time that many of them would wish to cancer patients (Herity, Hilliard, Moriarty, Fennelly, Conroy & Casey,1987).

Hospice Care. The concept of hospice dates back to Fabiola, a Roman matron during the reign of Emperor Julian the Apostate. Fabiola had a place for sick and healthy travellers and cared for the dying (McKenzie & Parris, 1997). Hospice is a medieval term representing a welcome place of rest for pilgrims in the Holy Land. St. Vincent de Paul, a seventeenth-century Catholic priest, founded the Sisters of Charity in Paris to care for the poor, sick and dying. This influenced Fliedner, a Protestant pastor, to found Kaiserwerth a hundred years later. Nuns from both the Sisters of Charity and Kaiserwerth accompanied Florence Nightingale in the Crimea (McKenzie & Parris, 1997). Our Lady's Hospice for the Dying opened at Harold's Cross, Dublin in 1879, 21 years after the death of Mother Mary Aikenhead, founder of the Irish congregation of the Sisters of Charity. The congregation established the Sacred Heart Hospice in Sydney, Australia in 1890 and St. Joseph's Hospice in Hackney, East London in 1902, where Cicely Saunders was to be a staff member 50 years later (Clark & Seymour, 1999). Cicely Saunders was the first full-time medical officer of St. Joseph's Hospice and is now considered the mother of palliative care (Craven & Wald, 1975; Allan, 1990; Campbell, 1986). Hospice care is concerned with achieving the best possible quality of the life remaining for cancer patients and for their families. Although the main concentration so far has been on those with advanced or terminal malignant disease, a few hospices have always welcomed some long-stay and/or frail elderly patients (Young, 1981).

A Jewish patient, David Tasma, gave the founding gift and first ideas which led to the opening of St. Christopher's Hospice in Sydenham, South London, in 1967. The foundation of St. Christopher's was how Saunders and Tasma coped with the truth of Tasma's terminal illness together. Tasma needed skills which were not then available. Attitudes and knowledge had to develop within the health care service to cope with the new philosophy inspired by a favourite phrase of Tasma's 'I want what is in your mind and in your heart.' The hospice movement continues to be concerned both with the sophisticated science of treatments and with the art of caring, bringing competence alongside compassion (Saunders, Summers & Teller, 1981).

The first goal in treating patients, where cure or prolongation of life no longer seem to be attainable goals, is to ensure that they receive optimal symptomatic management. Saunders sought to convince the medical community that it was totally unnecessary for cancer patients to die in pain (Craven & Wald, 1975; Allan, 1990; Campbell, 1986). From the hospice perspective the relief of pain requires multidisciplinary collaboration, constant evaluation and follow-up, a keen sense of the need to be pro-active and creative rather than reactive and static and as broad an understanding of the human condition as is humanly possible. In addition, it is crucial to the hospice concept of care that health care professionals understand that, for some individuals, certain ways of life and methods of coping with life (and death) can never be changed nor should they. Sometimes the best the health professional can do, with an attitude of humanity and kindness, is simply to be present with the patient and family (Pace & Meffert, 1997).

Recognising and alleviating psychological distress in patients with cancer

When pain and other symptoms are controlled or minimised, the multidisciplinary team can then turn its attention to the myriad psychological, social and spiritual concerns of the patient and family (Ajemian & Mount, 1981). Twycross (1994, 1997) stated: 'Anxiety often relates to uncertainty and fear of the future and the threat of separation from loved ones. It may present with physical symptoms such as nausea or diarrhoea, rather than with psychological complaints. Many patients with cancer sleep badly, have frightening dreams or are reluctant to be left alone at night. Explanation about the illness and special techniques such as relaxation training and cognitive-behavioural therapy are helpful forms of management but some patients also need anxiolytic drugs. If depressive symptoms are present a sedative antidepressant drug should be used. Recognising depression is important because patients often have a good response to antidepressant drugs. Depression is often missed because symptoms overlap with appropriate grief and sadness about dying and with the somatic symptoms of cancer, i.e. anorexia, constipation, weight loss'. Many patients also try to hide their negative feelings (Twycross, 1997). Patients may want to share in decisions about when to stop treatment aimed at prolonging life. Fear of death may make some want to go on, even when adverse effects are severe and the chance of improvement is minimal. Others may wish to opt for a shorter life of better quality when doctors are advocating more aggressive measures (Twycross, 1997).

Psychological problems are easily overlooked by doctors and nurses. Open questions such as 'how are you feeling?' and 'how are you coping?', when accompanied by a genuine attitude of concern, may facilitate the expression of negative emotion from patients. Suspicion that there is marked anxiety or severe depression may be confirmed by asking the patient to complete a screening test such as the Hospital Anxiety and Depression Scale (Twycross, 1997). Prevalence of depression in the total population is extremely difficult to assess and reports differ greatly between observers. As many as 25% of individuals with severe physical illness may be clinically depressed. Most patients with advanced cancer at times show symptoms of depression. In (1) *reaction to their unfavourable life situation*, patients complain of depression and misery consequent upon unhappiness relating to their illness, disturbed relationships or because of adverse social or financial situations. These situations are often faced by people with patients and may contribute to, or exacerbate, reactive or endogenous depression. (2) *Reactive depression* is induced by a major personal disaster such as loss. Patients facing imminent death frequently grieve over their anticipated loss. (3) *Endogenous depression* wells up from within the individual, lacks identifiable causative life events (though it may be associated with serious debilitating physical disease or major surgery) and is associated with self-criticism, anhedonia, a lack of future and suicidal thoughts, which, in patients with cancer, may find expression in a request for euthanasia. (4) *Schizo-affective disorders* may be associated with disorders of cognition similar to, but falling short of, true schizophrenia. This is rare in palliative care, except where the psychiatric condition was present before the cancer. Most patients with depression present a mixed picture with a greater or lesser degree of anxiety or somatic complaints (Hull *et al.*,1989).

Psychosocial interventions. The impact of the diagnosis, prognosis and treatment leads to a series of psychological and social responses by the patient, who may or may not continue to receive support from his or her family and friends and members of his or her health care team. These changes may seriously reduce the patient's quality of life (Ruckdeschel, Blanchard & Albrecht, 1994). Psychosocial oncology focuses on how the effects of the disease of cancer impact upon the cognitive, behavioural, social and spiritual aspects of the lives of patients with cancer. It is a multidisciplinary area and the skills and techniques of treatment methods, which can be utilised by a wide range of health care professionals, as long as they have received the appropriate training, aim to alleviate the emotional and social impact of cancer on patients and their families (Watson, 1991). All health professions share certain fundamental aspirations and goals, among which the most important ones are keeping the healthy person healthy, restoring the sick person to health and safeguarding and prolonging life (Szasz, 1974). Treatments for cancer have sometimes been perceived as worse than the disease and patients with cancer have been prepared to tolerate great discomfort in the hope of remission or cure (Cassileth, 1987). Consequently, quality of life for patients with cancer has become a major consideration, with a concern about the cost of cancer treatment in terms of damage to quality of life (Watson, 1991). This more humane, holistic, orientation to care, has helped to foster the growth of psychosocial oncology, which has come about also as a result of patients and families demanding that physicians pay more attention to patients' emotional needs (Slevin, Stubbs, Plant, Gregory & Massey, 1991).

There are four mainstream psychosocial interventions, which aim to diagnose and treat psychological, psychiatric and social morbidity for patients with cancer: behavioural therapy, educational therapy, psychotherapy and support groups. In general, their aims are to increase morale, self-esteem and coping and to decrease distress (Fallowfield, 1995; Weisman & Worden, 1976). Published controlled studies have shown their positive benefits in helping to reduce psychological morbidity, improve coping skills and reduce pain levels (Fallowfield, 1995). Patients like these approaches because they help to enhance their sense of control over symptoms and therefore over their adjustment to the disease itself. All these therapeutic interventions can be utilised alongside conventional drug therapy (Spiegel, 1990). Psycho-oncological methods do not remove the problem for patients but help them to increase their sense of mastery, self-esteem, confidence and control that the experience of cancer has undermined. These attributes can be broadly termed self-efficacy (Bandura, 1977), a powerful factor for mediating the stress response which, according to transactional models (e.g. Lazarus, 1966), is a psychological state involving aspects of both cognition and emotion. A stress response is elicited if an individual appraises a potentially stressful event as actually being stressful. Primary appraisal involves a person's appraisal of stressors within his or her environment and his or her relation to them. Secondary appraisal involves an appraisal of the individual him or herself and his or her evaluation of personal coping resources possessed to cope with any perceived stressors

(Lazarus,1966; Cox & Mackay, 1981). The form of the primary and secondary appraisals determines whether the individual shows a stress response or not. According to Lazarus' (1966) model, this stress response can take different forms: (1) direct action; (2) seeking information; (3) doing nothing; or (4) developing means of coping with the stress in terms of relaxation or defence mechanisms. Research indicates that self-efficacy may have a role in mediating stress-induced immunosuppression and physiological changes such as blood pressure, heart rate and stress hormones (e.g. Wiedenfeld, O'Leary, Bandura, Brown, Levine & Raska, 1990).

The individual's type of coping style may well mediate the stress-illness link and determine the extent of the effect of the stressful event on the person's health status. Coping styles have been classified as follows: problem solving (e.g. forming a plan of action); problem avoidance (e.g. refusing to think about the problem); wishful thinking (e.g. dreaming about better times); emotional social support (e.g. talking to people about feelings); instrumental social support (e.g. asking people for advice); informational social support (e.g. asking for more information); cognitive restructuring (e.g. redefining the problem); and distraction (e.g. taking drugs, drinking). Some of these coping styles are regarded as approach styles (e.g. problem-solving, social support) and some as avoidance coping (e.g. wishful thinking, problem avoidance). Most self-management therapies, cognitive-behaviour therapies and stress management techniques focus on training clients in effective coping with emotional reactions that interfere with daily functioning (Rosenbaum, 1993). Moos & Schaefer (1984) applied crisis theory to the crisis of physical illness. This theory suggests that psychological systems are driven towards maintaining homeostasis and equilibrium in the same way as physical systems are and that individuals attempt self-regulation using appraisal, adaptive tasks and coping skills applied to the stressor. If the outcome is perceived as unsatisfactory, further distress may result.

The physiological consequences of stress and their effect on health have been studied extensively. Research indicates that stress causes physiological changes that have implications for promoting both the onset of illness and its progression (e.g. Selye, 1956; Soreq & Friedman, 1996). The immune system plays a key role in controlling the growth of cancer cells. Cells of the immune system (particularly monocytes and lymphocytes) are programmed to recognise and eliminate foreign substances and malignant cells. Cytokines regulate general immune function, as well as specific activation against tumour cells, by both enhancing and suppressing complex immune interactions. Although stress responses (and thresholds) differ among individuals, chronic or recurring stressors can suppress cell-mediated and humoral immune responses through adrenergic activation (Post-White, 1996). Overall, psychosocial methods have major implications for helping to improve quality of life for cancer patients. Cancer pain involves complex physiological and psychological mechanisms that often necessitate a combination of clinical interventions to achieve effective management. Although analgesic medication remains the mainstay of treatment for cancer pain, the overall management of pain and the facilitation of patient comfort may be enhanced through the use of non-invasive techniques aimed at the promotion of physical and mental relaxation (Sloman, 1995; Golden, 1992).

Social support

Social support can be described as a person's perception that their welfare is of concern to a trusted other, resulting in their feeling cared for, loved, esteemed and a member of a network of mutual obligation (Cobb, 1976). Social support has long been thought to affect health outcomes directly or indirectly (Cohen &Wills, 1985). People intuitively know that the presence of caring relationships and the experience of social support contribute to the quality of a person's life (Burleson, Albrecht, Goldsmith & Sarason, 1994). Social support may be expressed functionally through the proffering of emotional, informational or practical support and structurally through social network size and frequency of social interactions (Wills, 1985). Scientists researching social support have become increasingly interested in the processes and behaviours through which support is elicited and provided. Within the broad category of emotional support, behaviours of particular interest are the strategies that people use in the effort to comfort those experiencing emotional distress (Burleson, 1994).

Research has found that stress resulting from everyday hassles and disappointments is a better predictor of mood and psychological well-being than stress resulting from major life events, such as the death of a spouse, or chronic conditions, such as living in poverty (e.g. Eckenrode, 1984; Kanner, Coyne, Schaefer & Lazarus, 1981). Stress resulting from daily upsets may even be a better predictor of physical health than the stress resulting from major life events (Delongis, Coyne, Dakof, Folkman & Lazarus, 1982). Supportive actions which express concern and solidarity help to prompt the articulation of feelings, display sympathy and understanding and provide new information or alternative perspectives on a distressful situation. Therefore, supportive actions by one person may significantly contribute to feelings of well-being, acceptance and control over events for another. These feelings, in turn, are important predictors of functional modes of coping with stress and several indices of physical and emotional health (e.g. Albrecht & Adelman, 1987).

The comfort and emotional support people receive from others helps them to feel better, relieves hurt and stress and improves quality of life. Comforting and other emotionally supportive actions are thus relationally significant behaviours (Burleson, 1994). Samter (1992) found that individuals whose friends placed a relatively low value on comforting skill were more lonely than people whose friends place a high value on this skill. People certainly seem to value the comfort and emotional support they receive from friends, family and co-workers. These activities play important roles in the development and maintenance of interpersonal relationships and help individuals cope with a variety of common stresses and upsets. Thus comforting and emotional support serve significant functions in everyday life. Research has shown the value of social support in oncology, a medical subspecialty concerned with the research and treatment and/or care of all aspects of the disease of cancer (Neuling & Winefield, 1988).

Originally, a matching model of stress and social support focused solely on characteristics of the stress as determinants of the most beneficial type of social support (e.g. Cutrona & Russell, 1990). Researchers now consider that characteristics of the relationship between the stress victim and the support provider must be considered as well (Cutrona & Suhr, 1992). Different stressful events pose different challenges and lead to different psychological needs which may be shaped both by the nature of the stress and by the nature of the relationship between the stress victim and the support provider (Cutrona, Cohen & Igram, 1990). The social support needs of patients with cancer are specific (Broadhead & Kaplan, 1991). In a recent study in Cambridge, England, forty three patients with a life expectancy of one year or less, who were being looked after in their own homes, were asked to give their views of the support provided by general practitioners, district nurses and Macmillan nurses. The content of their positive statements suggested that psychosocial aspects of support, including communication, kindness and consideration were valued most. Actions in the form of helpfulness, organisation of support and being accessible were important, while clinical aspects received less emphasis. Clinical aspects were emphasised more when patients expressed negative views of support. Patients' statements suggested that emotional and informational support were provided predominantly by Macmillan nurses (Grande, Todd, Barcley & Doyle, 1996).

Summary

Quality of life, symptom management and social support are the traditional foci for the practice of psychosocial oncology and clinical research into the behavioural and psychological aspects of cancer (Ruckdeschel *et al.*, 1994). Research into psychosocial oncology with patients at an advanced stage of the disease gives a clearer picture of the difficulties experienced at both an intra-and interpersonal level. The ideal aim is to implement psychosocial interventions following diagnosis, preferably at an early stage of the disease, so that patients with cancer are assured of support all through their disease experience at the level and of the type with which they are comfortable, in order to enhance their quality of life and to help them to cope more effectively as the disease advances. In an ageing population which is vulnerable to increased incidence of cancer, psychosocial treatment methods have implications for health economics by helping to increase the effectiveness of pharmacological treatment regimes for pain control and for anxiety and depressive disorders. Therefore, an understanding of the mechanisms of and influences upon the perception of the cancer patient's experience of pain, stress and support is required to maximise the effectiveness of psychosocial interventions. The aim of palliative care is not only to reduce symptoms but to increase the patient's hope (Schmoll, 1992). This does not mean offering false hopes of cure, but being able to help the person with cancer to find each day a little easier, happier and more meaningful. The following literature review examines in detail research relating to the variables of perceived pain, social support and psychological distress and how these variables may affect the quality of life of the person with advanced cancer.

PAIN AND THE PERCEPTION OF PAIN

The extent of the problem

Cancer has a profound impact on public health throughout the world. American Cancer Society estimates show that there are 520,000 deaths due to cancer and 1,130,000 new cases diagnosed each year in the United States alone (American Cancer Society, 1992). Without proper symptom control, severe pain will afflict most advanced cases (e.g. Daut & Cleeland, 1982; Carr, Jacox & Payne, 1997). The management of pain in the context of health economics is becoming increasingly recognised. Chronic non-malignant pain costs the American economy $40 billion a year. A recent attempt to quantify the total cost to the Irish economy of 95 patients attending a multi-disciplinary pain clinic, found that the total cost to the economy was approximately 1.9 million pounds at the time of referral. A subgroup of 22 patients, who were younger and unemployed, accounted for 1.5 million pounds (Sheehan, McKay, Ryan, Walsh & O'Keeffe, 1996). Health professionals concerned with pain control have been world-wide leaders in clinical and health services research to delineate those therapies that benefit the multiple dimensions of patients' quality of life (QoL). Pioneering studies on the under-treatment of acute and cancer pain motivated the International Association for the Study of Pain (IASP), the World Health Organisation (WHO), the Canadian Council on Health Facilities Accreditation, the U.S. Agency for Health Care Policy and Research (AHCPR) and the American Pain Society to prepare and distribute standards or guidelines for management of acute or cancer-related pain (WHO, 1992; McKenzie & Parris, 1997). The Cancer and Palliative Care unit of the World Health Organisation (WHO) has stated that 'Nothing would have more immediate effect on quality of life and relief from suffering, not only for cancer patients, but also for their families, than implementing the knowledge accumulated in the field of palliative care' (WHO, 1992).

In 1980, the WHO began a three-step effort to prevent cancers with known causes, improve detection and cure rates of cancer and to relieve cancer pain. Surveys in five countries in 1981 confirmed widespread prevalence of inadequate cancer pain relief. In 1982, a working group consisting of 1981 survey participants, as well as six experts on the treatment of pain, met in Milan to draft a guideline on which the 'Method for Cancer Pain Relief', Annex 1 was based in the initial WHO document (WHO, 1986). Further field testing and consultation were carried out prior to the first edition of 'Cancer Pain Relief' in

1986. The WHO approach is one in which pharmacotherapy is delivered by mouth, by the clock by the ladder (non-opioids, weak opioids, then strong opioids), for the individual, with attention to detail (Carr *et al.*, 1997).

The AHCPR Clinical Practice Guideline (Jacox, Carr & Payne, 1994) on the management of cancer pain is designed to help any clinician who works with any oncology patient in any setting understand the assessment and treatment of pain and associated symptoms. It also discusses briefly the management of pain in patients with human immunodeficiency syndrome (AIDS), because many principles of pain assessment and treatment are common to both cancer and AIDS. The AHCPR Guideline calls for (1) a collaborative interdisciplinary approach to the patient with cancer pain; (2) an individualised pain control plan developed and agreed on by patients, their families and practitioners; (3) ongoing assessment and reassessment of the patient's pain; (4) the use of both drug and non-drug therapies to prevent and control pain; and (5) explicit institutional policies on the management of cancer pain, with clear lines for pain management and for monitoring the quality of pain management (Carr *et al.* 1997).

The concept of pain, its source and its therapy have undergone several philosophical changes. It is only recently that pain has evolved from a philosophical, almost mystical concept, to one based on scientific foundations. In some instances, religion or superstitious sentiment has altered the view toward pain therapy. For example, it was once believed that, because pain was sent from the gods, it was something that had to be endured rather than eliminated (McKenzie & Parris, 1997). More than 2000 years ago, Aristotle described pain, like pleasure, as a 'passion of the soul', emphasising that pain is not just a physical sensation, by omitting it from his list of the five senses (sight, hearing, smell, taste and touch). This fundamental truth about pain has been incorporated in the definition of pain proposed by the International Association for the Study of Pain (IASP): Pain may be defined as an unpleasant sensory and emotional experience, associated with actual, or potential, tissue damage, or described in terms of such damage (Twycross, 1994). At the turn of the century a bitter battle was fought on the question of pain specificity. Von Frey (1895) argued that there are specific pain receptors, while Goldscheider (1894) contended that pain is produced by excessive skin stimulation and central summation. At this time Marshall (1894) claimed that pain is an emotional quality that colours all sensory events, prompting behaviour in the realm of emotion and motivation (Melzack & Wall, 1988). Von Frey's assumption that skin receptors are differentiated to respond to particular stimulus dimensions represents a major extension of Muller's concept of the 'specific irritability' of receptors. Sherrington (1900) defined the specificity of a receptor in terms of the lowest threshold for a particular stimulus to fire it. This concept of the 'adequate stimulus' (Sherrington, 1906) is so generally accepted that it is considered a biological principle (Melzack& Wall, 1988).

Pain is a personal experience and is composed of both physical and psychological factors. It is a specific sensation brought about by damage or threat of damage; therefore it has a high subjective content as to the individual's interpretation of threat or damage (Adams, 1997). Like any other sensory stimulus, pain has a threshold, known as the pain perception threshold (PPT) and defined as the least intensity of noxious stimulation at which a subject consciously perceives pain (Wells, Frampton & Bowsher, 1988). The pain perception threshold is variable from person to person. However, it is the pain tolerance threshold (PTT), the greatest intensity of noxious stimulation an individual can bear, that is highly variable from person to person and is affected by psychological and emotional factors (Wells *et al.*, 1988). When pain goes beyond a person's tolerance level, then the person will seek help. Acute pain may be of survival value and therefore beneficial, in that it calls attention to a real or perceived threat. It is frequently a symptom of underlying disease (Echternach, 1987). Chronic pain, on the other hand, appears to have no such value and seems to comprise peripheral input and changes in neural functioning which sustain pain circuitry beyond peripheral input (Adams, 1997). It is now recognised that to ignore pain, or to discourage acknowledgement of its presence, is detrimental to patient care (Twycross, 1994).

Since the times of ancient civilisation, medications have been used to relieve pain. Isolated from opium by Serturner in 1803, morphine was later named after the Greek god of dreams (McKenzie & Parris, 1997). In 1844 an American dentist, Wells, had one of his own teeth extracted painlessly while he was under the influence of nitrous oxide. The failure of a public demonstration in Boston prevented him from continuing his plan for painless extraction but another dentist, Morton, using ether vapour, put the practice into effect in Boston in 1846. Ether anaesthesia rapidly became the general practice in surgical operations (Boring, 1957). The discovery of hypodermic needles expanded the use of morphine which, combined with the use of ether as an anaesthetic, enabled surgery to be painless. Despite the constantly evolving study of pain, there are many instances, particularly in the case of chronic pain, where effective therapy is far from ideal (McKenzie & Parris, 1997). Many patients with advanced cancer continue to experience a significant amount of pain throughout the course of their disease, although very effective technological and pharmacological advancements have been developed to treat pain (Bonica, 1990; Swerdlow & Ventafridda, 1987). Satisfactory relief is not provided for most of the estimated four million people world-wide with cancer-related pain, resulting in unnecessary suffering (Twycross, 1994). The under use of opioids is related to a lack of education in pain medicine in medical, nursing and pharmacy schools, which, until recently, was compounded by a paucity of textbook pages devoted to pain. There have been several surveys of physicians, nurses and medical students regarding their knowledge and treatment of pain and there is still misunderstanding in the medical community, as well as in the lay public, with regard to the difference among opioid dependence, tolerance and addiction. There was no published epidemiological data on pain and no data on the psychosocial effects of cancer pain on patients and their families as late as the 1970s. In the late 1970s, because of the paucity of pharmacokinetic data on analgesia in cancer patients, Bonica formulated data based on extrapolations from both the United States and world-wide. This data suggests that 50% of all cancer patients and 75% of patients with advanced disease will experience a significant amount of pain. There are now societies devoted to advancing knowledge in the area of pain medicine, e.g. the American Pain Society (APS) and the International Association for the Study of Pain (IASP). The multifactorial nature of cancer pain is also being recognised and multidisciplinary pain centres are now gaining acceptance (McKenzie & Parris, 1997).

More than 50% of all patients with cancer are still treated knowing that cure is most unlikely. The therapeutic intent for these patients must be the prolongation of good quality of life and if this is not possible, optimising the quality of the remaining time (Slevin & Tate, 1998). Pain has been described as an experience that overwhelms the individual and consumes every aspect of life. The concepts of pain and quality of life have emerged over the past decade as central themes in palliative care (Ferrell, 1995). The palliative treatment of cancer may involve surgery, radiotherapy, chemotherapy and hormone therapies, physical and psychosocial symptom management, all used in varying combinations, depending upon the individual situation. When these treatments are proposed for patients in whom cure is not possible, there may be great concern that treatment side-effects will outweigh the benefits that the patient may receive. This concern often results in failure to refer the patient for specialist oncological opinion. Recent research increasingly indicates that achieving optimal tumour control by active treatment of the cancer can maximise quality of life (Slevin & Tate, 1998). Nevertheless, there remains considerable confusion and uncertainty among doctors treating cancer patients as to how to balance the potential benefits and toxicities when considering the active treatment of non-curable cancer (Slevin & Tate, 1998).

The experience of pain

The experience of pain has a specific sensory component and an emotional-cognitive component in that it is unquestionably a sensation in a part or parts of the body, but it is always unpleasant and is therefore an emotional experience. Some people report pain in the absence of tissue damage or any likely pathophysiological cause; usually this happens for psychological reasons. There is no way to distinguish their experience from that due to tissue damage (Twycross, 1994). If a person reports pain in the same ways as pain caused by tissue damage, it should be accepted as pain (Twycross, 1994). Pain is always a psychological state even though it usually has a proximate physical cause (Twycross, 1994). The word pain can be used to refer to the total experience of both sensation and emotion (Moon, 1985). The perception of pain is modulated by the patient's mood, morale and the meaning of the pain for the patient (Twycross, 1997). Melzack (1973) concluded that sensory, motivational and cognitive processes occurred concurrently, in parallel, interacting systems and that motivational/affective processes must be included in any satisfactory theory of pain.

Szasz (1957) proposed a model of pain which includes three levels. One is a biological level in which the concept of pain is that of a signal by which the perceptual part of the organism registers that there is a threat to its structural and functional integrity; in this concept of pain there is only one person involved. Two or more people are involved at another level in which the expression of pain is a fundamental method of asking for help. In the third aspect, the meaning of the word pain lies largely in its ability to communicate the experience of pain as an unpleasant affect or emotion (Moon, 1985). The pairing of the words pain and suffering is discussed by Cassel (1982) who stated that this phenomenon reflects a historically constrained and currently inadequate view of the ends of medicine. Medicine's traditional primary concern for the body and for physical disease is well known, as are the widespread effects of the mind-body dichotomy on medical theory and practice. The problem of measuring painful sensations was one that preoccupied the first experimental psychologists concerned with the mind-body problems. In the 1850s, Fechner wrote equations to describe the functional relationships between psyche or mental events and physical or material events. These methods have become an integral part of psychological technique (Skevington, 1995). As ideas of the separation of mind and body are called into question, physicians are concerning themselves with new aspects of the human condition. Suffering is experienced by people and the understanding of the person in human illness requires a rejection of the historic dualism of mind and body. The person in pain frequently reports suffering from pain when they feel out of control, when the source of the pain is unknown, when the meaning of the pain is dire or when the pain is chronic. In all these situations people perceive pain as a threat to their continued existence, not merely to their lives but to their integrity as persons. This relationship of pain to suffering must be acknowledged because suffering can be relieved, in the presence of continual pain, by making the source of the pain known, by changing its meaning and by demonstrating that it can be controlled and that an end is in sight (Cassel, 1982; Moon, 1985; Skevington, 1995).

Skevington (1995) stated that the concept of suffering involves four essential features. For a person to suffer (1) he or she must have had an experience or an event that was negative or unpleasant. These events or experiences can include, but are not limited to, physical pain, cognitive experiences or losses, real, potentially real or imagined. (2) Suffering only occurs when the person perceives the event as negative or unpleasant. (3) When the event is perceived as such, some type of distress results. (4) The negative event endures for some time, or, the event is expected to endure or to recur. Pain when present is only one component of suffering. Suffering is an unpleasant mental state resulting from an event or situation that is perceived to be harmful, uncomfortable, unpleasant or psychologically or physically painful. Suffering and pain are not synonymous. Suffering is a much broader concept than is pain. However, when a person is in pain, not only is the suffering compounded in many ways, but the pain makes it virtually impossible to address the wider issues involved with suffering (Benedict, 1981). Suffering is experienced by persons, not bodies and stems from a threat to the integrity of the person as a complex social and psychological entity. Suffering commonly occurs in a wide range of social conditions, may affect the sufferer's body image and may be connected to the fulfilment of social roles. Helplessness induced by severe loss or the perceived threat of destruction either of self or of significant others is a potent source of suffering. Patients may tolerate severe pain without considering themselves to be suffering if they know that the pain has an identified cause, can be dealt with and will be relatively short lived. On the other hand, relatively minor symptoms may cause suffering if they are believed or known to have a life threatening cause, be intractable and reflect a hopeless prognosis (Cassel, 1982; Skevington, 1995). It must be understood that the person who reports pain and is observed to be suffering, or who reports suffering, is not imagining pain. Malingering (the deliberate fabrication of symptoms) is also extremely rare. The reasons for suffering, however, may not be amenable to traditional biomedically based health care. Pain generally is a problem that has biological, psychological and social aspects, all of which must be analysed from the perspective of a biopsychosocial model (Waddell, 1992; Fordyce, 1995).

The distinction between 'disease' and 'illness' is crucial to understanding chronic pain. Disease is generally defined as an 'objective biological event' that involves disruption of body structures or organ systems caused by pathological, anatomical or physiological changes (Mechanic, 1986). In contrast to this customary view of physical disease, illness is defined as a 'subjective experience or self-attribution' that a disease is present; it yields physical discomfort, emotional distress, behavioural limitation and psychosocial disruption. In other words, illness refers to how the sick person and members of his or her family and wider social network receive, live with and respond to symptoms and disability. In contrast to the biomedical model's emphasis on disease, the biopsychosocial model focuses on illness and the result of a complex interaction of biological, psychological and social variables (Waddell, 1992; Fordyce, 1995; Turk, 1996). From this perspective, the diversity in illness expression (which includes its severity, duration and consequences for the individual) is accounted for by the inter-relationships among biological changes, psychological status and the social and cultural contexts that shape the patient's perception and response to illness. The biopsychosocial way of thinking about the differing responses of patients to symptoms and the presence of chronic conditions is based on an understanding of the dynamic nature of these conditions. That is, by definition, chronic syndromes extend over time. Therefore, these conditions need to be viewed longitudinally as ongoing, multifactorial processes in which there is a dynamic and reciprocal interplay among biological, psychological and social factors that shapes the experience and responses of patients (Dworkin, Von Korff & LeResche, 1992; Turk, 1996).

There is considerable variation in the ways that people in pain initially react to symptoms and how these responses change as the condition persists (Skevington, 1995). Severe, acute pain is accompanied by a 'fight or flight' response, whereas chronic pain is often associated with vegetative features similar to those seen in depression (Twycross, 1994). For example, within the terms of behavioural medicine, during the acute phase of the first two months of treatment, overt behaviours like a temporary decrease in activity and temporary reliance on medication and help-seeking from professionals tend to occur. Patients believe that their pain is controllable through medication, engage in active coping and display anxiety with other signs of autonomic arousal. By the pre-chronic phase of 2-6 months, alternating patterns of increasing and decreasing activity occur. Patients may withdraw from or become reliant on medication and recognise that their pain is not entirely controllable through medication. They may alternate active and passive coping styles, deny depression and focus on physical symptoms and pain of variable intensity, which is reactive to stress. By the chronic phase, 6-24 months after onset, activities have decreased indefinitely, pain is believed to be uncontrollable, depression is common, passive coping styles have been adopted and there is a strong preoccupation with bodily complaints. At this stage there is a reduction in autonomic arousal (Keefe, Block & Williams, 1980).

It is difficult to assess to what extent the tendency to approach illness behaviour in the negative terms of psychopathology has unduly influenced the way in which clinicians view their patients. Although some chronic pain patients appear to display signs of unusual behaviour, this consensually shared perspective has continued to generate an active search for psychopathology among those who attend for assessment, in a manner that has not been beneficial to the majority of patients. Central to the definition of behaviour that fits the description 'illness behaviour' is communication between the pain patient and health care professionals, while cognitive and affective components give emphasis to understanding within the terms of psychological disturbance (Skevington, 1995).

Supporting a move away from labelling, a situational view of illness behaviour looks at the environmental conditions and everyday behaviour associated with symptoms and illness (Skevington, 1995). Alonzo (1984) suggested four kinds of situations which have the potential to produce, contain and facilitate compromised performance of roles. In the first situation, a person routinely adapts to daily life in which participation in activities is unlikely to produce symptoms or signs and where occasional failures or derelictions of duty are acceptable. In the second situation, participation in activities is likely to affect a person's physical, psychological or social well-being. In the third situation a person's social life allows periods of free time that are designed to manage the difficulties posed by illness, with time-out allowed to tend to signs and symptoms by taking medication and rest. As the occurrence of this third type of situation increases, a person progresses towards becoming 'ill.' In the fourth situation, attention is largely focused on the illness of the person, health training or therapeutic difficulties which are now acknowledged to be uncontainable (Skevington, 1995).

Pain which is continuous for six months or more is categorised as chronic (Sternbach, 1974; Skevington, 1995). Such a definition, while of benefit in limiting referrals, does not make patho-physiological sense because most acute conditions heal in two or three weeks and, if pain is still present after treatment, it should be considered chronic (Twycross, 1994). If left for six months before being considered chronic, pain may well have become resistant to treatment (Bonica, 1990). 'Chronic benign pain' is a term which was introduced in the 1970s to distinguish chronic pain of nonmalignant origin from chronic cancer pain (Sternbach, Ignelzi, Deems & Timmermanns, 1976). Bonica (1990) has 'a deep conviction that chronic pain is never benign but is rather a malefic force that is deleterious to the patient, the family and society'. Twycross (1994) considers that the term chronic benign pain therefore should not be used. The term chronic pain of non-malignant origin or chronic noncancer pain should be used instead. Traditionally, a distinction has been made between the management of chronic pain associated with malignancy and pain of non-cancer origin (Allen & Zenz, 1999). Chronic pain caused by cancer is best thought of as acute pain persisting over time. Pain changes over time in cancer because of the concurrent involvement of different anatomical structures and because it is always evolving as a result of local tumour progression and metastatic spread (Shipton, 1999). Cancer patients in pain exhibit a mixture of both 'fight and flight' and vegetative reactions. The former is particularly manifest when pain is associated with symptoms of deterioration, such as anorexia, weight loss, decreasing exercise tolerance and increasing physical dependence. The patient realises that he or she is on a collision course with death. Such a realisation, even if partly subconscious, evokes an instinctive autonomic response (Twycross, 1994).

High levels of physiological arousal may provoke muscular spasms, vasoconstriction or visceral disturbance or cause an individual to label sensory events as pain rather than as the result of emotional distress. Also, anxiety that is evoked in a context relevant to the patient's fears, for example, anxiety about medical procedures, will result in a greater perception of pain (Breitbart, Payne & Passik, 1997).

The cognitive, emotional, socioenvironmental and nociceptive aspects of cancer pain are the important elements which point to the challenge of untangling the psychological and physical issues associated with cancer pain, while providing a framework to develop interventions designed to address the major dimensions of cancer pain. In patients with pain caused by cancer, therapy is directed at killing tumour cells and/or interrupting the nociceptive pathways, thus relieving the pain and accompanying distress (Allen & Zenz, 1999). Fortunately, somatically oriented interventions which have been specially designed to alleviate cancer pain have also been shown to reduce psychological distress, while psychosocial interventions that are aimed at relieving emotional distress have a profound impact on nociception (Breitbart *et al.*, 1997). Mood and morale have an impact on the intensity of all symptoms. Some patients, however, express negative emotions through physical symptoms (Twycross, 1994). The phrase 'total pain' was coined by Dame Cicely Saunders to emphasise the multidimensional (i.e. physical, psychological, social and spiritual) ramifications of pain in advanced cancer (Saunders, 1967). Twycross (1994) pointed out that patients with cancer sometimes describe their whole life as painful. Those caring for them must, therefore, address all aspects of discomfort and distress if the pain is to be relieved. Whereas it is assumed that the concepts of pain and quality of life are closely related, the nature of this relationship has only recently been fully acknowledged. Pain is known to create or increase many physical symptoms such as fatigue, anorexia, sleeplessness, constipation and nausea. Psychological effects of pain include anxiety, depression, a sense of loss and a feeling of diminished usefulness, increased fear and diminished coping. The physical and psychological suffering experienced by the individual impacts on their wider social network. Pain creates distress in family members as well as physical and financial burdens. Pain interferes tremendously with relationships and roles and with the ability to interact with loved ones. The social and spiritual aspects of cancer and pain are less understood. The last decade witnessed major advances in pharmacological treatments for pain. The heightened interest in quality of life as a concept represents an interest in evaluating the outcomes of treatments, procedures and medications on the overall status of patients. The development of physiological theories of pain has also added to the understanding of pain mechanisms (Ferrell, 1995).

Theories of pain

In the past the question of pain origin was explained by two major theories: (1) the summation or intensity theory in which Goldsheider (1894) postulated that there were no specific pain receptors and that each sensory stimulus, with sufficient intense stimulation, produced pain sensation. and (2) the later specificity theory, following von Frey's (1895) postulation of four modalities of cutaneous sensation, which assumed a rigid, fixed relationship between a neural structure and a psychological experience (Lampl, 1994; Melzack & Wall, 1988).

Specificity theory suggested that pain, similar to thermal and mechanical stimuli, has a specific ascending tract and pain centre located in the brain, thus proposing that a specific pain system carries messages from pain receptors in the skin to a 'pain centre' in the brain. The concept of modality separation in peripheral nerve fibres (von Frey, 1895) represented the most literal interpretation of the doctrine of specific nerve energies (Muller, 1842). Since fibre-diameter groups were held to be modality specific, the theory imparts 'specific nerve energy' on the basis of fibre size. The physiological assumption was that each of four types of receptors, touch, warmth, cold and pain, had one form of energy to which it was especially sensitive. Each receptor was attached to an afferent nerve and impulses were then transmitted through the lateral spinothalamic tract to a 'pain centre' in the brain. The concept of a direct, invariant relationship between a psychological sensory dimension and a physical stimulus dimension, essentially similar to Descartes' concept of pain proposed three hundred years earlier, has led to attempts at repudiation of the doctrine of specificity in its entirety (Melzack & Wall, 1988).

Reverberating Circuits. Livingston (1943) was the first to suggest specific central neural mechanisms to account for the remarkable summation phenomena found in the pain syndromes associated with phantom limb pain, causalgia and the neuralgias. The theory proposed that pathological stimulation of sensory nerves (such as occurs after peripheral nerve damage) initiates activity in reverberatory circuits (closed, self-exciting loops of neurons) in the grey matter of the spinal cord. This activity can then be triggered by normally non-noxious inputs and generate volleys of nerve impulses that are interpreted centrally as pain. There is no physiological evidence of functional reverberatory circuits, but Livingston's (1943) concept of sensory modulation to control pain has had a powerful impact on later ideas (Melzack & Wall, 1988).

Pattern theory. Several theories have emerged from Goldscheider's (1894) concept that stimulus intensity and central summation are the critical determinants of pain. All of them recognise the concept of patterning of the input, which is essential for any adequate theory of pain. The theory proposes that all fibre endings (apart from those that innervate hair cells) are alike, so that the pattern for pain is produced by intense stimulation of non-specific receptors. The physiological evidence, however, reveals a high degree of receptor-fibre specialisation, which the pattern theory proposed by Weddell (1955) and Sinclair (1955) ignores.

The Gate Control Theory (GCT) represented a major advance in scientific thinking about pain (Melzack & Wall, 1965) and is a type of pattern theory which proposes that the balance of the input between small and large fibres is important in pain sensation. It also incorporates a mechanism within the spinal cord for low level decoding of this pattern. Crucially, the GCT was the first to acknowledge and integrate known psychological mechanisms that affect individual perceptions and interpretations of pain. It is proposed that activity in the large afferents may inhibit activity in the smaller fibres where both connect in the dorsal horns of the spinal cord. A predominance of small fibre activity causes presynaptic facilitation, substantially increasing transmission cell (T-cell) activity, which constitutes an 'opening of the gate' and the consequent perception of pain as the brain interprets these impulses. Through a preponderance of large fibre activity, the gate is 'closed' and pain is not perceived (Skevington, 1995).

According to Stage 1 of the GCT, small-diameter peripheral nerve fibres, stimulated by injury, deliver impulses to T-cells in the spinal cord which transmit to local reflex circuits and to the brain. Stage 2 of the GCT proposes that there are facilitatory cells in the region of the T-cells because it is known that all cells in the dorsal horn of the spinal cord fire a prolonged burst of impulses after the arrival of a brief input volley (Wall, 1960). Stage 3 involves activity of two of three groups of neurons that are found in the dorsal horn (Lampl, 1994). Stages 4 and 5 concern the inhibitory mechanisms of the dorsal horn. In the dorsal horn of the spinal cord, close to the T-cells, there is a densely packed layer of small cells, the substantia gelatinosa (SG). Activity in the SG has been shown to effect one type of inhibition (Wall, 1964; Melzack & Wall, 1988). A revision of the GCT has shown how the cells of the SG have an inhibitory effect on the deeper dorsal horn neurons. Each large and small fibre excites a T-cell and sends a collateral to a suppressor cell in the SG, where large fibres excite the suppressor and small ones inhibit it. Activation of a T-cell by a large fibre is followed by inhibition as the suppressing SG cell is activated by the collateral, so closing the gate. Small fibres activate the T-cells and this effect is accentuated by the inhibition of the SG. The balance between the two is critical to the firing of the T-cells (Melzack & Wall, 1988; Skevington, 1995).

Shealy, Mortimer & Reswick (1967) theorised, as did Melzack & Wall (1965), that electrical stimulation of the large A-beta fibres of the dorsal columns would inhibit reception of painful small-fibre information at the SG of the dorsal horn. Shealy *et al.* (1967) presented the first clinical evidence for analgesia induced by electrical stimulation and called this treatment dorsal column stimulation, which was the rationale behind the introduction of transcutaneous electrical nerve stimulation (TENS) and dorsal column stimulation. The term spinal cord stimulation (SCS) is now used. This method is particularly useful in the treatment of pain due to peripheral vascular disease, has been used effectively in the treatment of intractable angina pectoris (e.g. Laffey, Murphy, Regan & O'Keeffe, 1998) and may, in some instances, be helpful in the treatment of cancer pain, although its effectiveness in the presence of deafferentation is not clarified (Payne, 1989).

Endogenous Opiate Theory. In the mid 1970s, the body's own internally secreted narcotic-like substances called endorphins were identified (Snyder, 1977). The term endorphin is a combination of the words 'endogenous' and 'morphine,' meaning 'morphine within'. It is believed that an impulse from the brain triggers the release of endorphins which lock into narcotic receptors at nerve endings in the brain and spinal cord to block nociceptive transmission, preventing the impulse from reaching consciousness (McCaffrey, Beebe, Latham & Ball, 1994). These substances are similar in effect to morphine and react at receptor sites to inactivate pain sensation. Endorphin research has helped in the understanding of individual differences in pain perception and the need for analgesia to vary from one individual to another. Differences in the amount of endorphin present in different individuals and the preliminary research suggest that endorphin levels may be increased by brief pain or stress, physical exercise, massive trauma, acupuncture, TENS, SCS, placebos and sexual activity or decreased by prolonged pain, recurrent stress and prolonged use of morphine or alcohol (e.g. Clark, Yang & Janai, 1986; McCaffrey *et al.*, 1994).

The physiology of pain

Tissue damage caused by injury, disease or inflammation releases endogenous algesic substances, including hydrogen and potassium ions, serotonin, histamine, prostaglandins, bradykinin and substance P, into the extracellular fluid that surrounds the nociceptors (Bonica, 1990). In addition to direct excitatory action on the membrane of nociceptors, these agents may have an indirect excitatory action by lowering the local microcirculation. Sensitisation leads to a gradual spread of hyperalgesia and/or tenderness (Bonica, 1990; Adams, 1997). Substance P, (SP), located in unmyelinated primary neurons and their terminals, in many regions of the central and peripheral nervous system, is a specific excitatory peptide having major importance in the pain pathway. It has a hyperalgesic effect and is inhibited by opiates (Lampl, 1994). SP comes closest to being a specific transmitter for noxious messages (Twycross, 1994)..

Ascending systems. The lateral (lemniscal system) comprises the *neospinothalamic* tract, and dorsal column tract (Adams, 1997). The 'fast' type A-delta pain fibres transmit mainly mechanical and thermal pain. They terminate in lamina I and V of the dorsal horn, exciting neurons of the *neospinothalamic tract*. The lateral system is involved with the rapid transmission of phasic discriminative information to quickly bring about a response that prevents further damage (Adams, 1997). The medial (non-lemniscal) system, involved with slower transmission of information, comprises the *paleospinothalamic* tract, the spinoreticular tract, the spinothalamic tract and the multisynaptic ascending system. The cell bodies are located in the deeper layer of the spinal grey matter. In this pathway, the peripheral fibres terminate almost entirely in laminae II and III of the dorsal horn, which together comprise the SG. The *paleospinothalamic* tract terminates very widely in the brain stem. There are fibre projections to the limbic system and the hypothalamus transmits to the emotional and autonomic centres, so that this system is responsible for the autonomic reaction such as sweat and increase in blood pressure and pulse as well as the affective-motivation component of pain. The *paleospinothalamic system* projects fibres of the nociceptive stimulus to the reticular formation in the medulla, pons and mesencephalon with the periaquaductal gray (PAG) matter being an important target for those fibres. The PAG and the gigantocellularic substance of the reticular formation cells to which it is connected are almost entirely responsive to pain sensations (Lampl, 1994).

It is thought that the *sensory cortex* together with the specific thalamocortical fibres, has a central role in adapting the discriminative component of pain stimulation (Lampl, 1994). The cortical receiving areas are apparently concerned with the discriminative, exact and meaningful interpretation of pain, but perception alone does not require the cortex (Ganong, 1991). It is likely that pain impulses entering the reticular formation, thalamus and other lower centres can cause conscious perception of pain (Bonica, 1990).

Descending pain control mechanisms. Serotonin is the neurotransmitter for a descending inhibitory pathway running from the PAG in the brain stem to the spinal cord (Mayer & Price, 1976). Noradrenaline is the neurotransmitter for a descending inhibitory pathway running from the lateral reticular formation of the midbrain to the spinal cord (Mayer & Price, 1976). Both serotonin and noradrenaline are involved in pain modulation (cf. Adams, 1997). Observations that emphasise the inter-relationship between serotonergic and opioidergic mechanisms in pain modulation are: (1) an increase in serotonin levels increases morphine analgesia (Sternbach *et al.*, 1976), (2) destruction of serotonergic pathways blocks the analgesic effect of morphine (e.g. Proudfit & Anderson, 1975) and (3) a decrease in serotonin levels decreases morphine analgesia (Twycross, 1994). Opioid and tricyclic antidepressants share a number of pharmacological characteristics in animal studies (Lee & Spencer, 1977). Tricyclic antidepressants block the presynaptic re-uptake of serotonin and noradrenaline; they also enhance morphine analgesia (Walsh, 1986).

Opioids have a central role in the decline of pain sensation. Five main groups of opioid receptors have been discovered. The mu receptor is mostly activated by morphine and is highly naloxone (morphine antidote) sensitive. Other receptors are the kappa, sigma, delta and epsilon. Mu receptors are heavily dissipated in the PAG, brain stem, limbic system and spinal cord, while other receptors are less active in the pain modulating system. As the study of opioid actions advanced, it became apparent that the various opioid receptor subtypes mediated different actions, underscoring the importance of establishing the differential distributions of subtypes of opioid binding sites. White and gray brain matter absorb different levels of radioactive emission, due to their different densities. Most brain regions contain a mixture of white and gray matter. Defatting the tissues eliminates differential quenching, but the procedure also greatly lowers opioid binding, eliminating any simple solution. Thus opioid binding studies should be interpreted with caution.

Three groups of endogenous opioid peptides have been found: (1) enkephalin, highly concentrated in the spinal and supraspinal systems with a high specificity for the delta receptor, (2) dynorphine, found in the hypothalamus, periaqueductal gray matter, reticular formation and spinal dorsal horn with a high specificity for the kappa receptor and (3) beta-endorphins, concentrated mostly in the hypothalamus, with a high specificity for the mu receptor. The opioid peptides form the chemical messengers of a widespread and complex inhibitory signalling system. Endogenous and exogenous opioids act to block both transmitter release from nociceptor afferent terminals and transmitter action postsynaptically. Destruction of nociceptive primary afferents leads to a significant reduction in opioid binding sites in the dorsal horn (Fields, Emson, Leigh, Gilbert & Iverson, 1980). This may in part explain the reduced opioid responsiveness observed with most neuropathic pains. The opioids have a specific function in the dorsal horn as they inhibit the releasing of SP, reduce the site of the peripheral receptive fields and act on the excitatory postsynaptic potential (EPSP). Their effect is therefore pre-and postsynaptic. The pain transmitting C fibres are more sensitive to opioids than the A-delta fibres (Twycross, 1994; Lampl, 1994). A more detailed account of the ascending, cortical and descending neurophysiological sytems involved in the transmission of nociception is available elsewhere (e.g. Adams, 1997; Lampl, 1994; Bonica, 1990)

Cancer pain

Many epidemiological studies report that about one third of adult patients receiving therapy for cancer and up to 60% of patients with advanced cancer experience moderate to severe pain sufficient to reduce their activity or to require the use of drugs (Foley, 1985). Pain is experienced by 20-50% of cancer patients at diagnosis and varies according to the primary site and by up to 75% of patients with advanced cancer (Kane, Wales, Bernstein, Leibowitz & Kaplan, 1984; Bonica, 1990; Twycross, 1994). Pain is moderate or severe in 40-50% of patients and very severe in 25-30% of patients (Bonica, 1990). Cancer pain is primarily produced by processes which affect nociceptors and their afferent peripheral nerve fibres (Payne, 1989). Pain associated with cancer may result from tumour infiltration of pain-sensitive structures, injury to nerves, bone and soft tissue resulting from chemotherapy, radiotherapy or surgery, or vascular occlusion by tumour (Payne, 1989; Foley, 1985; Twycross, 1994). Pain occurs with varying frequency in different cancers and is present most commonly in cancers affecting bone, the cervix and the mouth when it occurs in about 80-85% of patients. At the other end of the scale, it is far less common in cases of lymphoma (20%) or leukaemia (5%). Pain is caused by a number of factors including tissue destruction, pressure, trauma, neurological involvement, muscle spasm, infection, ischaemia or disturbed metabolic function. Each of these may require a different method of control, so a clear diagnosis of the cause of pain is required before logical treatment is prescribed. It is important to remember that many patients, particularly the elderly, may have multiple pathology and that their pain may not be related to their cancer but to other conditions such as arthritis (Hull *et al.*, 1989). The cancer patient with pain has served as a clinical model for the study of acute and chronic pain in humans (Payne, 1989). The Oxford Textbook of Palliative Medicine classifies pain as somatic, visceral, neuropathic or sympathetically maintained (Twycross, 1994). Patients with cancer may be expected to have co-existing somatic sources of pain due to tumour infiltration, possibly perpetuating a cycle leading to sympathetic overactivity.

Somatic and visceral pain share certain characteristics in that both types of pain are constant and aching, with somatic pain usually well localised while visceral pain is poorly localised (Twycross, 1994) and often referred to cutaneous sites (Payne, 1989). Metastatic tumour infiltration of bone and gastrointestinal and genito-urinary tumours that invade abdominal and pelvic viscera are very common causes of pain in the cancer patient (Foley, 1985). Metastatic bone disease, frequently associated with bone destruction and new bone formation, causes the most common pain syndrome in patients with cancer (Foley, 1985). Visceral pain is also common in the cancer patient and presumably results from the production of an inflammatory response and the release of algesic chemicals in the vicinity of nociceptors. Common examples are abdominal, back and shoulder pain resulting from liver metastasis and pancreatic cancer, often described as deep, squeezing and pressure and may be associated with nausea, vomiting and diaphoresis, particularly when acute. Visceral pain is often referred to cutaneous sites, which may be far from the lesion (e.g. shoulder pain resulting from diaphragmatic irritation) and associated with tenderness at the cutaneous site (Payne, 1989). Visceral pain is frequently accompanied by skeletal muscle contractures and spasms which last for a considerable amount of time and which contribute greatly to the patient's discomfort. Many forms of visceral pain are accompanied by autonomic reflexes such as tachycardia, a rise in blood pressure and sweating (Twycross, 1994). Although not nearly as well studied as their cutaneous counterparts, muscular and visceral nociceptors have been found in almost all organs studied and they appear to have anatomic and physiological properties similar to those of cutaneous nociceptors (Willis, 1985; Campbell & Myer, 1986; Foreman, 1986). The visceral fibres contain a very high amount of C fibres compared to A-delta fibres (Payne, 1989). The visceral nociceptive axons transduce pain stimuli characterised by an aching type of pain in the chest, abdomen and pelvis. All forms of visceral pain are poorly localised and most are felt in areas considerably larger than the size of the originating viscus. As the pain becomes more intense, so the somatic area in which the pain is felt becomes larger. This suggests that the representation of internal organs within the CNS is imprecise (Twycross, 1994). Somatic and visceral pain are managed by treating the tumour (when possible) and using appropriate nonopioid, opioid and adjuvant analgesic drugs (Payne, 1989).

The terms neuropathic, de-afferentation and dysaesthetic are terms used to describe pain associated with neural dysfunction (Twycross, 1994). Deafferentation pain results from injury to the peripheral and/or central nervous system as a result of tumour compression or infiltration of peripheral nerves or the spinal cord, or injury to peripheral nerves as a result of surgery, chemotherapy or radiation therapy for cancer. Deafferentation pain is most often a complication of tumour infiltration of large peripheral nerve trunks (e.g. metastatic brachial plexopathy in breast and lung cancer) but may also be a complication of cancer therapy, such as vincristine-induced peripheral neuropathy or radiation-induced myelopathy or plexopathy (Payne, 1989). Examples of deafferentation pain are metastatic or radiation-induced brachial or lumbosacral plexopathies, epidural spinal cord and/or cauda equina compression and postherpatic neuralgia (Foley, 1985). Pain due to deafferentation is experienced as paroxysmal shooting or electrical shock-like pain on a background of burning constricting sensation (Payne, 1989). These pain syndromes may be very difficult to treat by conventional analgesic or surgical therapies since the basic pathophysiology involves injury to the nervous system, which may not heal even if the underlying cause can be reversed. The use of adjuvant analgesic/antidepressant agents are often added to opioids and may be more useful than opioids in the management of deafferentation pain and anaesthetic blockade of somatic and autonomic nerves may be useful (Payne, 1989; Twycross, 1994). Neuropathic pain is pain initiated or caused by a primary lesion, dysfunction in the nervous system (Merskey & Bogduk, 1994). Individuals afflicted with neuropathic pain often show an exaggerated sensitivity to nociceptive stimuli (hyperalgesia) or perceive normally innocuous stimuli as painful (allodynia) (Payne, 1986). In spite of recent progress in pain research, understanding of this pain syndrome is limited, as are the available treatments which allow sufferers to lead a normal and productive life. Dysesthesia is an abnormal sensation whether spontaneous or evoked (Merskey & Bogduk, 1994). A number of neuroanatomical and neurochemical changes occurring after severe nerve injury may underlie the dysesthesias associated with neuropathic states. For example, it has been proposed that the large-diameter myelinated neurons undergo phenotypic changes in response to nerve injury, resulting in inappropriate synaptic connections (e.g. Woolf, Shortland & Coggeshall, 1992). In peripheral nerve lesions long-standing noxious input may eventually change the connectivity in the central pain pathways so that, even if the noxious input is removed, the pain still persists due to the central changes (Andersson, 1987).

At present there are no indications that the pathophysiology of cancer pain is essentially different from that of other types of chronic pain. However, it is possible that in certain conditions the cancer cells produce metabolites which have a potent action on nociceptors or afferent fibres, thus giving cancer pain a different dimension from other chronic pain (Andersson, 1987). The receptors of the slowly conducting C-fibres react to biochemical changes in the tissue. The nature of the chemical reaction is not fully understood. The effect may be mediated via algesic substances such as bradykinin, prostaglandins and SP which are formed in the tissue and which modulate the excitability of nociceptors. These affect vasodilation and the latter facilitates the extravasation of plasma and changes to the permeability of the small blood vessels. Prostaglandins play an important role in increased sensitivity of the nociceptors after tissue damage and during inflammation, having the ability to potentiate the receptor sensibility to such an extent that normally non-noxious stimuli become painful (Andersson, 1987). In cancer tumours the nociceptors may be influenced by mechanical stimulation due to growing tumour or high metabolic activity in the cells. In addition, occlusion of blood vessels or hollow organs by the cancer may create ischaemia, with a local decrease of pH and pO_2 and an increased accumulation of metabolic substances. Inflammatory reactions with chemical changes may also lead to increased sensitivity of the nociceptors and as a consequence the nociceptors have a lower threshold to nociceptive stimuli (Andersson, 1987).

A new aspect in the neurochemistry of pain was postulated by researchers who found that the NMDA receptor, a subgroup of the excitatory neurotransmitter glutamate, contributes to hyperalgesia by intensifying the pain message in the spinal cord. It seems that NMDA inhibition blocks the over-reaction of pain by leaving the normal sensation of pain intact. Due to the repeated pain messages after a tissue injury, the NMDA receptor probably sensitises the spinal cord cells for the next signal (Lampl, 1994). A repetitive transcutaneous stimulus to the receptive field of a C fibre in the rat leads to a dramatic increase in the neuronal response in the dorsal horn of up to 20 times. This phenomenon has been called 'wind up'. It reaches a maximum after 16 seconds. It can transform 30 seconds of stimulation into several minutes of response (Twycross, 1994). Nociception associated with wind up is less responsive to opioids (Dickenson & Sullivan, 1986). Further, although morphine cannot totally prevent wind up, pre-treatment with morphine is more effective than post-treatment. On the other hand, NMDA antagonists prevent wind up, converting the otherwise enhanced response into a steady one (Wilcox, 1991; Twycross, 1994). Another substance that may have a central role in pain message is GABA (y-aminobutryic acid), an inhibitory neurotransmitter. It probably reacts by the differentiation of sensory messages and prevents a mixture of pain sensation with other sensory inputs. The GABA is most likely active in the thalamus and dorsal horn (Lampl, 1994). 'Wind-up' is not identical to 'central sensitisation'. Following peripheral nerve injury, the terminals of myelinated afferents sprout into neighbouring regions of the dorsal horn. Sustained C fibre barrage in primary afferent fibres leads to other morphological changes in the dorsal horn with central sensitisation, which is manifested by the enlargement of primary receptive fields and alterations in stimulus-response relationships, clinically perceived as allodynia (perceiving a normally non-noxious stimulus as noxious) and hyperpathia (delayed and over reaction to a painful stimulus) (Shipton, 1999).

Pain syndromes associated with cancer therapy

Clinical pain syndromes occur in the course of or subsequent to treatment of cancer patients with surgery, chemotherapy or radiation therapy. Postsurgery pain can arise (a) post-thorocotomy, with pain in the distribution of an intercostal nerve characterised by a constant pain in the area of sensory loss with occasional intermittent lancinating pains ; (b) postmastectomy, with pain in the posterior arm, axilla and anterior chest wall in patients following radical mastectomy, due to interruption of the intercostobrachial nerve. The pain is characterised as a tight, constricting, burning pain in the posterior arm and axilla which radiates across the anterior chest. (c) Pain following radical neck dissection occurs from surgical injury or interruption of the cervical nerves. The pain is characterised by a constant burning sensation in the area of sensory loss. (d) Phantom-limb pain occurs following surgical amputation of a limb and is usually characterised by a burning, cramping pain in the phantom limb, often identical in nature and location to the preoperative pain. (e) Pain problems can also occur following (i) chemotherapy, due to neurotoxic effects of some drugs, (ii) radiotherapy due to fibrosis, radiation myelopathy or radiation induced tumours and (iii) long-term steroid therapy can induce bone necrosis and sudden withdrawal can induce pseudo-rheumatism (Foley, 1987).

Metastatic bone disease: causation and treatment

Bone metastases account for more than 95% of malignant bone tumours and are a frequent, very distressing complication of many cancers (e.g. Powell & Hoskin, 1998; McDonnell, 1999). The pain brought about by bone metastases is characteristically dull, unremitting and exacerbated by movement. Although usually localised, it may be referred or induce symptoms of nerve compression. It is well recognised that the extent of disease does not always correlate with the severity of symptoms. Patients may have widespread osseous metastases with minimal symptoms or conversely may have severe pain in the presence of only a solitary bone lesion (Powell & Hoskin, 1998). It is postulated that bone pain is caused by the presence of tumour causing local oedema, distortion of the periosteum and growth into surrounding tissues. It is widely recognised that cancer pain caused by the invasion of bony structures is probably the most common etiology of tumour-related pain. Myelinated and unmyelinated afferent fibres are present in bone and their density is greatest in the periosteum. Prostaglandins are necessary for osteolytic and osteoclastic metastatic bone changes and prostaglandin E_2 is known to sensitise nociceptors and produce hyperalgesia (Payne, 1989). The analgesic action of nonsteroidal anti-inflammatory drugs (NSAIDS) in bone pain is probably due to the inhibitory effects these compound have on prostaglandin synthesis (Johnson & Parris, 1997). Although virtually all cancers can give rise to bone metastases, it is carcinoma of the breast, prostate, bronchus and kidney that show a particular propensity for dissemination to bone and may present in up to 50% of patients with these malignancies. In general, once bone metastases have developed, the overall prognosis is poor and the patient is considered to have incurable disease. There are exceptions to this and these include germ-cell tumours, well-differentiated thyroid cancer and high-grade non-Hodgkin's lymphoma. In these malignancies curative systemic treatment is available. However, for the majority of patients who have incurable bone metastases, survival is greatly influenced by primary histology, patients with melanoma and lung cancer having a median survival of less than 6 months, compared with 2 years for breast and prostatic cancer. For this latter group of patients, where the disease may run a long clinical course and in whom bone may be the only clinically detectable site of metastases, effective palliation is of particular importance in maintaining function and improving quality of life (Powell & Hoskin, 1998).

The primary objectives of treatment of bone metastases are relief of painful symptoms, prevention of pathological fractures and treatment of spinal cord or nerve compression. Routine treatment consists of palliative chemotherapy, bisphosphonates and radiation (McDonnell, 1999). Radiotherapy is established as one of the most effective methods of alleviating bone pain from metastatic disease, although the biological basis of its action in providing symptom relief remains uncertain. The results of recent prospective randomised trials not only confirm its efficacy but suggest that a single dose of local irradiation will provide some degree of pain relief in the majority of patients. For those with multiple sites of pain, hemi-body irradiation can achieve similar rates of response and perhaps delay the inevitable progression of bone disease, although greater toxicity from the gastrointestinal tract and bone marrow may be expected (Powell & Hoskin, 1998). The recalcification and reossification of bone which takes place following irradiation are probably only partly responsible for the control of symptoms. Very low doses of irradiation can confer significant pain relief, often occurring within hours of treatment (Hoskin, Ford & Harmer, 1989). It has been suggested that this rapid analgesic effect is mediated by a cytotoxic response, with inhibition of the release of substances such as prostaglandins and kinins which are known to mediate the pain response (e.g. Hoskin, 1989). In summary, the etiology of bone pain can be attributed to two additive and possibly synergistic mechanisms: (1) invasion or stretching of the pain sensitive periosteum and (2) the sensitisation of nerves in bony tissue that are normally pain-insensitive by autocoids produced during osteoclastic activity. Effective treatment results from inhibiting the osteolytic activity, minimising the effect of heightened peripheral neuron sensitivity or stabilising pathological fractures (Johnson & Parris, 1997).

The use of analgesia for the relief of cancer pain

As it is the symptoms that are treated in palliative therapy rather than specific disease, it is more appropriate for palliative therapy to be discussed by symptom rather than by disease type. The symptoms are very dependent upon the site of the disease. Pain may be caused by either primary or secondary tumour at any site. In gynaecological cancer, for example, pain is commonly in the pelvis or in the small of the back, but if there is sacral plexus involvement there may well be radiation of pain down the inner aspects of the thighs and into the back of the knee. A patient presenting with pain such as this requires both radiotherapy for the long-term control of the symptom and also analgesia for immediate relief (Powell & Hoskin, 1998).

It has been more than a decade since the WHO established the primary role of opioid analgesia in cancer pain relief. The three step analgesic ladder outlines the titration of nonopioid, opioid and adjuvant analgesics alone or in combination, to meet the needs of the individual patient. The WHO 'analgesic ladder' serves as a model for choosing among the three steps of analgesic treatment, i.e. when nonopioids alone cannot control a person's pain, weak opioids and subsequently strong opioid analgesics are then added (Manfredi, Weinstein, Chandler & Payne, 1997). Some types of cancer pain respond to nonopioid drugs alone. Pain of an increasing intensity may be relieved by combining a weak opioid with a nonopioid or may require a stronger opioid and, in selected cases, analgesic adjuvants may also be useful. This approach is effective in lessening the pain in 71-97% of patients (Pace & Meffert, 1997). Validation of the WHO ladder of pain control over a ten-year period is reported by Zech, Grond, Lynch, Hertel & Lehmann (1995). In their study, 2118 patients were assessed over 140,473 treatment days, an average of 66 days per patient. A highly significant reduction in pain was achieved in the first week of treatment. Good relief was reported in 76% of the patients, satisfactory relief in 12% and inadequate relief in 12% of the patients over the treatment period. Neuropsychiatric symptoms, nausea, constipation and anorexia occurred on 20-25% of the treatment days. It is arguable that many of these symptoms could be the result of narcotic and adjuvant pain medication. However, with increasing advances being made in intervention pain techniques, the current WHO ladder is becoming perceived as not as comprehensive an approach to pain control as might be possible (McDonnell, 1999). Invasive procedures, such as nerve blocks and spinal epidurals, can be extremely effective in relieving pain and distress. The onset of relief after palliative treatments for bone metastases has a lag time, which with radiotherapy for example, can take four weeks to achieve maximum benefit. Short-term neural blockade can achieve optimal pain relief in this period (McDonnell, 1999).

Inflammatory Pain and NSAIDs Many health care professionals believe that every analgesic regimen should include a nonsteroidal anti-inflammatory drug (NSAID). NSAIDs are useful for treating cancer pain of mild intensity and also musculoskeletal and bone pain, especially when associated with inflammatory lesions. NSAIDs inhibit the enzyme cyclo-oxygenase (COX-1 and COX-2), thus resulting in a decrease in the pain-sensitising effects of prostaglandins (Pace & Meffert, 1997). The major advantage of NSAIDs for the control of pain is that, unlike opiates, chronic usage does not lead to tolerance or addiction. Aspirin, the most common NSAID, has been widely used for pain relief for decades. However, serious side effects are associated with the use of NSAIDs, including haemorrhage, gastric ulceration, renal and hepatic failure, skin reaction and asthma. In very recent years NSAIDs that can block COX-2, which produces prostaglandins, without interfering with the protective mechanisms of COX-1 have been successfully developed and shown to have fewer side effects (Bennett, 1999).

Opioids and cancer pain: Morphine is the drug of choice for the treatment of severe pain associated with cancer. As with other strong opioids there is no ceiling to the analgesic effect. However, side effects may intervene before optimal analgesia is obtained. Morphine is metabolised in the liver where it undergoes glucuronidation at the 3 and 6 positions. M6G binds to mu-and delta-receptors in the brain and spinal cord, with an affinity similar to that of morphine. Heroin is a semisynthetic lipid-soluble opioid analgesic rapidly metabolised to 6-acetyl-morphine and morphine. After oral administration neither heroin nor 6-acetyl-morphine can be detected in plasma. Heroin does not have any demonstrated advantages over morphine and is a less efficient way of delivering morphine (Manfredi *et al.*, 1997). With chronic morphine use a functional uncoupling of opioid receptors with G proteins, normally produced upon activation of opioid receptors, occurs and the acute effects of the drug decrease. As a result, tolerance develops and higher doses of opioid are needed to trigger the second messenger response. An increase in dose will usually restore analgesia without increasing side effects. Ketamine, a general aneasthetic with NMDA receptor antagonist activity, has been shown to induce analgesia in patients who do not respond to high doses of morphine. In addition to uncoupling opioid receptors from G proteins, chronic opioid administration decreases the synthesis of endogenous opioid peptides. Abrupt discontinuation of the exogenous opioid causes opioid-responsive neurons to enter a phase of rebound hyperexcitability. The increased firing of these neurons is the cellular mechanism of the opioid withdrawal syndrome. Eventually, G protein-opioid receptor coupling and endogenous opioid synthesis are restored and the withdrawal syndrome and tolerance are reversed. Hydromorphone, a semisynthetic opioid agonist, is a somewhat shorter-acting agent than morphine but has a higher peak effect. Because of its high potency and water solubility, hydromorphone is the drug of choice for subcutaneous administration (Manfredi *et al.*, 1997).

The use of opioid analgesics in the clinical treatment of neuropathic pain is a matter of considerable controversy. The view is held by a number of investigators that clinical neuropathic pain is resistant to amelioration by opioids. For example, neuropathic pains of several origins have been shown to be resistant to treatment with morphine infusions (Arner & Meyerson, 1988). In contrast, other studies demonstrate efficacy of opioids in controlling neuropathic pain, but in greater than normally administered doses (e.g. Jadad, Carroll, Glynn, Moore & McQuay, 1992). Hydromorphone infusions have achieved adequate analgesia in neuropathic pain patients. Thus it has been suggested that the reported failure of morphine and other opioid analgesics to relieve neuropathic pain is due to underdosing of the patient (Portenoy, Foley & Inturrisi, 1990). Clearly, additional investigations into the clinical utility of opioids, taking into consideration the pain modality, route of administration, dosage and opioids compound, need to be performed to fully evaluate treatment protocols for neuropathic pain (Ossipov, Malan, Lai & Porreca, 1997).

While opioids are the most useful drugs for controlling severe pain, nonopioids can be useful as an adjunct. Gabapentin is an anticonvulsant medication used recently as an effective adjuvant for treating neuropathic cancer pain. In a study by Caraceni, Zecca, Martini & DeConno (1999), gabapentin, administered as an ‘add on’ therapy to 22 patients with neuropathic cancer pain only partially responsive to opioid therapy, was considered by 20 patients to be efficacious in relieving their symptoms. There is strong evidence from systemic reviews of randomised trials that trycyclic antidepressants are effective treatments for neuropathic pain disorders. Used in addition to conventional analgesia, they can be particularly effective in patients with cancer who have pain in multiple sites, some nociceptive and some neuropathic, helping to improve sleep for these patients (McQuay, 1997). Calcitonin, affecting bone metabolism, is useful for bone pain or nerve compression. Steroids, such as dexamethasone, relieve bone pain by diminishing the inflammatory and oedematous reaction in and around the metastases, so reducing the tumour size. Anti-spasmodics, such as propantheline or hyoscine butylbromide, are often very helpful for colic-like pain possibly due to partial obstruction in the intestine, urinary or biliary tract. Baclofen and similar anti-spasmodics are useful for muscle spasm which may be very painful. Diuretics are useful co-analgesics (e.g. Hanratty, 1989).

In the last decade there has been an increased interest in the use of intrathecal opioids in the treatment of intractable pain due to cancer, when oral and parenteral administration of analgesics is insufficient or intolerable. Since 1993, continuous infusion devices have been implanted in selected patients with cancer in Ireland. Although considered a therapy of last resort and a technique requiring extremely careful physical and psychological screening, all patients showed marked improvement in pain scores and activity within two weeks of commencement of intrathecal morphine infusion therapy (Chambers & MacSullivan, 1994). A comprehensive account of analgesia for cancer pain is beyond the scope of this thesis. A working knowledge of the pharmacology of all agents is necessary so as to determine therapeutic efficacy and avoid unacceptable side effects (Parris, 1997). Effective pain control requires the consideration of all physiological and psychological factors concerning the person with cancer pain. Appropriate pharmacological intervention, designed to break the cycle of pain, of loss of sleep, increased anxiety and perception of pain (Twycross, 1994) and the methodology by which this is maximally achieved in any one individual, is now frequently evaluated and updated in hospice and pain care settings. Further information is provided by sponsored meetings, societies and associations dedicated to pain, newly published literature, seminars, conferences, journals, workshops, educational courses and information available through the Internet. Present limitations to the efficacy of pain control by pharmacotherapy may be overcome in the future. Through advances in molecular biology technology, improved pain control interventions may be made possible by the study of pain at the level of the gene, using transgenic mice. Progression in transgenic technology should contribute greatly to pain research. An outline of the mechanisms involved is described elsewhere (Shipton, 1999).

The psychobiology of pain

Pain must be approached as a fundamentally subjective state because no satisfactory objective indicators of pain exist. Even when the clinician elects to gather objective indicators of behaviour in measuring pain, it is necessary to validate such measures with subjective reports of pain (Bonica, 1990). In the second World War, over 200 seriously injured soldiers were asked about pain and their need of analgesia shortly after entry into a Forward hospital. Only 24% said they had severe pain and only a similar number (27%) requested medication, whereas 80% of a group of male civilians undergoing surgery required analgesia, although their tissue damage was similar to that of the soldiers (Beecher, 1956). The soldiers may have seen their wounds as a way of releasing them from duty at the front line and because they sustained their injuries in a heroic context, they experienced less pain than the civilians who saw surgery as an interruption of their daily lives (Sofaer, 1998). A more recent study of patients who underwent appendectomy in Lebanon following the war in 1975-1976 showed that these patients required less analgesia postoperatively than a similar group of patients who underwent similar surgery before the war. The findings implied that patients' perception of pain had changed due to the psychological trauma of war, resulting in patients requiring less analgesia to relieve postoperative pain (Armenian, Chamieh & Barak, 1981; Sofaer, 1998).

Pain thresholds vary both between and within ethnic groups, even under controlled laboratory conditions (Twycross, 1994). Keele (1967) found that normal individuals from a single ethnic group could be separated into hypersensitives, normosensitives and hyposensitives. Differences in pain sensitivity relate partly to differences in endogenous opioid production (Buchsbaum, Davis & Bunney, 1977). Ethnic and cultural factors (attitudes, beliefs, emotions, psychological states) are also important (Bates, Edwards & Anderson, 1993). The characteristics of pain to be quantified depend upon the patient population in question, the purpose of the assessment and perhaps the theoretical orientation or scientific assumptions of the clinician investigator. There is no universal index of pain that is equally useful for all health care professionals. The greatest difficulty in measuring pain is the intrinsic predicament of measuring subjective states of any sort: measurement is only valid when the numbers obtained correspond in a one-to-one fashion to the underlying variable that is being quantified. This validity can never be tested in the assessment of pain states; consequently, numbers obtained from patients or test instruments as pain measures are not so much actual scores as estimates of pain (Chapman & Syrjala, 1990). Cancer pain contains elements of both acute and chronic pain (Twycross, 1994) especially arousal and vegetative states. State (how a person feels at the moment) changes in measures drawn from chronic pain patients are usually of limited value because it is the trait (how a person feels generally) variable that is in question. Trait measures in contrast can allow the clinician to determine whether the chronic pain has really changed. The treatment of pain in a chronic pain patient should be seen as a long-range rather than a short-range investment. Therefore, assessment of chronic pain must involve trends and long-range change. In addition, such assessment usually extends beyond the measurement of pain intensity alone to the measurement of the impact of pain on patterns of physical and psychosocial functioning (Chapman & Syrjala 1990; Twycross, 1994).

Understanding the factors that promote pain perception are of primary importance in pain control. A study by Flor, Knost & Birbaumer (1997) supports the notion of pain-related implicit memory structures in the brain of chronic pain patients that may selectively draw attention to pain-related stimuli and may thus enhance pain perception. Dalton & Feuerstein (1989) concluded that patients with cancer did not report fear of pain and the results of their study did not support anecdotal impressions that the level of reported pain and fear of pain is significantly higher in patients with cancer pain compared to patients with non-cancer pain. However, a study by Asmundson, Kuperos & Norton (1997), which examined the nature of the apparent attentional bias for pain-related cues in patients with chronic pain, concluded that the operation of the information-processing system in patients with chronic pain may be dependent on their trait predisposition to fear pain. Strang (1997) concluded that, for patients with cancer, the fear of future pain problems was related to the duration of the pain. Partly unrelieved pain contributes to the overall total pain experience, not only by causing immediate physical suffering, but also by increasing anxiety levels and fear about the future. Pain is a multidimensional experience. Thus, not only pain intensity but an evaluative, subjective measurement of the patient's pain experience is required to avoid oversimplification of the problem of pain (Chapman & Syrjala, 1990; Twycross, 1994).

The effects of cancer pain

Le Shan (1964) makes the analogy between the experience of chronic pain and that of a nightmare. In the terror dream (1) terrible things are being done to the person, (2) others, or outside forces, are in control and the will is helpless; and (3) there is no time limit set, no ability to predict when the terror will end. People in pain are in the same terrible situation: terrible things are being done to them and they do not know if worse will happen; they have no control and are helpless to take effective action; no time limit is given. This aspect of the psychic assault on the integrity of the ego that accompanies pain is a major one; the patient lives during the waking state in the cosmos of the nightmare, which is further emphasised by the meaninglessness and inexplicability of pain, which makes it extremely difficult to cope with. It is common, in the generalisation from acute to chronic pain, to assign to pain the idea of a warning; a signal that something is wrong and that something should be done about it. Chronic pain, however, indicates only a state of existence. It does not warn or instruct and may be severe enough to disrupt potentially useful activities and habits. The adequate expression of thirst is to drink. The adequate expression of this kind of pain is only a scream (Le Shan, 1964).

Patients with persistent pain often have major life adjustment problems. Many of these patients are depressed and depressed mood may perpetuate their pain. However, a re-orientation of these expectations is necessary when working with cancer patients in pain. Relatively few patients with cancer will have operant-based pain (Cleeland & Tearnan, 1986). Massie & Holland (1987), Breitbart (1989) and Roth & Breitbart (1996) pointed out that an increased incidence of psychiatric disturbance, in particular, severe anxiety and depression, delirium and suicidal ideation, is found in patients with pain. All are more likely to occur in the cancer patient who has pain. Psychiatric symptoms in patients with cancer pain must be viewed initially as a consequence of uncontrolled pain (Breitbart 1989).

Pain is one of the most feared consequences of cancer (Cleeland, 1984a, 1984b). The presence of pain, despite efforts to treat it, represent a continued source of frustration for patients, their families and health care professionals. Although often one of the early indicators of the presence of disease, pain is not a significant problem for the majority of cancer patients in the early stages of disease, with approximately 5%-10% of patients with solid tumours reporting pain at a level that interferes with mood and activity. However, when metastatic disease is present, about one in three patients reports significant pain (Cleeland, 1984a, 1984b). Depending upon the type of cancer, one third of patients with metastatic cancer may report pain at a level of severity that interferes with their social and physical activity and enjoyment of life (Daut & Cleeland, 1982). As well as impacting upon mood status and sense of well-being, pain can interfere with a wide range of aspects of daily living, including sleep, appetite, mobility and physical exercise, producing adverse effects on heath status (e.g. Cleeland & Tearnan, 1986).

Acute cancer pain caused by direct tumour involvement or cancer therapy produces pathophysiological, psychological and emotional reactions. However, the interpretation of the meaning of the pain has implication for emotional adjustment. If the pain is the initial symptom of cancer, it may be considered to be the harbinger of a serious illness and is consequently associated with severe anxiety and other emotional reactions. On the other hand, pain associated with cancer therapy usually results in less emotional distress, partly because this type of pain is more easily managed pharmacologically (Bonica, 1990). The physical deterioration of patients with cancer is more severe than that of patients with non-malignant chronic pain, because the former have to contend not only with problems of sleep disturbance but also with lack of appetite and with nausea and vomiting (Chapman, Syrjala, & Sargur, 1985; Bonica, 1990). Daut & Cleeland (1982) examined the specific effects of painful cancer in 667 patients and found that increased levels of pain diminished activity and enjoyment of life and interfered with daily living when pain was moderate to severe. For any given level of pain, patients who believed that symptoms represented worsening of their condition reported the greatest interference with activity and pleasure and 60-65% of patients with advanced cancer reported that pain disrupted their sleep. The next most affected were those who regarded pain as the result of treatment and the least affected were those who felt the pain was a result of unrelated causes. Similar effects were experienced by patients studied by Greenwald, Bonica, & Bergner (1987). An interaction between pain and anxiety in the setting of somatic illness is widely recognised. A study by Velikova, Selby, Snaith & Kirby (1995) found the relationship between cancer pain and anxiety to be significant, even when the possible mediating effect of the variables of illness severity and age were removed. Zimmerman, Story, Gaston-Johansson & Rowles (1996) found that cancer patients with pain had higher scores of depression, anxiety, somatisation and hostility than did cancer patients without pain.

Many patients with cancer pain, knowing that the causative factors are unremovable, cannot give meaningful purpose to the pain and develop feelings of hopelessness and despair. These feelings, like sleeplessness, spiral to greater proportions as the patient is subjected to surgical operations, chemotherapy, radiation therapy and other anticancer therapy. With each treatment the patient experiences hopefulness; if the therapy fails, this is followed by disappointment and gradually by increasing bitterness, anger and resentment. Some patients with advanced cancer develop intense fears of abandonment to a condition of unrelieved suffering (Bonica, 1990). For many patients with cancer, pain becomes the central focus of their lives and of the lives of their families. Most patients with advanced cancer are no longer able to sustain employment, thus increasing economic and emotional stress and compounding feelings of dependency and uselessness. The physical appearance and behaviour produced by the patient's pain and suffering stresses the family emotionally. This family distress is often perceived by the patient, consequently aggravating their pain and suffering. Some patients with severe intractable pain become so discouraged and desperate that they contemplate suicide (Bonica, 1990). In the terminal stages of most cancer, the majority of patients will report significant pain (Cleeland & Tearnan, 1986). In terminally ill patients, physiological, psychological and emotional reactions to cancer and to the pain progress to a severe degree (Bonica, 1990). After several weeks or months of pain, particularly if associated with insomnia, many cancer patients become overwhelmed by pain. Pain envelops their whole mental outlook. Such patients often find it difficult to describe the location or the nature of the pain precisely (Twycross, 1994). The issues of hopelessness, death and dying become more prominent and the suffering component requires very serious consideration. These reactions are greatly exacerbated by inadequate control of pain in the dying patient (Bonica, 1990).

When pain is persistent but stable, it can be argued that the patient's continued reporting of pain to whomever will listen produces undesirable consequences including social and family alienation. A study by Madison & Wilkie (1995) was the first to compare patient and family perceptions of sensory pain and to describe the relationships between these perceptions and psychological factors in patients with lung cancer and pain. Their findings indicate that family members understand the patient's pain location about 75% of the time. However, family members rarely understand the patient's pain intensity, pain quality or pain pattern. Findings also indicate that family members tend to overestimate strategies used by patients to cope with pain, especially in patients with low levels of anxiety and in patients with an internal locus of control. The study provides additional evidence to suggest that discrepancies may exist between family members and patient perceptions of the cancer pain experience. In 'The Cancer Ward,' after Rusanov's hospitalisation, Solzhenitsyn writes: 'But, in a few days, this whole close-knit, ideal Rusanov family ... had receded until it vanished on the other side of the tumour ... the tumour had divided him from them like a wall, and he remained alone on his side of it ...'(Abram, 1969).

Strang (1992) studied the emotional and social consequences of pain in patients with cancer related pain. Most patients report a decreased activity due to pain and in most cases the decrease correlated significantly with the intensity of the pain. The study highlighted the profound consequences of pain: physical suffering, emotional distress, social handicap and altered family roles. The physical limitations, debility and emotional reactions imposed by cancer are increased by the presence of pain and a serious consequence is a reduction in patients' social activities and contact with friends (Bonica, 1990). It may not be the cancer itself or the pain but their effects that may be responsible for the greater proportion of the distress levels of patients with cancer (Bonica, 1990).

Rarely, a patient may refuse interventions aimed at pain control. A patient's refusal to use the methods or treatments that can offer good pain control stem from three recognisable spiritual and psychological causes. One is the avoidance of the adjustment task, which the patient will start when he or she is ready. For some people that time never comes. This is their choice and as such should be recognised and the patient still supported. The second cause is a perceived value and integration of the experience of the pain itself. The third cause is the desire to be totally lucid and alert, a condition that may be threatened by the side effects of opioids. Once the clinician or caregiver has provided good education and counselling concerning the realistic aspects of pain management, discussing such issues as fear of addiction, fear that tolerance will reduce the efficacy of the opioid later on when it is 'most needed,' alternative treatment modalities and predictable side effects, the clinician or caregiver must respect the patient's right to refuse pain management treatment, even if that means accepting a higher level of pain than the practitioner thinks is in the patient's best interests, while providing the best palliative care possible. It is just as much the informed patient's right to refuse pain management as it is his or her right to refuse any other treatment or therapy (Brenneis, 1997).

Suffering not only occurs in those with severe and chronic pain; minor pain can also cause great suffering if its cause is unknown. Suffering is also more likely if the pain is believed to be uncontrollable. Patients are more likely to suffer if they feel socially isolated. Their isolation may occur because the physician cannot legitimate their pain, perhaps implying that it may be psychological or faked, or in conditions where patients feel that they are unable to talk about their distress (Cassel, 1982). Individual differences in the ability to use language to describe emotional experiences and to express emotions are well documented, particularly where negative emotions are concerned (Rodin & Salovey, 1989) and this is directly relevant to expressions of distress and suffering commonly associated with pain. At a practical level, Cassel (1982) indicates that where meaning can be derived for threatening events, suffering can often be substantially reduced (Skevington,1995). Many people regard cancer as being associated with pain, destruction, loss and often with death (Bonica, 1990). Ferrell & Dean (1995) point out that a neglected area of pain management is enhancing the individual's ability to derive the meaning from pain and suffering associated with illness. Because pain is often a metaphor for impending death, the meaning derived from pain may contribute to the ultimate meaning of death for the individual.

Cancer pain in the elderly

With regard to the incidence of cancer pain, the most severely neglected study group is that of the frail elderly over age 85. In a study of 1308 outpatients with metastatic cancer from 54 Eastern Co-operative Oncology Group affiliated institutions, age of 70 or greater was one of the predictors of inadequate pain management for men and women (Cleeland, Gonin & Hatfield, 1994). The elderly are the single group most likely to suffer not only from cancer pain but from multiple other sources of chronic pain. Population-based studies have estimated that as many as 25-50% of community-dwelling elderly suffer with pain problems (Ferrell, 1991). Arthritis may affect as many as 80% of elderly over age 65, many of whom suffer significant pain. High incidence of morbidity associated with pain is prevalent in the elderly (Ferrell, Ferrell & Osterweil, 1990). In the study by Cleeland *et al.* (1994) more than half the patients had pain, although the exact prevalence rates among the older groups are not stated. The increasing prevalence of cancer with advancing age makes a persuasive argument that a significant percentage of geriatric patients suffer with pain (Stein, 1996). Factors that have been suggested as explanations of any differences in the pain experiences of older people include the possibility that, in this population subgroup, pain may be better controlled because of altered pharmacokinetics that increase the efficacy of analgesics, or elderly patients may report less pain because of increased stoicism, slowness to respond to painful stimuli, and/or mild cognitive deficit (Foley, 1994). Health care professionals may also have misconceptions about pain in the geriatric population. They may believe that older patients do not experience the same intensity of pain as do younger counterparts. They may also think that older patients are unable to tolerate opioid therapy or that those with some degree of cognitive impairment cannot be assessed for pain. Finally, they may believe that elderly patients without typical signs of autonomic discharge, as witnessed in acute pain syndromes, are not suffering from pain. Psychological distress is an important part of the total pain experience for the older patient with cancer pain. Some persons carry the burden of a lifetime of previous pain experience. Appropriate pain management of the elderly person with cancer pain requires continuing vigilance and consideration of all possible sources of pain (Stein, 1996).

Summary

Pain is experienced by 75% of patient with advanced cancer. Although major advances have been made in the treatment of cancer and its associated pain, undertreatment of cancer pain still constitutes a major public health problem in many areas of the world (Twycross, 1994). The concept of total pain is comprised of physical, psychological, emotional and social elements (Saunders, 1967), allowing for more understanding of the suffering pain can inflict (Cassel, 1982; Moon, 1985). The Gate Control Theory of pain represented a major advance in scientific thinking and allowed for past experience and anxiety to influence a person's perception of pain (Melzack & Wall, 1965; Sofaer, 1998). Since the late 1980s when the Gate Control Theory was expanded to include the idea of central sensitisation, the discovery that prolonged nociception led to central sensitisation made for the suggestion that prophylactic analgesia might be more effective than analgesia given after the onset of pain. Animal and human studies lend support to this hypothesis (Twycross, 1994). The aim of effective pain control is to pre-empt the pain, in order to counter further nociceptor sensitisation. If adequate pain medication is given in the early stages of pain experience, the effect of analgesia can be longer lasting, as preventing an increase in nociceptor sensitisation should maintain a higher nociceptor threshold to nociceptive stimuli (Twycross, 1994). At present there are no indications that the pathophysiology of cancer pain is different from that of other types of chronic pain (Andersson, 1987). Increasing awareness of the complexities of acute pain perception makes the dismissal of chronic pain states as psychological phenomena more difficult (Sofaer, 1998). Pain must be approached as a fundamentally subjective phenomenon (Bonica, 1990

The perception of pain has been shown to be attenuated or accelerated by emotional processes (Craig, 1983; Dalton & Feuerstein, 1989). Wilkie & Keefe (1991) point out that interventions aimed at reinforcing or expanding a patient's pain coping repertoire should be developed, with consideration given to the patient's anxiety level, pain intensity, pain quality and pain expression preference. This has implications for patients' and health care professionals' communication abilities. In a study looking at the influence of cancer and cancer pain on existential issues for cancer patients, Strang (1997) found that the fear of future pain problems was related to the duration of the pain. Partly unrelieved pain contributes to the 'total pain experience', not only by causing immediate physical suffering, but also by increasing the anxiety level and fear of future Effective symptom control is a prerequisite for a good quality of life. Wakefield (1995) discussed the fundamental problem for health care practitioners in achieving a quantum leap in order to establish an attitudinal shift from one using scientific strategies in pain management to one that encompasses the notion of humanistic, eclectic principles. Optimal pain control, utilising holistic priniciples, should aim to bring a peaceful transition to the mind, body and spirit to enhance quality of life (Pace & Meffert, 1997).

THEORIES OF STRESS, EMOTION AND COPING AND THEIR APPLICATION TO CANCER

Definition and theories of stress

The word stress is derived from Latin and was used popularly in the seventeenth century to mean 'hardship, straits, adversity or affliction'. During the late eighteenth century its use evolved to denote 'force, pressure, strain or strong effort,' with reference, primarily, to a person or to a person's organs or mental powers (Hinkle, 1973). Since the beginning of the twentieth century the social and biological sciences have begun to investigate the effects of stress on the physical and mental health and well-being of people. In 1910, for example, Sir William Osler assumed a causal relationship between hard work, stress and strain with his patients suffering from angina pectoris (Davidson & Cooper, 1983). Stress appears to arise when there is a departure from optimum conditions which the organism is unable to easily correct and can be thought of as an imbalance between demand and the organism's capacity. For stress to occur, the consequences of failure must be important for the person concerned. Therefore, stress is linked to motivation. Almost all theories of motivation agree on the basic principle that action arises in an effort to improve conditions which are less than optimal. The action becomes more powerful, up to the limit of the organism's capability, as the departure from optimum becomes greater. Stress can be conceived as arising when motivating conditions are not reduced by the organism's actions (Welford, 1974). In a review of the psychological literature on stress three different approaches may be identified: (1) an engineering, or stimulus-based approach, treating stress as an independent variable; (2) a medicophysiological, or response-based approach, treating stress as a dependent variable; and (3) a dynamic psychophysiological process, intervening between stimulus and response, mediated by a person's cognitions (Cox & Mackey, 1981; Weinman, 1987).

The engineering model treats stress as a stimulus characteristic of the person's environment, either in terms of the level of demand placed upon the individual or as some aversive or noxious element of the environment (e.g. Fletcher, 1988; Cox, 1995). When discussing psychological disorders of RAF flying personnel, Sir Charles Symonds (1947), wrote: 'it should be understood once and for all that (flying) stress is that which happens *to* the man, not that which happens *in* him, it is a set of *causes* not a set of *symptoms*' (Cox, 1995; Cox & Mackey, 1981). Viewed this way, stress has the capacity to produce a strain reaction which, although often reversible, might also prove to be irreversible (e.g. Sutherland & Cooper, 1990). Individual differences applied to the concept of a stress threshold were used to account for differences in stress resistance and vulnerability (Cox, 1995). The older formulation can be traced to Hooke's Law (1660) a seventeenth-century engineering input-output analysis of load (force applied to an object) and strain (the resulting deformation of the object). According to Hooke's law, a load placed upon metal results in a deformation due to internal strain. If the strain produced within the structure of the metal is within the 'elastic limit' of the material, when the load is removed the metal will eventually return to its original condition. If, however, the strain passes beyond the elastic limit, then permanent damage will result (Cox & Mackey, 1981). In engineering, strain is disequilibrium or tension in the physical object, just as stress in living creatures is a biological disequilibrium that activates or drives behavioural and physiological efforts to restore the disturbed equilibrium. Individuals may vary in the degree to which they can tolerate stress and certain individuals may show high stress resistance (Cox & Mackey, 1981).

Ultimately the analogy to load, stress and strain in engineering failed because psychological stress and emotion cannot be adequately defined without reference to an individual's motivation and the way that individual evaluates his or her relationships with the environment, a process termed appraisal (Lazarus & Folkman, 1984). The quality and intensity of an emotional response to the appraised relationship also depends on the coping process, because what a person thinks and does to alter a troubled relationship with the environment changes either the relationship or the way it is appraised, thereby changing the emotions that flow from it (Lazarus, 1991a). The concept of stress has undergone a transition from formulations emphasising the objective environment to subjective, cognitive formulations. When it was defined strictly in terms of environmental stimulus conditions (stressors) which bring about behavioural disturbances, subjective distress and physiological tension, the formulation was basically similar to Duffy's (1962) or Lindsley's (1951) concept of activation. However, the concepts of strain and activation are in no sense equivalent or parallel to the concepts of appraisal and coping. Strain and activation are unidimensional concepts, whereas the stress process is a complex, multivariate, feedback system as is the emotion process (Lazarus, 1991b).

Before surveying the medicophysiological model of stress as defined by Selye (1950, 1956) an outline of the physiology of the stress response is appropriate. In the human organism the response to a stressor is determined by the brain, leading to a physiological response for dealing with the stressor. The stress response is initiated the instant the stressor is detected by the senses. The cortex generates signals to various parts of the body and the response is geared emotionally by the limbic system, particularly the amygdala. Situated above the kidney, the adrenal gland consists of two separate areas, the adrenal medulla and the adrenal cortex, which appear to be involved in different aspects of the stress response. From the hypothalamus nerve signals are transmitted to the adrenal medulla, resulting in the release of adrenaline and noradrenaline, known as catecholamines, quite distinct in their chemical structure, with different effects upon body organs. For instance, in a fear response there is an increased secretion of adrenaline, whilst in a response associated with anger noradrenaline is increased. The adrenal cortex produces cortisol as one of several hormones produced in response to more long-term demands (Gregson & Looker, 1996; Palmer & Dryden, 1996).

The initial responses to a stress situation appear to be brought about by increased activity in the sympathetic nervous system which acts in conjunction with the catecholamine secretion of the adrenal medulla. The physiological responses to the catecholamines include increases in respiration, rate and strength of cardiac contractions and blood pressure, peripheral vasoconstriction, decrease of gastro-intestinal activity, stimulation of the sweat glands, pupillary dilation and the mobilisation of the liver energy store through the release of glucose stored as glycogen in the liver. This rapid mobilisation of bodily resources was described by Cannon (1927) as preparing the body for 'fight or flight' (i.e. for an immediate emergency or alarm reaction). Cannon was among the first to actually use the term stress and he clearly indicated that both physiological and psychological components were important. Cannon's (1928, 1929) studies demonstrated that emotional stressors such as pain, fear and rage could cause significant changes in physiological functioning and suggested that adrenaline played an important role in adaptation by arousing the organism and thereby enabling it to respond more rapidly to danger. Thus when extremely frightened or enraged, the organism may experience an arousal that may be uncomfortable, but which readies it to act against the stimulus that frightens or angers it (Gatchel, 1995). If a stressor is relatively minor or of short duration, there may be little further physiological response over and above these immediate ones. However, if the stress situation is very intense or continues over a period of time, then the response system involving the adrenal cortex will be increasingly involved.

The activity of the adrenal cortex is largely regulated by the level of adrenocorticotrophic hormone (ACTH) in the blood. ACTH is released by the anterior pituitary, part of the pituitary gland at the base of the brain. Information concerning a sustained or intense stressor is processed by the central nervous system and transmitted to the hypothalamus which secretes corticotrophin-releasing factor (CRF) which, in turn, stimulates the anterior pituitary to release ACTH. This hormone has a direct effect on the endocrine activity of the adrenal cortex, resulting in the release of corticosteriods, the most important of which is cortisol, which has an anti-inflammatory effect and helps the body to resist stress (e.g. Weinman, 1987; Feist & Bannon, 1988; Gatchel, 1995). The division of function between the adrenal medulla and cortex may have been overstated in the past since there is now evidence that the adrenal cortex may also be important for bringing about changes occurring during the initial or 'alarm' stage of the stress response (e.g. Weinman, 1987; Feist & Bannon, 1988). Noradrenaline is also a neurotransmitter of the autonomic nervous system. Its action as a neurotransmitter or hormone depends upon location. Neurotransmitters work at the synapse whereas hormones circulate through the blood. Noradrenaline has both actions and is produced in many places in the body, not just the adrenal medulla, unlike adrenaline which is produced exclusively in the adrenal medulla. Activation of the sympathetic division of the autonomic nervous system in response to a stressor is rapid as is all neurotransmission whereas the action of the neuroendocrine system is slower. Together the two systems form the physiological basis for the stress response as well as the basis for psychophysiological illness (Feist & Bannon, 1988).

The medicophysiological model of stress as defined by Selye (1950, 1956) defined stress as 'a state manifested by a specific syndrome which consists of all the nonspecific changes within the biologic system that occur when challenged by aversive or noxious stimuli.' Selye formulated a response-based approach to stress, largely conceptualised in terms of the activation of the two neuroendocrine systems, the anterior pituitary-adreno-cortical system (PAC) and the sympathetic-adrenal medullary system (SAM) (e.g. Cox, Cox, & Thirlaway, 1983). Selye, (1950, 1956) considered that the stress response is triphasic in nature, involving an initial alarm stage (sympathetic-adrenal medullary activation), followed by a stage of resistance (adrenocortical activation) which gives way under some circumstances, to a final stage of exhaustion (terminal reactivation of the sympathetic-adrenal medullary system). In the second, resistance stage, assuming demand to be constant, the centre of activity passes from the adrenal medulla to the adrenal cortex and is characterised by a further increase in catabolic mechanisms which promote or maintain readiness for action and decrease in those which are concerned with reproduction and growth (anabolic). The outcome is an increased resistance to the specific stressor, but a decreased resistance to other stimuli. If the demand is prolonged or severe, bodily reserves are eventually depleted and at this point resistance to demand increases sharply. The third and final phase, the stage of exhaustion then occurs. During this third phase, the sympathetic-adrenomedullary activity characteristic of the first phase reappears (Cox & Mackey, 1981).

Selye (1950) argued that the wear and tear on the body caused by the stress response contributed to physical pathology. This was true where the response was frequent, of long duration, or severe. Therefore, following relentless stress, bodily changes are prolonged and animals can suffer irreversible body damage or even death. Particular diseases, for example, kidney disease, arthritis and cardiovascular disease, which might occur during, or as a consequence of, this weakened state, are thought to depend on a number of factors, including genetic predispositions, psychosocial factors, immunosuppression, acquired physical weaknesses and specifically learned bodily responses (e.g. Weinman, 1987; Gatchel, 1995). Diseases with a stress related aetiology, Selye termed 'diseases of adaptation' because, although the stress response had evolved as adaptive in the short term, increasing the animal's (or person's) ability to respond actively to an aversive or noxious environment, in the long term could contribute to and/or result in a disease process. Selye's theory developed as a result of his biochemical research which looked at the effects of extracts of ovary tissue, then extracts of other organs, and then substances not derived from bodily tissue. All toxic substances produced the same syndrome. Selye realised that the reaction produced mimicked that of disease: (1) adrenal enlargement, (2) gastrointestinal ulcers and (3) thymicolymphatic shrinkage were the omnipresent signs of damage to the body when under disease attack. Thus the three changes became the objective indices of stress and the basis for the development of the entire stress concept (Selye, 1956; 1979a; Gatchel, 1995). This triad of responses was called non-specific because it appeared to be caused by any noxious or aversive event.

In using the concept of non-specific responses, Selye then went on to define the stress syndrome as 'all of the non-specifically induced changes that were produced by a noxious agent'. Stress itself was considered a specific state that was the 'common denominator of all adaptive reactions in the body'. Exposure to a stressor, such as injection of a pathogen, created a response pattern involving among other things, the original triad of physiological responses. Selye called the response to aversive stressors the general adaptation syndrome (GAS) general because it is produced only by agents that have a general effect upon large portions of the body; adaptive because it stimulates defences and thereby helps inure the body to hardship and syndrome because its signs are coordinated and partly dependent on one another (Selye, 1956; 1979a). Thus, this theory of stress was built upon the concept of homeostasis and vital energy. Confronted with stimuli that threaten the constancy of their 'milieu interieur', organisms were claimed to have little choice other than to initiate a counter reaction to correct the disturbance and reinstate the original homeostasis. Although stress was at first seen as part of a catastrophe scenario (typical stressors were: haemorrhage, bone fractures, burns, explosions and poisons), Selye managed to generalise his stress theory to everyday life by claiming that, since homeostasis is constantly threatened, stress is part of life; the only way to avoid it is to transform bad stress ('dystress') into good stress ('eustress') (Dantzer, 1993). Based upon Selye's work (1956), a model put forward by Kagan & Levi (1971), which related psychosocial stimulation and levels of stress failed to spell out the mechanisms by which 'increased wear and tear' occur and translate into disease. The effects of external psychosocial stimuli are conditioned by a number of 'interacting variables'. These may be intrinsic or extrinsic, mental or physical (Cox & Mackey, 1981).

Mason (1975) disagreed with Selye's formulation of stress as a nonspecific response to any number of noxious stimuli and with Selye's explanation of the underlying mechanisms of the disease resulting from stress. Stress situations all shared the element of emotional stress, among the most potent and prevalent natural stimuli capable of increasing pituitary-adrenal cortical activity, which Mason considered to be an explanation for a general physiological response in laboratory animals exposed to various stressors. Mason (1975) considered stress likely to be a specific response rather than a non-specific one. Mason proposed that stress be conceptualised as analogous to pathogens–factors that can, but do not inevitably, cause disease. The role of psychological factors in eliciting secretion of adrenaline and noradrenaline has also been demonstrated by Frankenhauser (e.g. Frankenhauser, 1972; Patkai, 1971; Gatchel, 1995). Cox & Cox (1985) described evidence of differentiation in the response of the catecholamines (reflecting sympathetic-adrenal medullary activation) to stressful situations. Cox, Cox, Thirlaway & Mackay (1982) examined the physiological response to three different types of task associated with short-cycle repetitive work by measuring urinary catecholamine excretion rates using an adaptation of Diamont & Byers' (1975) assay technique. Cox *et al.* (1982) found that both adrenaline and noradrenaline were sensitive to work characteristics, such as pay scheme and pacing, but differentially so, and suggested that noradrenaline activation was related to the physical activity inherent in the various tasks and to the constraints and frustrations present, whereas adrenaline activation was more related to feelings of effort and stress (Cox, 1995).

The dynamic interaction between the person and his or her environment defines the third psychological model approach, taking account of cognition, to the definition and study of stress (Cox, 1995). Variants of this psychological model are prevalent in contemporary stress theory and among them two are distinct types, the interactional and the transactional. Among the various interactional theories of stress, which focus on the structural characteristics of a person's interaction with his or her environment, two are particularly salient: they are those of French, Caplan & van Harrison (1982) and Karasek (1979) (Cox, 1995). French *et al.* (1982) formulated a theory of work stress based on the explicit concept of the person-environment (P-E) fit. Several researchers have shown that the goodness of fit between the person and his or her environment frequently offers a better explanation of behaviour than individual or situational differences (e.g. Bowers, 1973; Ekehammer, 1974). Two basic aspects have been identified: the degree to which a worker's attitudes and abilities match task requirements and the extent to which the work environment meets the worker's needs and especially, the extent to which the individual is permitted and encouraged to use his or her knowledge and skills in the work setting. It has been argued that stress is likely to occur and well-being is likely to be negatively affected when there is a lack of fit in either or both (French, Rogers & Cobb, 1974) (Cox, 1995).

Karasek (1979) provided a structural model of work stress which draws attention to two major dimensions of the person-environment fit, i.e. decision latitude and work demands. He suggested that these work characteristics may be non-linearly associated with health and that they might combine interactively in relation to health. He demonstrated his theory through secondary analyses of data from the USA and Sweden, finding that workers employed in situations which allowed them low decision latitude, whilst at the time, placed high demands on them, were especially likely to report poor health and low satisfaction. Later studies appeared to confirm this theory. For example, a representative sample of the male Swedish workforce was examined for depression, excessive fatigue, cardiovascular disease and mortality. Those workers whose jobs were characterised by heavy workloads, combined with little latitude for decision making, were represented disproportionately on all those outcome variables. The lowest probabilities for illness and death were found among work groups with moderate workloads, combined with high control over work conditions (e.g. Karasek & Theorell, 1990) (Cox, 1995).

Transactional models, primarily concerned with cognitive evaluation and coping, represent a development of interactional models. The distinguishing feature of transactional thought is that transaction implies a newly created level of interaction in which the separate person and environment elements are joined together to form a new relational meaning (Cox, 1995). Lazarus & Folkman (1984) define coping as 'the person's constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person'. Therefore 'transaction' highlights a quality missing in the concept of interaction. Transactional theories owe much to the work of Lazarus (1966) and his concept of 'cognitive appraisal' (evaluation). The approach by Lazarus & Folkman (1984) to psychological stress emphasises cognitive appraisal, which centres on the evaluation of harm, threat and challenge. An appraisal does not refer to the environment or to the person alone, but to the integration of both in a given transaction. As such it is a transactional variable. To say that someone is threatened is an evaluation limited to a particular encounter in which particular environmental conditions are appraised by a particular person with particular psychological characteristics (Lazarus & Folkman, 1984). Lazarus & Folkman (1984) state that the transactional model views the person and the environment as being in a dynamic, mutually reciprocal, bi-directional relationship. What is a consequence at Time 1 may become an antecedent at Time 2, its cause either in the person or in the environment. Transactionalism, which is also related to systems theory and dialectics, has a long history which has been traced by Phillips & Orten (1983) and is constantly being rediscovered, for example, in Bandura's (1978) idea of reciprocal determinism.

The Stress Process

Process is concerned with the unfolding or flow of events. The environment and the person and his or her relationship with it are constantly changing. In a stressful encounter, a person may feel a range of different emotions. For example, anxiety may be followed by anger and, depending on the perceived outcome of the same encounter, feelings of guilt and despair or joy may follow later. These feelings express what is happening as the encounter unfolds and as the person's own behaviour and that of the environment alter the appraised significance of the encounter (Lazarus & Folkman, 1984). The process of social stress can be seen as combining three major conceptual domains: the sources of stress, the mediators of stress and the manifestations of stress. In the search for sources of stress, major interest has been focused on life events and also on chronic life strains. In research concerned with discovering conditions capable of mediating the impact of stressful circumstances, coping and social support have risen to prominence and research with regard to stress ranges from the microbiological substrates of stress to its overt emotional and behavioural expressions (Pearlin, Lieberman, Menaghan & Mullan, 1981). Stress arises from both the occurrence of specific, discrete life events and the presence of relatively continuous problems. Underlying life-events research is the assumption that adverse events lead to stress because the organism is fundamentally intolerant of change (Cannon, 1935; Selye, 1956). The ensuing struggle for readjustment can be wearing and exhausting and, under these conditions, the organism becomes very vulnerable to stress and its physical and psychological consequences. Lazarus & Cohen (1977) have delineated three general categories as stressors: cataclysmic events, personal stressors and background stressors or daily hassles. Both cataclysmic events and personal stressors are strong and may be unexpected and include events that are powerful enough to challenge adaptive abilities, whereas background stressors are much less powerful than the other two categories. However, over time these daily hassles may pose threats equally serious (Gatchel, 1995). One explanation as to why some events come to be stressful suggests that events do not necessarily impact upon people directly, but may instead exert their effects through a wider context of life strains and that the two major sources of stress, i.e. eventful experience and chronic strains, may converge in the production of stress because life events can function to bring into focus the unfavourable implications of life problems and it is the new meaning of old problems that creates distress (Pearlin *et al.,* 1981).

Lazarus & Folkman (1984) point out that life events and daily hassles are related because negative life events, such as death of a loved one, divorce or job loss, are apt to disrupt social relationships and the habits and patterns of daily living, thereby causing hassles. In explaining how daily hassles might result in damaged morale, impaired social and work functioning, psychological symptoms and somatic illness, one theory is that the process is simply additive, with all the hassles people experiences summing to a total amount of stress in a given period. An alternative theory centres on the appraised meaning and salience of hassles and the quality of the coping process in their management. Research (e.g. Lazarus & DeLongis, 1983) strongly suggests that baseline conditions of people's lives influence which transactions will be viewed as hassles or as uplifts, the latter referring to positive or satisfying experiences conceived as the opposite to hassles (Lazarus & Folkman, 1984). For example, chronically ill people more readily endorse as uplifts getting a good night's sleep or feeling energetic. By the same token, it could be expected that people would be more likely to endorse inclement weather as a hassle when they are on holidays than when they are at work.

Life events become distressing largely to the extent that these events create or exacerbate difficulties in the enactment of ongoing social roles. Life events may generate role strains which result in a diminution of self. Two dimensions of self-concept relevant in this regard are mastery, referring to the extent to which people see themselves as being in control of the forces that importantly affect their lives and self-esteem, which involves the judgements people make about their own self-worth (Pearlin *et al.*, 1981; Pearlin, 1983). The protection and enhancement of the self are fundamental goals for which people strive. The enduring presence of noxious circumstances, precisely of the kind represented in role strains, apparently function to strip away the insulation that otherwise protects the self against threats to it (Kaplan, 1970). Persistent role strains can confront people with evidence of their own failures and with inescapable proof of their inability to alter the unwanted circumstances of their lives, so that they become vulnerable to loss of self-esteem and to erosion of sense of mastery (Pearlin *et al.,* 1981).

If self-esteem and mastery are intrinsic to depression, then there would be no instance in which an increase in a person's level of depression occurred without a similar decrease in his or her self-esteem and mastery. On the other hand, if these components of self are not merely symptomatic of depression but are conditions contributing to it, it should be possible to hypothesise circumstances in which depression would vary independently of change in self-esteem and mastery. If an adverse life event is perceived as a consequence of chance rather than as resulting from personal deficiency, it is likely to lead to the intensification of depression but to be unrelated to changes in self-esteem or mastery. Thus, these components of self and depression are not simply different indicators of the same underlying state. It appears reasonable therefore to treat damaged self-concepts not as symptomatic of stress, but as sources of it (Pearlin *et al.*, 1981). According to Lazarus & Folkman (1984), appraisal is comprised of primary and secondary processes. In primary appraisal, individuals ask themselves whether a particular encounter is relevant to well-being and in what way. If the encounter is relevant and is defined as stressful rather than as benign or irrelevant, then more specific appraisals are made, such as those of loss or threat (of harm). Thus, primary appraisal is associated with assessing the emotional content of a stressful transaction. Secondary appraisal is concerned with the question of coping. Emotion cannot be divorced from cognition, motivation, adaptation and physiological activity. When a person reacts with an emotion, especially a strong one, every fibre of his or her being is likely to be engaged: attention, thought, needs, desires and physical sensations. This reaction indicates whether an important value or goal has been engaged, is being harmed, placed at risk or advanced (Lazarus, 1991a). To expand psychological stress theory into a theory of emotion requires the consideration of the conditions under which the person benefits and from which positive emotional states are generated. That is, emotions can be described in kind as well as intensity, thereby allowing for a rich variety of kinds of emotion or emotion families (Dewey, 1971). Diverse negative emotion states arise from particular harmful or threatening relationships, positive emotions from particular beneficial ones. In the following excerpt from '*Emotion and Adaptation*' Lazarus (1991a) focused on the diverse perspectives on emotion: those of the individual, the observer, the society and the biological species.

'*The individual*. Because the all-encompassing nature of some emotional experiences makes them difficult to ignore, emotions often disrupt or interrupt some ongoing task or activity, and so have been referred to as interrupt phenomena (Mandler, 1984). When a person is in a traumatic situation, for example, when a patient is told that he or she has inoperable cancer, perception and thought may be impaired, blocked, distracted or even paralysed. This is because threatening encounters are apt to constrict a person's ability to think and perform, due to the person's strong efforts to protect him or herself from anticipated danger. In contrast, a challenge lifts morale and improves function, with relevant thoughts coming easily and a subjective impression of achieving aims. An emotion may also be informative to the person who experiences it, a source of insight into him or herself and what is happening and this knowledge may be useful in helping him or her to deal with recurrent emotional distress (Lazarus, 1991a). Individual differences appear to influence and determine the level of emotional excitement that is optimal for subjective well-being. This variation may be the result of different personality traits, which lead to different emotions in the same or different situations (Epstein, 1983; Wessman & Ricks, 1966).

An observer is one who infers the presence of an emotion in another from what is seen and heard. Social behaviour is guided constantly by cues that people interpret about the emotions of others. People decode and interpret complex and often conflicting communications and mis-communications that are sent and received in social interactions and can learn certain information from the emotional reactions of others. What is revealed about persons from their emotional lives is also revealed about social communities and *the society* in which emotional patterns are widely shared. The findings of social scientists underlie and are illustrated by some of the classic sociological evaluations of community mental health (e.g. Faris & Dunham, 1939; Hollingshead & Redlich, 1958).

The biological species. From a phylogenetic point of view emotion undoubtedly has many survival-related functions. These include the sociobiological function of communication, and the ability to stimulate and sustain psychological and physiological mobilisation in the face of essential biological needs that are not being met, as well as challenges from the environment. Emotions can be said to serve as amplifiers of the cognitive processes that permit an animal (or person) to evaluate the potential harm or benefit in an encounter with the environment and to cope with it. Every animal species faces adaptational problems that must be dealt with successfully in order to survive. A central theme of the biological-evolutionary approach to emotion is that there has been a gradual decoupling of adaptive behaviour from hardwired reflex actions (Smith & Lazarus, 1990). The basic arena of analysis for the study of the emotion process is the person-environment relationship. The basic unit of this relationship is an adaptational encounter or transaction between person and environment influencing personal goals which are brought to the encounter and with respect to which the environmental conditions are relevant. The task has to do with realising these goals as well as managing the demands, constraints and opportunities presented by the environment (Lazarus, 1991a)'.

Lazarus (1991a) presented a cognitive-motivational-relational theory of emotion which he described in terms of the following five metatheoretical themes:

(1) 'The theory is a system theory in which the emotion process involves an organised configuration of many variables. No single variable is sufficient to explain the emotional outcome and all variables are interdependent.

(2) Emotions express two interdependent principles: one, the process principle, referring to flux or change, the other the structure principle, referring to the idea that there are stable person-environment relationships that result in recurrent emotional patterns in the same individual.

(3) The biological and social variables that influence the emotions develop and change from birth through the life-span.

(4) The emotion process is distinctive for each individual emotion. This specificity principle implies that the major task of emotion theory is to generate subtheories in which the emotion process in each individual emotion (for example anger, anxiety and pride) is spelled out. This is carried out by drawing on Principle 5, which follows.

(5) The key substantive theme of the theory is the relational meaning principle which states that each emotion is defined by a unique and specifiable relational meaning. The emotional meaning of these person-environment relationships is constructed by the process of appraisal which is the central construct of the theory'.

The appraisal process involves (a) a set of decision-making components which create evaluative patterns that differentiate among each of the emotions; (b) three primary appraisals, which concern the motivational stakes in an adaptational encounter; and (c) three secondary appraisals which have to do with the options for coping and expectations. The primary appraisal components are goal relevance, goal congruency or incongruency and type of ego-involvement (Lazarus, 1991a). In primary appraisals, a situation is perceived as being either irrelevant, benign-positive or stressful. Those events classified as stressful can be further subdivided into the categories of challenge, threat and harm/loss. In the appraisal of challenge a person may see an opportunity to prove him or herself, anticipating gain, mastery or personal growth from the venture. The situation is experienced as pleasurable, exciting and interesting and the person is hopeful, eager and confident to meet the demands. Threat occurs when the individual perceives being in danger or when the person anticipates future harm or loss. Harm or loss can refer to physical injuries and pain or to attacks on one's self-esteem. In threat appraisal, if future prospects are seen in a negative light, the individual still seeks ways to master the situation faced. Individuals are restricted in their coping capabilities, striving for a positive outcome of the situation in order to gain or to restore their well-being (Jerusalem & Schwarzer, 1992). Threat is a relational property concerning the match between perceived coping capabilities and potentially hurtful aspects of the environment (Bandura, 1991). In the experience of harm or loss, some damage to the person has already occurred. Damages can include the injury or loss of valued persons, important objects, self-worth or social standing. Instead of attempting to master the situation, the person surrenders, overwhelmed by feelings of helplessness. Beck's cognitive theory of anxiety and depression (Beck & Clark, 1988) is in line with these assumptions, mentioning threat as the main cognitive content in anxiety with loss its counterpart in depression (Jerusalem & Schwarzer, 1992). The secondary appraisal components are blame or credit, coping potential and future expectations. The individual evaluates his or her competence, social support and material or other resources in order to re-adapt to the circumstances and to re-establish an equilibrium between person and environment. Each individual emotion is distinguished by its pattern of primary and secondary appraisal components. Coping also plays an important role in the personal significance of the person-environment relationship and influences the appraisal process and hence the emotion through feedback (Lazarus, 1991a).

The task of appraisal is to integrate the two sets of antecedent variables, personality and environment, into a relational meaning based on the relevance of what is happening. This is to facilitate understanding the emotional response in terms of how what is happening is construed by the person from the standpoint of personal interest and adaptation. If the significance of what is happening involves personal harm or benefit, an emotion is generated that includes an innate action tendency, which provides the basis for the unique physiological activity characteristic of each individual emotion. The coping process, which may be consistent or in conflict with the action tendency and may over-ride or inhibit it, is more psychological and deliberate and it also influences the actions and physiological pattern (Lazarus, 1991a). The person's primary appraisal is an assessment of what it is that he or she judges to be at stake in the transaction and the magnitude of its potential costs and/or benefits (Lazarus & Folkman, 1984). A fundamental feature of secondary appraisal is the extent to which a person senses that something can or cannot be done to alter the troubled person-environment relationship. Lazarus & Folkman (1984) emphasise that appraisal is a process that occurs in a particular context and, therefore, trait or generalised dispositional concepts such as locus of control, a sense of coherence (Antonovsky, 1992) and generalised beliefs about mastery or self-esteem do not apply. However, Jerusalem & Schwarzer (1992) disagreed with this latter point. Jerusalem (1990) and Schwarzer, Jerusalem & Stiksrud (1984) developed a process model of cognitive appraisal which extended Lazarus' original stress theory by integrating ideas from Seligman's Helplessness Theory (1975).

Seligman's (1974, 1975) mediational learning theory was formulated to explain the behaviour of dogs given inescapable shock followed by escapable shock which they passively accepted, implying that animals can acquire what might be called a 'sense of helplessness' when confronted with uncontrollable aversive stimulation. This helplessness later tended seriously and deleteriously to affect their performance in stressful situations that could be controlled. They appeared to lose the ability and motivation to learn to respond in an effective way to painful stimulation. On the basis of this and other work on the effects of uncontrollable stress, Seligman (1974, 1975) felt that learned helplessness in animals could provide a model for at least certain forms of human depression. Like many depressed people, the animals appeared passive in the face of stress, failing to initiate action that might have allowed them to cope. A state of helplessness is predicted as a long-term consequence of cumulative experience of personal uncontrollability. Accordingly, a theoretical model of appraisal processes was built to describe the potential development of loss of control and personal helplessness by means of cognitive appraisal processes in academic failure situations. At any point in time all three cognitive appraisals may occur simultaneously, but to differing degrees, therefore leading to different emotions. For instance, challenge may cause curiosity, exploration and productive arousal; threat may cause anxiety and loss of control may cause helplessness or even depression (Jerusalem & Schwarzer, 1992). Jerusalem & Schwarzer (1992) concluded that general self-efficacy as a resource or buffer against feeling distressed when confronted with achievement demands serves as a moderator for the impact of those demands. High self-efficacy subjects tend to select positive cues, such as stable and favourable self-evaluations, rather than negative signals, such as situational failures, in appraising the stressing person-environment relationship. Low self-efficacy subjects see themselves confronted with negative achievement cues and negative self-evaluations, with the possibility of both information sources being combined and attached to high importance (Jerusalem & Schwarzer, 1992).

Lazarus (1991a, 1991b) listed twelve issues that any theory of emotion should address. They are (1) definition, (2) the distinction between emotion and non-emotion, (3) whether or not emotions are discrete, (4) the role of action tendencies and physiology, (5) the manner in which emotions are functionally interdependent, (6) the links between cognition, motivation and emotion, (7) the relationship between the biological and sociocultural bases of emotion, (8) the role of appraisal and consciousness, (9) the generation of emotions, (10) the matter of emotional development, (11) the effects of emotion on general function and well-being, and (12) the influence of therapy on emotion. The early theories of emotion, including those of Darwin (1872), McDougall (1928), James-Lange (1884, 1885) and Cannon-Bard (1927, 1934), lacked a cognitive component, now considered essential in understanding the process nature of transactionalism (Strongman, 1996). There are many important and comprehensive theories of emotion which fit the criteria of a good theory of emotion listed by Lazarus, (1991a, 1991b). However, Strongman (1996) pointed out that pride of place for cognitive theory should go to Lazarus himself, as his theory covers so much ground.

Coping

The concept of coping, like that of stress, is not a unified construct with a readily agreed upon meaning. Rather it more accurately represents a general metaconstruct under which a number of phenomena are included. For example, coping resources have been discussed as representing characteristics of the person or of his or her environment that are associated with low levels of distress or physical symptoms following the onset of stressors. Similarly, coping responses have been conceived in the literature as a multidimensional set of cognitions and behaviours called upon to help the person manage or tolerate the demands imposed by chronic or acute stressors (Eckenrode, 1991). What distinguishes coping from other aspects of human behaviour is its relevance to adaptation in the face of stressful life experiences or conditions (Lazarus & Folkman, 1984).

The emotion and coping relationship has been discussed in the context of two distinct systems of thought. In the animal model, emotion and coping are viewed from a Darwinian phylogenetic perspective as drive, activation or arousal motivated behavioural responses that enable the animal to protect itself and/or vanquish its enemy, thus emphasising learned behaviours that facilitate survival in the face of life threatening dangers. In the psychoanalytic ego psychology model, coping is defined as cognitive processes, such as denial, repression, suppression and intellectualisation, as well as problem solving behaviours that are invoked to reduce anxiety and other distressing emotional states (Folkman & Lazarus, 1988). A second difference is that the primary criterion of successful coping in the animal model is survival, whereas the ego psychology model includes criteria concerning the quality of the process, such as its adherence to reality and its flexibility (Menninger, 1963; Haan, 1977) as well as a large range of adaptive outcomes including psychological well-being, somatic health and social functioning (Folkman & Lazarus, 1988). The feature common to both the animal and ego psychology models is that coping is viewed as a response to emotion and as having the function of arousal or tension reduction (Folkman & Lazarus, 1988).

Two key difficulties are inherent in the traditional animal and ego psychology models of coping and emotion. The first is incompleteness, which results from emphasising emotional arousal or drive tension as the antecedent of coping. Coping is not merely a response to such tension, it is also strongly influenced by the appraised significance for well-being of what is happening, which is incorporated in the emotional arousal and affects the quality of the emotion, for example, whether it is a negative or positive emotion. The second difficulty is that the relationship between emotion and coping is usually spoken of as if it were unidirectional and static. Undoubtedly emotion both facilitates and interferes with coping; however, if what is happening is viewed over time, it will be seen that coping can also affect the emotional reaction (Folkman & Lazarus, 1988). In a cognitive-motivational-relational approach, coping consists of cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984). These cognitive and behavioural efforts are constantly changing as a function of continuous appraisals and reappraisals of the person-environment relationship, which is also always changing. Studies have shown that people rely on both forms of coping and their subvarieties in managing the demands of stressful encounters (e.g. Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986).

Lazarus (1966) sees coping as having three main features. Firstly, it is a process; it is what the person actually thinks and does in a stressful encounter and how these thoughts and actions change as the situation unfolds. This approach contrasts with structural, trait-oriented approaches, which refer to what the person usually does, would do or should do (Folkman, Chesney, McKusick, Ironson, Johnson & Coates, 1991). For example, a person can reappraise a problem especially if a stressor cannot be eliminated. The motives behind the distressing behaviour of others can be reappraised so that instead of becoming enraged at the actions of another, the empathic person attempts to see the situation from the other's viewpoint. Secondly, coping is context dependent as it is influenced by the particular appraisal that initiates it and by the resources available to manage that encounter. Thus, coping is not determined solely by personal dispositions but by the person's appraisal of the demands of a particular situation. The contextual approach highlights specific stressful situations as opposed to general stressful conditions (Folkman *et al.,* 1991). Finally, coping as a process should be defined independently of whether or not it was successful (e.g. Lazarus & Folkman, 1984). Thus, it is defined without reference to its outcome, as it refers to efforts to manage, not the success of those efforts. To equate coping with successful outcomes also implies that all effective coping results in mastery. However, people are often confronted with situations or conditions that are recurrent or that cannot be mastered. In such cases, effective coping involves coming to terms with undesirable outcomes rather than mastering them (Folkman *et al.* 1991). This approach to coping has important implications for interventions. Coping processes, which by definition are changeable, lend themselves to modification through education, counselling and psychotherapy. In contrast, coping traits and dispositions, which by definition are relatively stable and enduring properties of the person, are not easily changed, especially through brief interventions (Folkman *et al.,* 1991).

Coping has two major functions: to manage or alter the situation that is causing distress (problem-focused coping) and/or to regulate emotional responses to the problem, for example anger, anxiety and/or grief (emotion-focused coping) in conjunction with changes in the person that are a result of feedback about what has happened and from changes in the environment that are independent of the person (Folkman & Lazarus, 1988). In general, problem-focused forms of coping are relied upon more when situations are appraised as amenable to change, whereas emotion-focused forms of coping are relied upon more when situations are appraised as not amenable to change (Folkman *et al.* 1991).

The physiological correlates of problem-focused coping in animals have mainly been studied by using negative reinforcers, i.e. stimuli whose removal or prevention increases responding. Electric shock has been the preferred stimulus because of its ease of application. When offset of electric shock is contingent upon responding, the negative reinforcement operation is designated 'escape'. When non-occurrence, or postponement, of electric shock is contingent upon responding, the negative reinforcement is designated 'avoidance' (Dantzer, 1993). The coping hypothesis predicts that, in the yoked control design, experimental subjects (i.e. those receiving escapable stress) should show less arousal than yoked control subjects. To test this prediction, a number of physiological indices of arousal have been used. Plasma levels of ACTH and cortisol have been found to be lower in animals exposed to controllable negative reinforcers than in animals exposed to uncontrollable negative reinforcers. For example, rhesus monkeys, trained to terminate an intense noise by pressing a lever, responded to a one hour session of noise presentation with a smaller increase in plasma cortisol than monkeys with no control over noise. In addition, removal of the contingency between lever presses and noise termination resulted in a similar increase in plasma cortisol to that observed in animals having no control over noise (Hanson, Larson & Snowdon, 1976). Several studies have failed to find different pituitary-adrenal responses in experimental and yoked control subjects. Some authors have suggested that the main difference between experimental and yoked control subjects is not in the peak level of the pituitary-adrenal response but in the time taken to return to baseline (Dantzer, 1993). Studies of social conflict in tree-shrews, rats and mice suggest that pituitary-adrenocortical activity is more elevated in animals which behave defensively or passively and become submissive compared to offensive animals which remain active and become dominant (Dantzer, 1993).

Problem-focused forms of coping include cognitive problem solving and decision making, interpersonal conflict resolution, information gathering, advice seeking, time management and goal setting, as well as problem-oriented behaviours. Problem-focused coping has been shown to confer psychological benefits by increasing self-esteem, sense of control and efficacy (D'Zurilla & Sheedy, 1991). Problem-focused coping requires components of critical thinking, such as considering alternatives. People who think creatively and constructively about their problems are better able to resolve them, avoid negative emotions, such as anger and hostility, and even reduce physiological arousal (Katz & Epstein, 1991). Pearlin & Schooler (1978) in a Chicago-based community study, showed education level and family income to be related to strategies effective in coping with certain types of chronic strains such as maintaining optimistic outlooks in the face of financial or job-related strain (Eckenrode, 1991). In another community study, Billings & Moos (1981) found that persons with few social resources tend to use avoidance more than persons with higher levels of social resources. Strickland (1978) reviewed studies linking beliefs in self-efficacy to more active modes of coping with health threatening events. Research by Pearlin & Schooler (1978) indicated that coping resources in the form of mastery, beliefs and self-esteem were more effective in buffering the effects of role strains over which the person has little control, such as work related strains, whereas active coping responses were more effective in diminishing the consequences of strains in role domains over which the person had some control, such as in the marital relationship. Such findings argue against a simple notion of resources leading to coping responses. They also reinforce a view of coping as being sensitive to situational constraints (Eckenrode, 1991).

Like coping resources, coping responses have been construed in the literature as a multidimensional set of cognitions and behaviours used by an individual to manage or tolerate the demands imposed by chronic or acute stressors. One popular assessment tool, the Ways of Coping Checklist (Lazarus and Folkman, 1984) contains 67 distinct responses which fall into eight discrete categories (Folkman *et al.* 1986). Moos & Schaefer (1986) presented a framework for organising cognitions and behaviours that could hypothetically be included under the coping umbrella. They outline a set of adaptive tasks common to many situations and crises. Specific coping strategies such as appraisal, problem and emotion focused coping can be evaluated in terms of the degree to which they meet perceived needs (Moos & Schaefer, 1986).

Mattlin, Wethington & Kessler (1990) contributed to the body of research on situational determinants of coping and presented the first large scale analysis of situational determinants of coping effectiveness in response to a wide variety of stressful life events and chronic difficulties. Mattlin *et al.* (1990) state that in previous general population studies of coping, respondents were asked to describe either their 'typical' ways of coping with stress or the ways in which they coped with one particular stressful situation. Using the second approach to analyse situational determinants of coping in a general population sample of 1,556 men and women, at the end of each interview each respondent was asked to designate the one situation 'that has been the most stressful to you over the past year'. Qualitative information about the context of this 'most stressful' situation was obtained in order to rate each situation on the dimension of loss or threat. Loss was rated on the basis of evidence that some valued person, object or idea was harmed. Threat was rated on the basis of evidence that future harm might result from the situation. Mattlin *et al.* (1990) discriminated between stressful events and difficulties. An event was defined as a discrete occurrence that happened within the 12 months before the interview. These researchers state that the distinction between events and difficulties is important because the kind of coping strategies used to manage long-term stressful situations almost certainly differ from those used in response to acute stress. The effectiveness of particular coping strategies also may differ depending on whether the stress is acute or chronic.

In addition to their classification of event versus difficulty and degree of loss or threat, Mattlin *et al.* (1990) also divided events into six categories. Analysis yielded six coping strategies: avoidance, positive appraisal, religion, active cognitive, active behavioural and social support. Two substantive profiles detected by this study were characterised as versatility and passivity. Versatile copers, who comprised 49% of the sample reported using virtually all coping strategies. Passive copers, less than 4% of the sample, reported using each strategy either 'not at all' or 'only a little.' Active behavioural and versatile coping occurred most frequently in response to practical problems. Passive coping was rare. However, coping responses differed across situations; active behavioural coping was least likely in response to a death and religion was less likely to be used in response to practical problems. Religion was most commonly reported by those coping with the long-term illness or death of a loved one (Wethington & Kessler, 1991).

In social cognitive theory, Bandura (1986) proposed that perceived self-efficacy in exercising control over potentially threatening events plays a central role in anxiety arousal. Bandura's notion of 'self-efficacy' overlaps with part of the coping process. Essentially, it proposes that an individual's expectation of how well he or she will be able to accomplish a challenging task is a major determinant, and therefore a good predictor, of subsequent performance. As originally proposed, self-efficacy is task specific rather than global, but it seems to be used sometimes as indicative of cognitions that extend broadly across situations, which, in effect, makes it the equivalent of dispositional mechanisms. Self-efficacy would seem to fit nicely as part of the appraisal process, affecting the coping behaviours that are chosen. In return, the outcomes of coping behaviour would likely affect self-efficacy, in the continuous cycle of feedback between cognitions and behaviour (Zamble & Gekoski, 1994). In order to understand a person's appraisals of external threats and his or her affective reactions to them, it is necessary to analyse the judgements of his or her coping abilities which are instrumental in determining the subjective risk of environmental events. A high level of anxiety arousal results from an individual focusing negatively on his or her own coping deficiencies, and on those aspects of the environment that cause concern, potentially increasing the perceived severity of possible threats (Bandura, 1992). Research shows that this may result in accelerated heart rate, increased blood pressure and increased catecholamine secretion. However, after perceived efficacy is optimally strengthened by guided mastery, previously intimidating tasks no longer elicit differential autonomic or catecholamine reactions (e.g. Bandura, Taylor, Williams, Mefford & Barchas, 1985). Studies show that exposures to stressors without the ability to control them impairs the immune system (cf.. Coe & Levine, 1991; Wiedenfeld *et al.*, 1990). The rate with which people acquire a sense of controlling efficacy has been shown to be a good predictor of whether exposure to acute stressors enhances or suppresses various components of the immune system (Bandura, 1992).

Another relevant way of looking at coping responses is as a means of solving problems (D'Zurilla, 1986). As research on social problem-solving and the transactional model of stress grew in the 1970s and early 1980s, it soon became apparent that there was overlap between these two approaches. The transactional view of stress and coping has influenced the present problem solving approach by suggesting that the nature of a real life problem and the social problem-solving process can best be understood by viewing them within a transactional perspective and highlighted the fact that life problems are often stressful and that emotional variables are likely to influence the problem-solving process significantly (Janis & Mann, 1977). Social problem-solving is at the same time a social-learning process, a self-management technique and a general coping strategy. Since the solving of a problem results in a change in performance capability, it is a learning process (Gagne, 1966). A problem is defined in this case as a life situation that demands a response for effective functioning, but for which no effective response is immediately apparent or available to the individual or group confronted with the situation (D'Zurilla & Goldfried, 1971). The individual or group in such a situation perceives a discrepancy between 'what is' (current or anticipated circumstances) and 'what should be' (circumstances which are demanded or desired) under conditions where the means of eliminating this discrepancy are not immediately apparent or available due to some obstacle or obstacles (e.g. ambiguity, uncertainty, skill deficit, or lack of resources) (D'Zurilla, 1986).

A current problem may be a time-limited event which keeps recurring, or it may be a continuous, ongoing situation, such as chronic illness. The demands in the problematic situation may originate in the environment (e.g. objective task demands) or within the person (e.g. a personal goal, need or commitment). They are best described as perceived demands, since an individual is likely to be influenced more by his or her perception of the demands of the situation when identifying problems than by the objective demands themselves. As defined here, a problem should not be viewed as a characteristic of the environment alone. Instead, it is best described as a person-environment encounter or 'transaction' (Lazarus, 1981), involving a reciprocal relationship between environmental variables and person variables which are constantly changing over time. Thus, a problem can be expected to increase or decrease in difficulty or significance over time, depending on changes in the environment (e.g. objective demand characteristics,) the person (e.g. appraisal of task demands, response availability) or both.

Transactional stress theory, with its emphasis on specific person-environment transactions in which demands (external and internal) tax or exceed coping resources or capabilities as perceived by the individual (Lazarus, 1981; Lazarus & Folkman, 1984) is very similar to the concept of a problem (Schonpflug, 1983). Stress usually begins with concern about a problem and problems are likely to be stressful if they are at all difficult, because difficult problems are likely to involve conflict, uncertainty and/or perceived uncontrollability (e.g. Epstein, 1982). If problems can be viewed as stressors, then social problem solving is an activity that is often carried out under stressful conditions (e.g. Janis, 1982). A solution is a coping response or response pattern that is effective in altering a problematic situation and/or reactions to it so that it is no longer perceived as a problem, while at the same time maximising other positive consequences (benefits) and minimising negative consequences (costs) (D'Zurilla & Goldfried, 1971). The relevant benefits and costs to an individual include effects on others as well as self, along with long-term implications as well as short term effects. The effectiveness of any particular solution may vary for different individuals or different environments, depending on the norms, values and goals of the problem solver or significant others who are responsible for judging the performance of the problem solver (D'Zurilla, 1986).

Problem solving refers to the process by which an individual or group discovers a solution to a problem. Solution implementation refers to the performance of the solution response, which is a function not only of problem-solving, but also of other factors related to the individual's learning history, such as performance skill deficits, emotional inhibitions and motivational (reinforcement) deficits. Social competence is the broadest concept of the three, referring to a wide range of social skills, behavioural competencies and coping behaviours, which enable an individual to deal effectively with the demands of everyday living (Goldfried & D'Zurilla, 1969; McFall, 1982; Wruble, Benner & Lazarus, 1981). The objective problematic situation may produce conditioned and/or unconditioned emotional responses which vary in nature and intensity across situations and individuals, depending on each person's past associative learning experience. Aversive stimuli which are likely to produce emotional arousal in most people include:

(a) Harmful or painful stimuli which threaten the homeostatic balance of the body, including various pathogens and any intense physical stimulus (e.g. noise, heat, cold and pressure) (Selye, 1983);
(b) conflict (e.g. conflicting stimulus demands, conceptual conflict, decisional conflict, (Epstein, 1982; Janis & Mann, 1977);
(c) frustration (e.g. an obstacle preventing a goal response) (Mather, 1970);
(d) loss or deprivation of customary reinforcers (Mowrer, 1960);
(e) unpredictability (uncertainty) or uncontrollability of aversive events (Hamberger & Lohr, 1984);
(f) ambiguity (Wrubel *et al.,* 1981);
(g) complexity or novelty that cannot be assimilated successfully with stored information or prior experience (e.g. McClelland & Clark, 1966).

Problem produced emotional responses may influence problem orientation cognitions (problem-perception, problem appraisal) and these cognitions may in turn affect the nature and intensity of the original emotional responses (D'Zurilla, 1986). Ambiguity and uncertainty are usually present during problem solving because most problems are initially vague and poorly defined. If the problem is at all difficult or complex, there will also be uncertainty and conflict regarding the choice of the optimal solution. According to Janis & Mann (1977) such decisional conflict is likely to be most stressful when there are simultaneous tendencies to accept and to reject a given course of action, under conditions where there are significant risks associated with all the available alternatives (D'Zurilla, 1986).

Stress and Cancer

It can be seen that the major theories of stress, emotion and coping focus on the organism's intolerance of uncertainty and change, with the aim of appraisal and coping being to regain a state of equilibrium both physiologically and psychologically. In the context of a chronic illness such as cancer, this need for homeostatic regulation has major implications for how a person with cancer might view different cancer treatment and care options and what factors he or she perceives might confer assistance, benefit, relief of distress and help to reduce expectations of harm or loss, thereby increasing relief and hope and helping to restore a sense of adequate self-efficacy. The idea that cancer might in some way be related to stress or emotional factors is as old as the history of recorded medicine. Galen's treatise on tumors, 'De Tumoribus', noted that melancholy women were more susceptible to cancer than other females. The earliest English definition of cancer appearing in 1601 was : 'Cancer is a swelling or sore coming of melancholy blood, about which the veins appeare of a blacke or swert colour spread in the manner of a creifish claws.' In 1701 Gendron, an English physician, emphasised the effect of 'disasters of life as occasion much trouble and grief' in the causation of cancer. In the mid 1800s, Walshe's 'The Nature and Treatment of Cancer' called attention to the 'influence of mental misery, sudden reversals of fortune and habitual gloomings of the temper on the disposition of carcinomatous matter'. Toward the end of the century another English physician, Snow, reviewed more than 250 patients at the London Cancer Hospital and concluded that 'the loss of a near relative was an important factor in the development of cancer of the breast and uterus' (Rosch, 1984). In studies of life histories of sets of twins, Greene, a haematologist, found that the twin out of each set who contracted and died of leukemia had experienced a psychological upheaval, in contradiction to the healthy twin who had not undergone any emotional trauma (Greene & Swisher, 1969). In another 15-year study of patients with lymphoma or leukemia, those diseases were most apt to occur in a setting of emotional loss or separation which engendered deep feelings of anxiety, anger, sadness or hopelessness (Greene, 1962).

Utilising Rorschach techniques, a variety of questionnaires and detailed personal interviews with patients as well as close relatives, Le Shan concluded that the most important factors in the development of malignancy were: (1) a loss of raison d'etre (hopelessness/helplessness); (2) an inability on the part of the individual to express anger or resentment; (3) a marked amount of self-dislike and distrust; and (4) most significantly, loss of an important emotional relationship (Le Shan, 1977). Much of the early literature linking stress and cancer is clearly subjective, anecdotal and methodologically poor, having inadequate or no controls or very small samples. More recent controlled and systematic studies have produced contradictory results and do not present such a consistent or clear-cut picture as that of earlier observations (Burgess, 1987). Jacobs & Charles (1980) using an improved design, found that children with cancer had experienced events of greater emotional importance than controls (Burgess, 1987). Cooper, Davies-Cooper & Faragher (1986) undertook a prospective study of 2,163 women undergoing breast examination which yielded four groups of patients with malignant disease, with cysts, with benign breast disease and disease free. Although the group of patients with cancer had experienced fewer stressful events than the other groups, the events experienced by the patients with cancer tended to be severely rated loss or illness-related events. Along with the patients with cysts, they also reported fewer 'coping skills' than the other two groups and there was evidence that the cancer patients tended to suppress their feelings. This study indicates that it may not be stressful events per se which are implicated in the development of cancer, but rather the way in which individuals perceive and subsequently cope with stress which is crucial (Burgess, 1987). For example, Greer & Morris (1975) found a positive association between a diagnosis of breast cancer and a behavioural pattern persisting throughout life of extreme anger suppression which reached statistical significance in women under 50 years of age. Similarly, Morris, Greer, Pettingale & Watson (1981) found that in addition to being associated with suppression of anger, breast cancer was also associated with low anxiety, a finding later replicated in subsequent psychological studies of women with breast cancer (Greer, 1983). However, this contrasts with other findings in the literature. For example, a study by Maguire, Lee & Bevington (1978) found moderate to severe anxiety in 27% of breast cancer patients compared to 14% of controls. Although the availability of relevant literature is limited, anxiety disorders appear to be more common in persons with cancer than in persons without cancer (Noyes, Holt & Massie, 1998). Based on Epidemiologic Catchment Area Program data, Wells, Golding & Burnam (1988) reported that nearly 12% of persons with chronic medical conditions had anxiety disorders compared to 6% of those without. Cancer was one of the conditions that showed an especially strong association with anxiety and other psychiatric disorders. In the general population, anxiety disorders are associated with female gender, younger age and lower socio-economic status. In cancer populations these demographic variables appear less important. Noyes *et al.* (1998) noted that the diagnostic recognition of anxiety disorders is complex. Patients often interpret their distress as a normal reaction to their disease and, therefore, do not seek relief from what they feel they must cope with alone. Also, patients may be ashamed to reveal their anxiety and therefore physicians may fail to recognise the level of distress that patients experience. It is not clear from the literature whether anxiety disorders are more or less prevalent in patients with cancer than in patients with other illnesses. According to Cassileth, Lusk & Strouse (1984), the distress associated with chronic disease is similar to that of major illness groups including cancer. Existing studies indicate that anxiety disorders are also prevalent in medically ill patients in general (Noyes *et al.*, 1998).

It is quite clear that the hallmark of stress is being out of control. It is also becoming clear that progressive loss of control is a characteristic of civilisation and cancer rates may correlate with such stressful and disruptive effects on the 'internal environment' and homeostasis (Rosch, 1984). This concept is far from novel and was actually suggested by Tanchou in his 'Memoir on the Frequency of Cancer' presented to the French Academy of Sciences in 1843 (as quoted in Le Conte, 1846):

> *M. Tanchou is of the opinion that cancer, like insanity, increases in a direct relation to the civilisation of the country and of the people. And it is certainly a remarkable circumstance, doubtless in no small degree flattering to the vanity of the French savant, that the average mortality rate from cancer in Paris during 11 years is about 0.80 per 1,000 living annually, while it is only 0.20 per 1,000 in London. Estimating the intensity of civilisation by these data, it clearly follows that Paris is four times more civilised than London (Rosch, 1984).*

The functional integration of the nervous and endocrine systems is known to be so complete that they are now regarded as one system (Pettingale, 1985). Exposure to a variety of environmental and psychosocial stressors can alter the functioning of the immune system (Dantzer, 1993). Psychoneuroimmunology looks at the interaction between the central nervous system and the immune system and may clarify some of the questions regarding the possible influence of psychosocial factors on cancer (Sabbioni, 1991). Experimental and clinical studies demonstrate that both laboratory and natural stressors alter lymphocyte and macrophage functions, both of which are important effector mechanisms which could eliminate cancer cells (Pettingale, 1985). The marked biological heterogeneity of human tumours means that it may not be possible to prove that psychological factors play an independent part in their development. However, growth of the whole organism and its constituent parts is under hormonal control. Psychological responses, particularly emotional reactivity, produce alterations in many tissues via limbic-hypothalamic-pituitary release of 'stress' hormones. Cancer is a disorder of cell growth involving some imbalance in normal tissue regulation. It seems reasonable therefore to postulate that psychoneuroendocrine mechanisms may play a part in cancer development: how great a part is at present conjectural (Pettingale, 1985).

Considerable research on the effects of stress on cancer growth in laboratory animals also provide corroborative data. Pavlov reported that dogs subjected to severe and chronic stress had a marked increase in malignancy of internal organs (Rosch, 1984). In a study by Riley & Spackman (1976) of a highly cancer-prone strain of mice, 60% of the animals developed tumours within 8-18 months after birth under usual laboratory conditions. When placed behind a protective barrier insulating them from the stress of normal laboratory commotion and noise, only 7% of the same strain of mice developed cancer during a 14 month period. Another experiment showed that by slowly rotating the animals on a turntable the incidence of cancer rates increased (Riley, 1981).

In animal studies, the existence of a direct influence of 'psychosocial factors' on cancer, operationalised as stress, control over stress and as stress buffering, through such factors as different housing conditions, can be demonstrated (e.g. Sklar & Anisman, 1979). However, knowledge gained from animal studies cannot be directly transferred to the human situation, particularly because of the tumour models used. The assumption that all tumours are equally affected by psychosocial factors must be dismissed because of the biological heterogeneity of different neoplasms. Although the influence of various factors on cancer morbidity and mortality may be very different, the assumption can be made that there is a small but significant contribution of psychosocial factors to cancer risk and survival which might vary depending upon the specific neoplasm considered (Sabbioni, 1991). Animal research indicates that stressful conditions can inhibit as well as promote tumour growth, although similar studies relating stress to cancer in humans are far less definitive (e.g. Newberry, Jaikins-Madden, & Gerstenberger, 1991). It appears that acute uncontrollable stress is likely to stimulate tumour development, whereas similar controllable stress is much less likely to have such an effect. For example, Sklar & Anisman (1979) found that inescapable, but not escapable shock stimulated tumour development. In this study growth of syngenic P815 mastocytoma in DBA/2J male mice was evaluated as a result of various stress regimens. A single session of inescapable shock resulted in earlier tumour appearance, exaggeration of tumour size and decreased survival time in recipient animals. Escapable shock had no such effects. The effects of the inescapable shock were mitigated if mice received long-term shock treatment.

A wide range of external substances and factors have been implicated as the cause of various cancers due to carcinogenic activities of a physical or chemical nature. The two most important internal mechanisms which have been demonstrated to influence malignant growth are hormonal factors and the immunological competency of the individual. Both endocrine and immune function are so sensitive to the influence of stress that they are used to measure its effects in humans (Rosch, 1984). The immune system contains a number of effector mechanisms which could eliminate cancer cells, including cytotoxic T lymphocytes and natural killer (NK) cells as well as macrophages (Pettingale, 1985). It has been suggested that malignant cells intermittently develop in various tissues and organs and, in susceptible individuals, are able to gain a foothold and multiply into clinically detectable malignant lesions. Normally, an efficient immune system is able to recognise and destroy such abnormal cells (Rosch,1984). Recent evidence suggests that the transformation from a normal to a malignant state does not involve a qualitative change in the composition of the cell, but a quantitative alteration in cell physiology, thus suggesting that no surveillance system could detect the very earliest malignant cell and that only when the functional change has succeeded could such a cell be recognised and eliminated (Pettingale, 1985).

Adrenal-cortical hormones interfere with the body's immune system or ability to make antibodies. Selye's (1950, 1956) research clearly demonstrated that stimulation of the adrenal cortex was the hallmark of the organism's response to acute stress. As part of this 'alarm reaction' there was also a marked involution of lymphatic tissue and of the thymus, major producers of immune system components. Thus, because of strong effects on both endocrine and immune factors, stress would appear to have profound potential influence on susceptibility to malignancy as well as its clinical course (e.g. Rosch, 1984). Greer & Watson (1985) point out that there is no reason for excluding psychological variables as contributory factors in the development of cancer. Contrary to Cartesian dualism which sharply separates body from mind and given the complexity of the human organism, it seems reasonable to postulate the existence of an integrated psychobiological control system, failure of which permits cancer, once initiated, to grow and disseminate. Greer & Watson (1985) do not presume that psychological factors are implicated in the initiation of malignant transformation nor that they are necessary or sufficient promoting agents. Their hypothesis is that, in some individuals, through interactions with biological homeostatic mechanisms, psychological factors contribute to the promotion of certain cancers. Psychological factors could play a part at this phase in several ways. Firstly, a patient's psychological 'make-up' may influence his or her behaviour which in turn may increase his or her exposure to carcinogenic agents. The most obvious example of this mechanism is smoking tobacco, but certain dietary and alcohol consumption habits and suntanning may also be harmful. Secondly, psychological factors could influence the susceptibility of the cell to respond to a carcinogen or influence the various enzymes which repair damaged DNA (Pettingale, 1985).

Different cancers have different aetiologies and different prognoses and the literature regarding the role of the immune system in carcinogenesis is controversial (Kripke, 1988). In the original idea that the immune system served as a means of controlling carcinogenesis, damage to the immune system in the form of immunosuppression would increase the likelihood of precancerous cells escaping the surveillance system and developing into full-blown cancers (Burnett, 1970). However, studies have shown that where cancers develop in individuals immunosuppressed by specific deficiencies, organ transplant procedures or the AIDS virus they are of a specific nature and do not include the most prevalent cancers such as cancers of the lung, breast, stomach and colon. The conclusion that overall 'the general immunological reactivity of the host need not be impaired for most neoplasticities to occur and progress' (Kripke, 1988) has refocused immunological research from examining systemic changes to examining the effects on local tumour-specific function. Although the concept of systemic immunoregulation of cancer aetiology and/or progression is not strongly supported, local immune changes surrounding tumour sites may well play a role alongside other factors in tumour progression (Cooper & Watson, 1991).

Presently, factors such as coping strategies and social support are hypothesised to alter host resistance through a variety of endocrine and immune pathways and consequently affect cancer survival. Much of the current work on host resistance and cancer survival has focused on breast cancer survival in women. Greer, Morris & Pettingale (1979) divided women with stage 1 and stage 2 breast cancer into groups with five different coping strategies. Psychological responses to cancer predicted survival at 5-, 10- and 15-year follow-up, with fighting spirit and denial (positive avoidance) responses protecting against mortality, compared with responses characterised as fatalistic, anxious preoccupation and helplessness/hopelessness. Later research has confirmed these results in women with both early and late stage disease. Longer survival was associated with higher levels of hostility, depression, guilt and total negative affect and shorter survival was associated with higher anxiety and higher external locus of control (e.g. Dean & Surtees, 1989). In addition, hopelessness has been shown to be associated with shorter survival in people with any type of cancer (e.g. Jensen, 1987).

Psychosocial factors examined in psycho-oncological research are as follows: (1) a hypothesised 'cancer-prone' personality, characterised by an inability to express emotions and to have satisfactory relationships; (2) the experience of depressive symptoms, feelings of hopelessness/helplessness or of bereavement which is believed to be associated with cancer risk or survival; and (3) the experience of distress, or the chance to buffer stress by improving coping or by providing social support and their influence on cancer risk or survival. The development or progression of cancer has been suggested to be associated with a type C personality, characterised by suppression of emotional reactions, especially anger and by conformity and compliance (e.g. Greer & Watson, 1985; Temoshok, Heller, Sagebiel, Blois, Sweet, DiClemente & Gold, 1985; Cox & Mackey, 1982). The clinical significance of the type C response (i.e. social compliance/conformity) may be linked to the degree of emotional suppression maintained and the specific biological response pattern with which it is associated. Data suggest that individuals who readily express their feelings experience less stress somatically because there is a rapid return to equilibrium through discharge of feelings associated with physiological arousal (Greer & Watson, 1985). A case-controlled study by Ramirez, Craig, Watson, Fentiman, North, & Rubens (1989) has found an increased relative risk of breast cancer recurrence associated with severe life events and difficulties during the post-operative disease-free interval. In a study of patients with malignant melanoma, death or severe disease progression was associated with high levels of distress and dysphoric emotions on self-report scales (Temshok, 1985).

Coping with Cancer

Cancer threatens not only patients' physical health but also their emotional well-being (Jarrett, Ramirez, Richards & Weinman, 1992). Women with breast cancer commonly experience transient emotional distress in relation to their diagnosis and treatment. Around one quarter develop clinically significant and persistent anxiety and depression in the first two years after diagnosis, which might partially be explained by patients' cognitive and behavioural coping responses to the diagnosis accounting for individual differences in psychological adaptation. It has been shown that the majority of patients use a wide repertoire of coping responses (Jarrett *et al.,* 1992). It would appear that life threat appraisals are the primary appraisals most salient to cancer given the fears of death, physical deterioration and disease recurrence associated with the disease. Life threatening appraisals are likely to relate negatively to adjustment by upsetting subjects' general equilibrium (Lazarus & Folkman, 1984). In a study of cognitive appraisals in patients with cancer by Jenkins & Pargament, (1988), using interviews with outpatients in a correlational design, the primary appraisal of perceived life threat appeared negatively related to adjustment. Several secondary appraisals emerged as correlates of adjustment: perceived personal control, God-control and chance-control, along with perceived control over emotional reactions (Jenkins & Pargament, 1988).

Three broad influences determine patients' coping with cancer. Of prime importance is the nature of the stress, cancer and cancer-related variable (e.g. site of disease, stage, treatment and course). Next come the individual variables, such as when in the life course cancer occurs and what emotional and social resources are available. Finally, the sociocultural climate within which the diagnosis and treatment of cancer occur contributes to coping. Also, cancer as a stressor fits Lazarus's (1966) concept of a high-stake situation. Gradations in response may be affected by the nature of the diagnosis and treatment. For example, a female patient who is told she has an in situ lesion of the cervix faces a different set of adaptational demands than the patient who is told she has an invasive tumour of the cervix with likely metastatic involvement. When confronted with a diagnosis of cancer, individuals respond psychologically in several different ways and particular coping responses adopted by patients with cancer may influence prognosis (Watson, Greer, Young, Inayat, Burgess & Robertson, 1988b). In a prospective, multidisciplinary study of 69 consecutive female patients with early, non-metastatic breast cancer, patients' psychological responses to the diagnosis of cancer were assessed three months post-operatively. The inclusion criteria for participation in this study were age less than 70 years, no previous history of malignant disease, a breast lump less than 5 cm in diameter, with or without palpable axillary glands, no deep attachment of the lump and no distant metastases. Psychological responses were related to outcome 5 years after operation. Recurrence-free survival was significantly common among patients who had initially reacted to cancer by denial or who had a fighting spirit, compared to patients who had responded with stoic acceptance or feelings of helplessness and hopelessness (Greer, Morris & Pettingale, 1979). One drawback with regard to this study is the lack of accurate information regarding node status which could have implications for survival. In a prospective follow-up study by Barraclough, Pinder, Cruddas, Osmond, Taylor & Perry (1992), of 204 newly diagnosed breast cancer patients for 42 months after primary surgical treatment, experience of adverse life events (severe events and difficulties not stemming from own health, major depression of over three month's duration and lack of a full confidant) were not associated with a substantial increased risk of relapse of breast cancer. However, the importance of the main biological variables already known to predict a poor prognosis in breast cancer, i.e. axillary node involvement and large primary tumour, was clearly confirmed in this study (Barraclough *et al.*, 1992).

The findings by Greer *et al.*, (1979) were supported by a study by Pettingale, Morris, Greer & Haybittle (1985) which indicated that patients whose response to cancer was categorised as 'fighting spirit' or 'denial' were significantly more likely to be (a) alive and (b) free of recurrence, at ten year follow-up compared to patients who responded with 'stoic acceptance' or 'helplessness/hopelessness'. In a study by Di Clemente & Temoshok (1985) stoic acceptance among women and helpless/hopeless responses among men were significantly associated with unfavourable outcome. However, these findings are challenged by a study of 359 patients with cancer by Cassileth, Lusk, Miller, Brown & Miller (1985a) who concluded that social and psychological factors individually, or in combination, do not influence the length of survival or the time to relapse. Although these factors may contribute to the initiation of morbidity, the biology of the disease appears to predominate and to override the potential influence of life-style and psycho-social variables once the disease process is established. It should be noted that the population studied by Cassileth *et al.* (1985a) included patients either with advanced malignant disease or with malignant melanoma at high risk for recurrence. Cassileth *et al.* (1985a) concluded that psychosocial factors shown to predict longevity in general populations or longer survival in patients with cancer (i.e. social ties, job satisfaction, use of psychotropic drugs, life satisfaction, subjective view of adult health, hopelessness/helplessness and perception of the adjustment required to cope with the diagnosis) were not useful clinical predictors of the length of survival in newly diagnosed patients with advanced metastatic disease.

However, in a study of 35 women with metastatic breast cancer, Derogatis, Abeloff & Melisaratos (1979) found that psychological coping mechanisms correlated with length of survival. Patients who died in less than one year from baseline were categorised as short-term survivors, while patients who lived for one year or longer were assigned to the long-term survivor group. Short-term survivors revealed significantly lower levels of hostility, with higher levels of positive mood compared to long-term survivors, who were perceived by their treating oncologists to show significantly poorer adjustment to their illness and poorer attitudes towards their physicians compared to short-term survivors (Derogatis, *et al.*, 1979). Emotional expression may contribute to a more adequate coping style: as a person begins to express needs and feelings, thus recruiting more genuine social support, he or she may have a more positive health outcome as psychological and biological equilibruim is restored. On the other hand, conscious hopelessness and learned helplessness are hypothesised to contribute to unfavourable health outcomes, as the individual gives up trying to achieve equilibruim in any area and the previous state of chronic biological disequilibruim is exacerbated. This model may be used to understand why some studies have found that Type C is associated with cancer outcome measures, while others have found that helplessness/hopelessness or emotional expression is related to outcome (Temoshok, 1987). Watson (1999) investigated the impact of psychological response to cancer in a large cohort of women with early breast cancer (n=578) to determine impact on survival at five year follow-up. Results of this study indicated no effect for fighting spirit, but, for five year event-free survival, a high helpless/hopeless response had a detrimental effect.

Adjustment to cancer may be defined as the cognitive and behavioural responses the patient makes to the diagnosis of cancer. Katz, Weiner, Gallagher & Hellman (1970) found psychological disturbance to be greater where the patient's coping response involved either fatalism, displacement or projection. Weisman & Worden (1977) found denial and acceptance of the diagnosis to be related to greater vulnerability, whereas a study by Watson, Greer, Blake & Shrapnell (1984) found denial to be associated with less distress. To what extent this is due to differences in methods of assessment, or to genuine differences in coping responses and attitudes is unclear. Watson *et al.* (1984) aimed to assess the extent to which patients responded to the stress of a cancer diagnosis by denying the seriousness of the illness and how this related to both level of distress and prior delay in seeking treatment. Results indicated that patients who denied the seriousness of a cancer diagnosis experienced significantly less mood disturbance during the period from first discovering a lump to visiting a doctor to have it examined than those who were more accepting of the diagnostic implications. These findings suggest that a denial rather than a confrontational-coping response may reduce initial short-term distress. The study failed to show any association between this response and length of delay in seeking treatment for a breast lump. Watson *et al.* (1984) suggested that ‘denial of the seriousness of the diagnosis, once it is known, is a good short-term adaptive response and that encouraging confrontation and acceptance during this period does not necessarily encourage coping.' The point in an individual's life at which cancer occurs is also considered a major determinant of coping. Again, using the example of cervical cancer, it is apparent that a diagnosis of this type of tumour has a different impact depending on the age of the woman (Rowland, 1989). Prospects for marriage and childbearing will be an issue for the young woman, management of a family in her absence may worry the middle-aged woman, whereas concern for financial burden and social support during convalescence or prolonged illness are more likely to be considered problematic for the older woman (Rowland, 1989).

The course of any illness can be affected by coping capacity. Thus, the repertoire of personal skills and cognitive capacities will be affected by age and level of independence and will affect coping ability as will values and beliefs. A person's prior illness experience has important repercussions for coping in times of sickness. Lipowski (1970) stressed the importance of the personal meaning of and attitudes toward sickness, injury and dysfunction in determining an individual's coping strategies and ability. The most typical meanings of cancer are as challenge, enemy, punishment, weakness, relief, irreparable loss or danger and finally, even positive value. Previous personal experiences with cancer also dramatically influence coping strategies. For example, a person who has lost several relatives to cancer (particularly of the same site) is likely to fear the disease more, be more likely to delay seeking treatment, or to adopt a futile, hopeless stance in the face of a diagnosis of cancer, compared to a person whose experience has been with cancer cures. It has been found that knowledge of someone who did well and confidence in the therapy both aid patient recovery from breast cancer. Individuals who firmly expect to be successfully treated will probably battle their disease more actively. Although there is strong anecdotal support for the positive impact of religious attitudes and activities on individuals' responses to serious illness, this relationship has not been well studied (Rowland, 1989).

Little is known about what predisposes individuals with cancer to cope in specific ways. Research has indicated that an individual will cope differently as a function of the particular situation involved. For example, an adaptive strategy for coping with physical discomfort might be problem focused, e.g. taking medication or seeking the advice of a physician, whereas the best strategies for dealing with ambiguity about the future might be emotion-regulating, e.g. distraction or avoidance. Dunkel-Schetter, Feinstein, Taylor & Falke (1992) identified five patterns of coping with cancer: seeking or using social support, focusing on the positive, distancing, cognitive escape-avoidance and behavioural escape avoidance. Level of appraised stress from cancer was related to three of the five patterns of coping. Medical factors, i.e. type of cancer, time since diagnosis and whether the cancer was currently being treated, were not strongly associated with coping when other factors were controlled. Of the personal characteristics studied, age, education and religiosity proved to be especially important in explaining how people coped. In general, people with cancer may be predisposed by virtue of premorbid factors such as life stage, socioeconomic status or personal beliefs, to cope in particular ways with their illness (Holahan & Moos, 1987; Dunkel-Schetter *et al.* 1992).

Psychological distress and coping in cancer

Derogatis, Morrow, Fetting, Penman, Piasetsky, Schmale, Henrichs & Carnickee (1983) indicated that the prevalence of psychiatric disorders, as defined by DSM III (American Psychiatric Association, 1980) criteria, was 47% among a large sample of newly admitted cancer patients. The majority of these were cases of depression or anxiety judged to be treatable. More recent surveys suggest that very serious disturbance is confined to between 5 and 15% of recently diagnosed patients (Watson, 1991). For many people the diagnosis of cancer, or the discovery of recurrence, is a catastrophic event. Individuals react as they do to other extreme stressors with an initial phase characterised by shock, denial, anger, dysphoria, emotional lability, anxiety, depression and hostility (Edgar, Rosberger & Nowlis, 1992; Mermelstein & Lesko, 1992; Gottschalk & Hoigaard-Martin, 1986). This manifestation of psychological distress is often accompanied by disturbances of sleep, concentration and participation in usual activities (Weisman & Worden, 1976). The profound psychosocial impact of a diagnosis of cancer, or a recurrence, is a severe traumatic event comparable to the stressor criterion in the Diagnostic and Statistical Manual of Mental Disorders, (DSM IV, American Psychiatric Association, 1994). According to clinical research, a predictable pattern of responses follows serious life events. Initially, intrusive symptomatology is prominent. The person may have recurrent, intrusive recollections or distressing dreams, during which the event is replayed.

Occasionally, the person may experience dissociative states, where components of the event are relived and the person behaves as though actually experiencing the event. Intense psychological distress or physiological reactivity often occurs. Such states of mind are very painful and warded off by avoidant manoevres. During a normal working through process, the person will unconsciously regulate intrusive thought content to tolerable levels by oscillating between intrusive and avoidant states of mind, finally attaining an adaptive completion. This cognitive-behavioural response pattern influences subsequent emotions and behaviour (Tjemsland, Soreide & Malt, 1996a, 1996b; Lazarus & Folkman, 1984). Crucial variables in the development of Post Traumatic Stress Disorder (PTSD) are the intensity of the threat to one's integrity and life, duration of stressor and lack of control over the traumatic situation (helplessness).

Tjemsland *et al.* (1996a) applied the concept of acute traumatic stress response to breast cancer diagnosis. A total of 106 patients were studied before surgery, by means of a psychiatric interview and questionnaires. The traumatic stress response was related to age, marital status, occurrence of breast cancer in first-degree relatives, previous physical and psychological parameters, social support and life events during the previous year. Of the patients, 44% reported a high level of intrusive symptoms and 29% reported avoidance symptoms. Younger age and being married were positively correlated with intrusive symptomology, while patients with a first degree relative with breast cancer had less intrusive disease. Previous physical and psychiatric health parameters showed no association to acute traumatic stress symptoms except for those who had experienced a serious illness, accident or hospitalisation in the previous year who had more avoidant symptomology. Tjemsland *et al.* (1996a) found that a major acute stress response to cancer diagnosis is common and frequent, but high levels of traumatic symptoms beyond the acute phase were most predictive of later adjustment problems. In a further study of patients with a confirmed diagnosis of cancer undergoing breast surgery, the level of acute post-traumatic stress response to breast cancer was best predicted by premorbid variables (Tjemsland *et al.* 1996b). In addition to the anxiety elicited by the knowledge that they have cancer, the etiology of psychological distress and the clinical depressive syndromes seen in cancer patients result from a combination of medical factors, type of required treatment, the presence of pain, psychological factors and social and risk factors. For these reasons, early recognition, diagnosis and management of a depressive disorder within the context of cancer becomes a priority (Mermelstein & Lesko, 1992).

Effective psychotherapy for depression has been found to affect the course of cancer and to reduce anxiety, depression and pain. In three randomised studies psychotherapy resulted in longer survival time for patients with breast cancer (18 months), (Spiegel, Bloom, Kraemer & Gottheil, 1989) lymphoma and leukemia (Richardson, Shelton, Krailo & Levine, 1990) and malignant melanoma (Fawzy, Cousins, Fawzy, Kemeny, Elashoff & Morton, 1990a, 1990b). Four fundamental possibilities for psychotherapeutic effects on physiological change include health maintenance behaviour, health-care utilisation, endocrine environment and immune function. Thus, effective treatment of depression in patients with cancer results in better patient adjustment, reduced symptoms and reduced cost of care and may influence disease course and so, may be considered a part of medical as well as psychiatric treatment (Spiegel, 1996). A high score for depression in patients with early breast cancer has been shown to be associated with significantly worse survival rates at five-year follow-up (Watson, 1999). Unidentified and untreated depression significantly compromises the patient's quality of life. There is a need for routine screening for depression and implementation of cost-effective management strategies in oncology settings (Berard, Boermeester & Viljoen, 1998). Depression in patients with cancer is best managed utilising a combination of supportive psychotherapy, cognitive-behavioural techniques and antidepressant medications. Cognitive-behavioural approaches explore patients' beliefs about the cancer diagnosis and its treatment in order to elicit irrational or unhelpful thoughts that lead to feelings of helplessness and hopelessness and attempt to correct these maladaptive thoughts, along with providing new coping behaviours (e.g. Moorey, 1991; Passik, McDonald, Dugan, Edgerton & Roth, 1997; Watson, 1999).

The etiology of psychological distress and the clinical depressive syndromes seen in patients with cancer result from a combination of medical factors (site and clinical course of the disease, type of required treatment and the presence of pain), psychological factors (adjustment to prior illnesses, coping ability, developmental life phase) and social factors (availability of support from family, friends, coworkers and medical staff). Factors which predispose patients with cancer to develop a depressive disorder include social isolation, recent losses, a tendency to pessimism, the presence of pain (especially if uncontrolled), and socioeconomic pressures (Mermelstein & Lesko, 1992; Weisman & Worden, 1976). Other predictive factors are a prior history of mood disorders, suicide attempts, the presence of alcoholism or substance abuse as well as the site of disease (Plumb & Holland, 1981; Massie & Holland, 1987). Additionally, some of the commonly used medications (corticosteriods, vinblastiine, vincristine, procarbazine, interferon), metabolic derangement (hypothyroidism, hypercalcemia) and medical conditions (Addison's disease) produce depressed mood (Mermelstein & Lesko, 1992).

Studies demonstrate that assessment of acute stress responses can better identify the emotional impact of cancer than mere assessments of emotions such as anxiety and depression (Cella, Mahon & Donovan, 1990; Kaasa, Malt, Hagen, Wist, Moum & Kvidstad, 1993; Stuber, Meeske, Gonsales, Houskamp & Pynoos, 1994, Tjemsland *et al.*, 1996a; 1996b.). Cella *et al.* (1990) studied stress response symptoms shortly after recurrence in a heterogeneous sample of 40 patients undergoing cytotoxic therapy for cancer. A majority of patients showed a high level of avoidant stress symptoms and nearly half had a high level of intrusive symptoms. Patients undergoing their first recurrence experienced somewhat more traumatic distress compared to those with two or more recurrences. In a study by Cordova, Andrykowski, Kenady, McGrath, Sloan & Redd (1995) quality of life (QoL) and PTSD-like symptoms were assessed in 55 women post-treatment for breast cancer. PTSD symptomology was negatively related to QoL, income and age. Time since treatment, type of cytotoxic treatment and stage of disease were unrelated to PTSD symptoms. Findings suggested that in survivors of breast cancer, PTSD symptoms might be fairly common and may exceed the base rate of these symptoms in the general population. Alter, Pelcovitz, Axelrod, Goldenberg, Harris, Meyers, Grobois, Mandel, Septimus & Kaplan (1996) measured the rate and determinants of PTSD in a group of cancer survivors. Patients who had a history of cancer diagnosis with at least three years since diagnosis, receiving no active treatment, such as chemotherapy or radiation, were compared with a community-based control group matched for age and socio-economic status. One member of the survivor group (4%) and no members of the control group met criteria for current PTSD. Six of the survivors (22%) and no control subjects met lifetime criteria ($p<0.02$). These researchers concluded that cancer patients have a higher rate of PTSD than found in the community. Symptoms closely resemble those of individuals who have experienced other traumatic events. Watson (1999) found that depressed patients with cancer had a high incidence of intrusive memories, symptomatic of PTSD, compared to non-depressed controls.

Despite the prevailing belief that patients with early stages of cancer and good prognoses should have nothing to worry about, it is apparent that patients with newly diagnosed cancer, regardless of their prognosis, exhibit symptoms of psychological distress similar to those undergoing bone marrow transplantation as a last resort treatment for leukemia, patients with AIDS, and other patients with cancer in general. Apparently, these patients, who are otherwise high-functioning and healthy, are still dealing with the immediate stress of being diagnosed as having a possible life-threatening disease (Fawzy, Cousins, Fawzy, Kemeny, Elashoff & Morton, 1990a). The diagnosis of cancer immediately and prematurely imposes a perceived disruption in the 'life trajectory' of the patient. Irrespective of his or her age or phase in the life cycle, the patient is generally concerned with the fear of death, morbidity associated with treatments, fear of recurrence, fear of becoming dependent or a burden, fear of abandonment, fear of loss of function, social value, or financial independence and inability ultimately to complete goals. Such concerns cause varying degrees of psychological distress and adjustment problems (coping) that can be expressed in psychobehavioural terms and seriously compounded by the side effects of both the disease of cancer and its treatment (Fawzy *et al.,* 1990a). These effects can be debilitating, long-lasting and produce considerable distress, for instance pain, nausea, vomiting and/or neurological or cognitive impairment (e.g. Burish & Redd, 1994).

Pain and coping

The attributes of the pain experience and their relationship to coping seem to strongly correspond with the postulates of stress theory. Thus, in considering pain as a stressor (Selye, 1979b) cognitive appraisal has pivotal significance for emotional responses and cognitive and affective appraisals used to interpret and guide coping responses to the pain experience. The emotional responses to the pain experience of patients with advanced cancer include anxiety, depression and anger, along with the physiological and psychosocial effects and the meaning or significance of the pain experience appraised as future threat, actual harm and/or challenge (Lazarus & Folkman, 1984). From the viewpoint that little is known about the relationship between coping processes and cancer pain, Arathuzik (1991a; 1991b) examined the relationships between the appraisal of pain and the coping strategies and behaviours used by patients with metastatic cancer to deal with pain. Results indicated the overwhelming impact of the pain stressor on these patients, which interfered greatly with the patients' activities and which caused them much anxiety and depression. Two predominant patterns of correlations between the cognitive and affective pain appraisals emerged that were associated with the coping behaviours and strategies used to manage the pain experience. Subjects who perceived pain as threatening or harmful and as causing greater physiological and psychosocial effects, were withdrawn and very distressed, whereas subjects who were able to view their pain as challenging, with some positive connotations, were able to devise and use a variety of strategies to deal with pain, which may have helped to reduce emotional distress associated with their pain.

Cognitive-behavioural interventions and coping

Anxiety arousal can be induced by an individual focusing negatively both on his or her own coping deficiencies, as well as those aspects of their environment that cause concern, potentially increasing the perceived severity of possible threats. Self control refers to the process by which individuals consciously decide to take control of their own behaviour. When people are engaged in self-controlled actions they also have to engage in 'process-regulating cognitions' (PRC) which precede any self-control behaviour. PRCs are similar to cognitive functions of the self-system in Bandura's (1978) social cognitive theory. The self-system refers to cognitive structures that provide reference mechanisms and to a set of sub-functions for the perception, evaluation and regulation of behaviour. A self-monitoring phase is followed by a self-evaluation stage in which individuals engage in primary and secondary appraisals (Lazarus & Folkman, 1984). In the primary appraisal phase individuals decide whether a behavioural change is desirable or not, and in the secondary appraisal phase they decide whether they are capable of changing their behaviour. At the latter phase individuals develop expectations for self-efficacy. Following the person's appraisal of goals and their perceived ability to achieve them, they commence the process of self-control. Behavioural alternatives are generated and evaluated and decisions are made as to what is the best course of action. The specific kind of self-control behaviours that will be used by individuals will be determined by goals for the self-control process. Most self-management therapies, cognitive-behaviour therapies and stress management techniques focus on training clients in redressive self-control, i.e. effective coping with emotion reactions that interfere with daily functioning (Rosenbaum, 1993).

Cancer pain involves physiological and psychological mechanisms that often necessitate a combination of clinical interventions to achieve effective management. Although analgesic medication remains the mainstay of treatment for cancer pain, the overall management of pain and facilitation of comfort may be enhanced through the use of noninvasive techniques aimed at the promotion of physical and mental relaxation. Research shows that there is a relationship between muscle tension, autonomic hyperarousal, anxiety and pain (e.g. Fishman & Loscalzo, 1987). Non-invasive behavioural techniques may help people with cancer pain and related distress. Research suggests that relaxation is antagonistic to anxiety and that it may reduce anxiety through a mechanism of reciprocal inhibition (Sloman, 1995). Few controlled clinical trials of psychological interventions for cancer pain relief exist in spite of frequent support for their importance as adjuncts to medical treatment. Syrjala, Donaldson, Davis, Kippes & Carr (1995) concluded that relaxation and imagery reduces cancer treatment-related pain. A study by Arathuzik (1994) examined the effects of a combination of cognitive and behavioural nursing interventions on pain perception, pain control and mood in metastatic breast cancer patients who were experiencing physical pain. Results indicated that these interventions could be useful clinical nursing interventions for selected cancer patients experiencing physical pain.

Locus of control and coping

The perception that the causes of specific events will be attributed to personal (internal control) or situational (external control) elements, has been the focus of numerous studies and is considered an important influence on adaptation to stress (Watson, Greer, Pruyn & van den Borne, 1990). The locus of control (LOC) construct comprises three presumably independent dimensions: internality, chance and powerful others. Antonovsky (1992) states that the inference that internality is functional for patients is highly attractive to contemporary thought in nursing. However, chance and more especially, powerful others, contribute to patient outcomes. The patient role is one of diminished capacity for autonomous functioning. The cancer patient at any stage is dependent upon powerful others for all types of aid, knowledge, skills and resources. However, the beliefs of a patient may determine whether benevolent powerful others are perceived as possessing qualities which cast the patient into a dependent or passive role or whether those same powerful others are seen as facilitating growth, choice, responsibility and active co-operation. These beliefs may depend on the patient's locus of control. Most patients with terminal cancer have at least some awareness of impending death but the daily realities of pain and incapacity may present even more salient problems. Among other tasks, it is necessary for the person with terminal cancer to learn to use medical assistance and internal resources to minimise pain and to retain as much self-sufficiency and personal dignity as possible (Stone, Cohen & Adler, 1979).

Summary

In the context of Selye's (1950, 1956) classic formulation of stress as one of physiological and endocrine processes, coping is a process that modulates neuro-endocrine function while Lazarus' transactionalist view considers that the consequences of the stress are conceived more broadly than as just those stemming from adverse responses to adrenal gland secretion. Behavioural, cognitive and emotional consequences are implicated along with sympathetic nervous system and adrenal medullary/cortical activation. Thus Selye's view puts the stressor outside the person, whereas Lazarus' view argues that the stressor is a mental construct. Selye would look toward physiological state to assess the utility of a coping strategy whereas Lazarus would assess psychological well-being (Singer, 1983). Folkman & Lazarus (1988) point out that two principles need to be emphasised. The first is that every encounter, even the most simple, is usually complex and contains multiple facets and implications for well-being that either exist side by side or arise sequentially, which is why there can be more than one emotion in any encounter. The second principle concerns the temporal and unfolding quality of emotion and coping processes. Coping in an anticipatory context offers an important opportunity to influence what happens at the point of confrontation by possibly preventing or ameliorating a harm or facilitating a benefit. After confrontation, coping must be aimed at managing the consequence and their implications for the future. Emotions constantly shift throughout this process, according to the changing status of the person-environment relationship. Together, these two principles highlight the complex and dynamic nature of emotions and coping in social encounters (Folkman & Lazarus, 1988).

The diagnosis of cancer is a traumatic event for many people, some of whom may respond with symptoms similar to those of PTSD. Approximately 50% of patients with cancer suffer some type of mood disorder (Derogatis *et al.,* 1983). The recognition of psychological distress and clinical depressive syndromes are vital for maintaining patients' quality of life (Berard *et al.,* 1998) and have implications for survival rates (e.g. Watson, 1999). For the patient with cancer, other people are both part of the problem and a necessary ingredient to the solution. By facilitating patients to feel supported, some of their distress might be alleviated and their sense of coping enhanced. For the person with cancer, coping well depends on the social context, including supportive others (Weisman, 1979). Coping assistance can be provided for patients to mitigate the problems that the experience of cancer imposes. For example, learning about cancer pain and pain management options is a responsibility that can be shared by the patient, his or her family and the health care team. Effective pain management involves assessment, treatment, reassessment of results and sometimes referral. It entails continuity of care, including patient education and use of community resources. Together the patient and health care team can seek the most effective methods of managing pain, changes in pain levels and any new pain that may occur throughout the illness (Breitbart, 1994). For the person with cancer, this inclusive patient-centered approach, which has implications for anxiety reduction, enhanced self-efficacy and improved quality of life, centres on the provision of adequate social support. Benner & Wrubel (1989) point out that, for people with cancer, relationships with family and friends are beset with communication and relational difficulties. People with cancer face the extra burden of having to make the illness bearable for their friends and family as well as for themselves. Therefore the provision of adequate support becomes a necessity for both patient and family (Northouse & Peters-Golden, 1993).

SOCIAL SUPPORT

The concept of social support

The term social support refers to the structure, functioning or subjective evaluation of interpersonal relationships. The belief that human health and mortality is influenced by the absence, or sudden loss, of social relationships has been a recurrent theme in psychological, sociological and medical literature (Ell, Nishimoto, Mediansky, Mantell & Hamovitch, 1992). Interest in the association between social relationships and mortality has been spurred further by recent large-scale population-based studies (e.g. House, Landis & Umberson, 1988). A rapidly evolved literature has established a link between social support and adaptation to stressful circumstances (Depner, Wethington & Ingersoll-Dayton, 1984). Two seminal articles reviewing animal and human research concluded that primary social relationships and the coping resources they provide are essential in managing stress and thereby influencing both psychological and physical health (Cobb, 1976; Cassel, 1976). Research has demonstrated that social support may influence an individual physiologically (for example, by dampening the adrenaline release leading to the fight or flight reaction, thus reducing stress), psychologically (for example, decreasing emotional distress) or behaviourally (for example, encouraging healthy behaviours such as regular exercise) (Keeling, Price, Jones & Harding, 1996; Ganster & Victor, 1988). The relationship between a lack of social support and psychological impairment is generally considered to be strong (Milne, 1997). Either through direct protective effects or by buffering the adverse consequences of life stress, social support is associated with a decreased likelihood of physical and psychological disorder (e.g. Orford, 1992). Considerable research now indicates that social support reduces the adverse psychological impact of exposure to stressful and ongoing life events (e.g. Cohen & Wills, 1985). Understanding how the adequacy of an individual's support can be improved could therefore have major implications for the treatment and prevention of psychological impairment (Milne, 1997).

The concept of social support has emerged as a major psychosocial variable in health related research (e.g. Cobb, 1976; Unger & Powell, 1980) which has been measured differently from study to study. There is a lack of agreement about defining social support and how it functions to protect health or buffer the effects of stressors. At one extreme, presence of another during a stressful experience is described as social support and at the other extreme, elaborate formulations about social network properties are suggested as essential properties to study (Norbeck, Lindsey & Carrieri, 1981). The term social support is a general rubric that encompasses a host of more specific definitions (Depner *et al.,* 1984). Carveth & Gottlieb (1979) concluded that 'there is little agreement about the definition of social support nor is there consensus about the utility of distinguishing among sources of support.' Emotional social support was defined by Cobb (1976) as information leading the subject to believe that he or she is cared for and loved, esteem support as information that a person is valued and esteemed, and network support as information that a person belongs to a network of mutual obligations. Social support has also been defined in a less strictly interpersonal way as any input towards goals which the receiver desires (Caplan, Robinson, French, Caldwell & Shinn, 1976). A similar definition was adopted by Tolsdorf (1976) who stated that social support is any action or behaviour that functions to assist the focal person in meeting his or her personal goals or in dealing with the demands of any particular situation. Kahn defined social support as interpersonal transactions that include one or more of the following: the expression of positive affect of one person toward another; the endorsement of another person's behaviours, perceptions or expressed views and/or the giving of symbolic or material aid to another (Gottleib, 1981).

The importance of relationships with others for mental health is a key assumption underlying the conceptualisation of social support as fulfilment of ongoing social needs. Weiss (1974) proposed six different functions served by relationships with others and conceptualised these functions as provisions that are required for well-being. These include attachment, social integration, reassurance of worth, guidance, reliable alliance and opportunity to provide nurturing. Caplan (1974) hypothesised a similar set of basic interpersonal needs, including love and affection, freedom to express personal feelings, validation of personal identity and worth, satisfaction of nurturance and dependency needs, help with tasks and support in handling emotion and controlling impulses. Social support is defined as access to relationships that meet these kind of fundamental interpersonal needs (Kaplan, Cassel & Gore, 1977; Lin 1986). Although terminology differs from theorist to theorist, a core set of functions served by relationships appears recurrently. This core includes emotional, informational and tangible support as well as enhanced esteem. This perspective predicts a 'main effect' for social support; it predicts that for persons facing both high and low levels of adversity, those with higher quality social support will enjoy greater physical and mental health (Cutrona, 1996).

Some researchers have adopted a more focused definition of social support that emphasises fulfilment of needs that arise as a consequence of stressful life events or adverse personal or environmental circumstances. This conceptualisation arose in the context of research on the adverse effects of poor living conditions and stressful life events on mental and physical health (e.g. Caplan, 1974; Cobb, 1976). Research revealed that although some people succumb to illness in the wake of negative life events, many others do not (Rabkin & Streuning, 1976). A search for factors that might protect people against the deleterious effects of stress has been undertaken (e.g. Pearlin, Lierberman, Menaghan & Mullan, 1981). High quality relationships with others have been identified as a potential protective factor or buffer. The primary emphasis in this approach is on the stress-buffering functions of social support. In other words, the primary benefit to the recipient of social support is protection against the deterioration of health and well-being that would otherwise be caused by the pressures of recent or ongoing stressful events. At low levels of support, those with high levels of stress experience poor mental and physical health outcomes. However, when protected by high levels of support, even those experiencing a high stress load do not succumb to declining health or experience a less severe decline (e.g. Pearlin *et al.*, 1981). Research indicates that measures of overall network structure and of instrumental support are less efficacious in producing stress-buffering effects than is emotional aid (e.g. Turner, 1981).

It is very difficult to assess social support through any means other than subjective self-reports. The individual who has experienced a relationship is best qualified to evaluate whether a given relationship meets his or her needs, either long-standing or crisis generated. This approach has been criticised because of its subjectivity and the potential for contamination by factors other than experiences with the support provider. For example, the mood or personality of the support recipient may bias his or her assessments of the relationship (Procidano & Heller, 1983).

Researchers who are dissatisfied with the subjectivity, potential inaccuracy and vulnerability to bias of perceived social support assessments, prefer to focus on actual support transactions. In their approach, the target individual is asked to report on more objective indices of support, for example, the frequency of support behaviours received from others in a specified period of time (Barrera & Ainley, 1983). Critics of the received social support approach argue that the number of recent help-intended behaviours does not provide an index of the quality of support experiences (Turner, Frankel & Levin, 1983). Not all attempts at supportiveness are successful. Some are perceived as intrusive, demeaning or insensitive (Wortman & Lehman, 1985). Thus the importance of retaining a qualitative or evaluative component in the assessment of social support has been argued (Turner *et al.*, 1983).

Caplan (1979) specified two dimensions, objective-subjective and tangible-psychological, that form four variations of social support. Objective tangible support is behaviour directed toward providing the person with tangible resources that are hypothesised to benefit his or her mental or physical well-being. Objective psychological support is behaviour directed toward providing the person with cognitions (values, attitudes, beliefs and perceptions) and toward inducing affective states that are hypothesised to promote well-being. Objective support is measured by an outside observer. Subjective tangible support and subjective psychological support are analogous to their objective counterparts, but they are determined by the target person's perception that supportive conditions exist. Thus social support can be measured from the frame of reference of the target person, the subjective or phenomenological approach, or from the perspective of an outside observer, the objective approach. Objective assessment is not prone to the self-reporting biases inherent in the phenomenological approach and it provides a standard of comparison across individuals. However, in favour of the more subjective approach is the argument that individuals have different needs and tastes; therefore the nature and number of interpersonal contacts with friends, relatives and others necessary to achieve social health may vary greatly. These differences may not be adequately reflected in measures of objective social health constructs (Gottlieb, 1981). The most efficient predictor of a person's physiological behaviour in a given environment may consist of how s/he perceives that environment (Kiritz & Moos, 1974).

Three different research traditions related to social support have developed over less than twenty years. Firstly, epidemiological studies have focused on the effects of social networks (House, 1981; Wills, 1985; Krishnasamy, 1996), defined as the set of all others with whom a person has social relations (Hirsch, 1979). Individuals with strong natural support systems have been hypothesised to be less likely to develop psychological or physiological disorders when under stress than are individuals with weak or nearly non-existent support systems (Caplan, 1974; Cassel, 1975). For instance, Hirsch (1979) found that social networks can provide considerable quantities of support to individuals under stress. Denser or more integrated social networks may give greater quantities of support, though less satisfying emotional support. Secondly, the buffering hypothesis proposed that social support acts to protect people from the stresses of life (Cobb, 1976; Wills, 1985). Thus, individuals with a strong social support system should be better able to cope with major life changes, while individuals with little or no social support may be vulnerable to life changes, particularly undesirable ones. Clearly, this hypothesis concerns an interactive effect: the recurrence of events in the presence of social support should produce less distress than should the occurrence of events in the absence of social support (Thoits, 1982). Social support may be expressed structurally, via support integration, marital status, size of support network and/or frequency of social interactions. This type of support is perceived as buffering minor daily stresses. Social support may also be expressed functionally, offering emotional, tangible, appraisal or informational support. This type of support is considered to have the capacity to buffer major life events (Wills, 1985). The third research tradition, closely related to the buffering hypothesis, has focused on groups of people who have all undergone a common stressful experience (Dunkel-Schetter, 1984; Krishnasamy, 1996).

Early studies on social support focused on the quantity of significant social relationships in an individual's social network. Most people know hundreds of other people in many different ways (McCallister & Fischer, 1978). Schaefer, Coyne & Lazarus (1981) found that the adequacy of support as perceived by the recipient was a better predictor of psychological adjustment than the actual availability of support. More recent research and theory development effort has tended to confirm the importance of the individual's perception of social support, the nature of the relationship within which the support occurs and the issue at which the support is directed (Milne, 1997; Sarason, Pierce & Sarason, 1990). Up to 1986, little was known about the aspects of support which were protective and the mechanisms and conditions that made support attempts beneficial or harmful. Following publication of research finding a significant interaction between a sociodemographic category and the experience of events and/or strains, this interaction effect was termed 'psychological vulnerability' (e.g. Thoits, 1982). Thoits (1984) tested the hypothesis that the psychological vulnerability of disadvantaged persons to undesirable life events could be explained by the joint occurrence of high event exposure and low social support resources in such persons' lives. Social support was operationalised by Thoits (1984) as the relative presence or absence of an intimate, confiding relationship. Results showed that differential vulnerability could not be accounted for by the joint occurrence of undesirable events and lack of support. However, emotional support was found to have a significant negative main effect on changes in anxiety and depression. That is, individuals who maintained intimate, confiding relationships with others experienced reduced psychological distress over time, even if adverse life events occurred.

Despite problems, social support has been shown to be a robust variable in a wide range of health-related contexts. In a study of nearly 5,000 adults by Berkman & Syme (1979), socially isolated individuals were more than twice as likely to die in the nine-year follow-up period than those with the most social contacts. This association was independent of prior health status, socio-economic status and health practices. Although similar findings have been reported in a wide variety of health, illness, recovery and coping situations, research findings suggest that certain aspects of social support crucial to one situation may not be important in others. For example, in a study by Sokolovsky, Cohen, Berger & Geiger (1978), networks with a low degree of connectedness (density) were associated with higher rates of re-hospitalisation for people with schizophrenia. This suggested that for this population, more successful functioning may be related to greater network density. In contrast, in situations requiring personal growth or changing social roles, low density networks appear to be more useful to people who do not suffer from schizophrenia (Bott, 1972; Hirsch, 1979, 1980).

Social support as coping assistance

Thoits (1986) proposed a theory emerging from a similarity between typologies of coping functions and social support functions, suggesting that social support could be reconceptualised as coping assistance. As discussed in chapter three, coping theorists (e.g. Lazarus & Folkman, 1984) identify several major ways of coping with stressors. Problem-focused coping consists of direct actions on the environment or on the self to remove or alter circumstances appraised as threatening. Emotion-focused coping consists of thoughts or actions to control the undesirable feelings that result from stressful circumstances. It is clear that coping and social support have a number of functions in common. Problem-focused coping and instrumental aid are both directed at managing the stressful situation. Emotion-focused coping and emotional support attempt to ameliorate the negative feelings that typically accompany stress exposure and are attempts to alter meaningful aspects of stressful situations. Thoits (1986) suggested that the same coping methods utilised by individuals in response to their own stressors are also the methods that are utilised by others as assistance. Therefore, social support may be considered as coping assistance, as it is the active participation of significant others in an individual's stress-management efforts. Thus, social support might work like coping by assisting the person to change the situation, to change the meaning of the situation, to change their emotional reaction to the situation or to change all three. Both coping and social support thereby eliminate or alter problematic demands or they control the feelings of anxiety or depression usually engendered by those demands (Thoits, 1986).

Thoits (1986) considered that the essence of social support is others suggesting alternative techniques or participating directly in an individual's coping efforts, thereby supplementing or reinforcing those efforts. Supportive efforts closely parallel coping efforts and can be derived from the same model. Techniques of coping assistance used by others can include behavioural and cognitive problem-focused support such as exerting situational control by direct intervention or by helping others to reinterpret situations so that they seem less threatening. Effective support is most likely to come from socially similar others who have faced or are facing the same stressors and who have done so, or are doing so, more calmly than the distressed individual (Thoits, 1986). Both sociocultural and situational similarity enhance the likelihood of the perception and reception of empathic understanding, the condition under which coping assistance should be most effective. Comparison models are not randomly selected. People who share the same characteristics and values are selected when they are available (e.g. Goethals & Darley, 1977). Social and value similarities enhance an individual's confidence in their comparative self-evaluations and such similarities increase the perceived applicability of the experience and guidance of others. On a more concrete level, sociocultural similarity increases the probability that a significant other will suggest coping techniques or attempt to influence circumstances in ways that are viewed by the individual as acceptable. Similarity in social background and values reduces the probability that others will offer inappropriate or unacceptable coping assistance.

More important than sociocultural similarity, but enhanced by it, is similarity of situational experience. Distressed individuals feel that others who have experienced the same situation are most likely to really understand (Gottlieb, 1985). The empathic understanding of others provides reassurance that emotional reactions are valid, even if socially undesirable and potentially dysfunctional. Comparisons with empathic others should reduce self-condemnation for what might be viewed by the individual as inappropriate or deviant feelings (Thoits, 1985). It is relevant that when an individual presumes expertise in a helper, this can over-ride the importance of sociocultural and situational similarity. Empathic helpers can accept feelings that others find aversive or socially inappropriate. Acceptance enables the individual to ventilate or discuss those feelings freely, a crucial first step for many individuals that reduces pent-up tension (Wortman & Lehman, 1985), enables reassuring affective comparisons and facilitates coping guidance.

In their critical review of measurement approaches, House & Kahn (1985) organised assessment strategies under three major headings: existence, supportive content and network structure. When selecting measures of social support, consideration should be given to (a) the central characters in the adaptation process and whether it is important to differentiate among the support of family, friends and co-workers; (b) whether there is a particular type of support that facilitates adaptation or whether it is simply knowing that such resources are available if needed; and (c) the relevancy of the full network of relationships within which the focal person functions (Depner *et al.*, 1984).

Supportive exchanges and functions of social support

Shumaker & Brownell (1984) defined social support as an exchange of resources between at least two individuals perceived by the provider or the recipient as intended to enhance the well-being of the recipient. There are two ways in which this definition differs from others as it includes the concept of exchange, and, because the outcome is tied to the perceived intentions of either participant, the actual effects of support may be positive, negative or neutral. According to an exchange theory of relations, people who are sources of rewarding interactions will be particularly important in shaping the behaviours and attitudes of others (McCallister & Fischer, 1978). There are limitations in the degree to which exchange concepts, derived from economic theories, are relevant to support. In its broadest sense, social support is the essence of being 'social' in that it is mutual and caring (Shumaker & Brownell, 1984). This is particularly important in the context of nursing in which profession there is a growing realisation that caring is central to effective nursing practice (Kyle, 1995). Exchange models provide methods for addressing the interdependency of relationships involved in supportive exchanges and suggest ways in which this interdependence may affect support seeking and acceptance, as well as the overall quality of relationships over time. The process of giving and receiving is more fluid than is implied by economic modeling, however, and the imposition of exchange concepts can trivialise the phenomenon by reducing mutual caring to a cost/benefit analysis.

A clear distinction must be made between the content of supportive exchanges and the purposes or functions of social support. Because this distinction is not made, little attention is given to how support is supposed to work, how it does work and what its effects are. Studies on support include network characteristics (e.g. size, density). In operationalising the concept, however, researchers do not always specify the connections between networks and support (Shumaker & Brownell, 1984). The term social support is sometimes applied to constructs that should properly be termed social integration or social networks. Social integration is an important construct because the absence of such ties (social isolation) is known to be a serious health risk factor. For example, a series of large-scale epidemiological studies has documented a two-to-five fold greater risk for mortality among socially isolated persons over a three-to-ten year time span (e.g. Berkman & Breslow, 1983). A person's social network includes the people with whom he or she interacts on a regular basis. Members of the social network are potential sources of social support. Although a large social network does not ensure that the key functions of social relationships (e.g. attachment, guidance, reassurance of worth, tangible assistance) will be provided to the target person, there is generally a significant positive relation between network size and perceived social support (Cutrona, 1986). In other words, the probability of receiving support increases as a function of the number of social ties.

Implicit in a network approach is the recognition that support involves at least two individuals. Yet most investigators do not recognise that issues relevant to interdependent relations and characteristics of all participants may significantly influence the phenomenon. A distinction needs to be made between harmful interpersonal relations and the potentially harmful effects of supportive exchanges. Further distinctions need to be made among interactions that are intentionally harmful, those that are unintentionally harmful and those that seem harmful but are actually beneficial. This point underscores the importance of considering both provider and recipient perspectives. Also, it is necessary to consider the difference between the short-and the long-term effects of social support. For the most part, outcome measures are restricted to global indices of mental and physical health. Thus, investigators ignore when they intercept these ongoing health phenomena (e.g. Cohen & Syme, 1985) and they overlook the immediate effects of supportive exchanges (Shumaker & Brownell, 1984).

Most of the recent theoretical and empirical work on support is embedded within a stress and coping paradigm. This implies that support is only relevant to health when individuals are stressed. A clear, theoretical distinction needs to be made between the health-sustaining and the compensating (stress buffering) aspects of this phenomenon. Shumaker & Brownell (1984) believe that support is important to mental and physical health in the absence as well as in the presence of stress, but that support operates differently in these two situations. The final problem referred to by Shumaker & Brownell (1984) involves the contextual nature of support. By considering context, researchers are forced to distinguish clearly between dimensions of support (e.g. its specific functions and resources) and situational variables (e.g. organisational structure, physical design).

Social support in the context of cancer

With respect to cancer, Reynolds & Kaplan (1990) found evidence linking social relationships to cancer incidence, mortality and prognosis during a 17-year follow-up in a population-based sample of 6,848 adults (Reynolds & Kaplan, 1990). Socially-isolated women were shown to be at significantly elevated risk of dying of cancer of all sites and of smoking-related cancers. While cancer incidence or mortality were not prospectively associated with social connections among men, men with few social connections showed significantly poorer cancer survival rates (Ell *et al.*, 1992). In a study by Ell *et al.* (1992), which examined the relationship between social relationships and social support and survival following a first diagnosis of breast, colorectal or lung cancer, results suggested that the emotional support provided by primary network members was a critical factor in explaining the relationship between various indicators of social relationship and mortality, consistent with results from previous studies of psychological adaptation to cancer (e.g. Bloom & Speigal, 1984). At the same time, results of the study by Ell *et al.* (1992) provided important evidence that social relations and social support may operate differently depending on cancer site and extent of disease and suggested that emotional support from primary network members is protective with respect to survival during the earlier stages of disease and among women with breast cancer. No such effect was found at more advanced stages of illness or among lung or colorectal cancer patients, underscoring the strength of biological processes over psychosocial processes at advanced stages of disease. On the other hand, the association between emotional support and marital status and survival among patients with less extensive disease and among women with breast cancer raises numerous questions about the mechanisms by which supportive relationships may influence cancer recovery (Ell *et al.*, 1992).

Results from the study by Ell *et al.* (1992) suggest that while support buffers the stress of life-threatening illness with respect to psychological response, this is unlikely to be the sole or even the primary mechanism by which support influences survival. An alternative explanation is that support exerts an effect by increasing healthy behaviours by patients, such as appointment-keeping and treatment compliance and by reducing potentially harmful coping behaviours that might be employed to cope with the diagnosis, such as smoking and drinking. Findings from a randomly controlled intervention study employing three different educational support programmes provided evidence that support can influence patients' behaviours (Richardson *et al.*, 1990). In this study, receipt of supportive interventions was an independent predictor of survival and treatment compliance was significantly better among experimental patients when compared with control patients. Results of the study by Ell *et al.* (1992) marginally suggest that support may operate differently among women and men. For example, in the analysis of women with breast cancer, marital status was found to be a risk factor rather than a protective factor with respect to survival. It is possible that some of these women experienced conflict or stress in their marital relationships that was precipitated by the demands of a life-threatening illness and subsequently impaired their exchange of social support with their partner (Coyne, Ellard & Smith, 1990).

Communication as social support

The uncertainties and fears experienced by a person diagnosed with cancer focus upon pain, physical changes, treatments and recurrence and rejection by loved ones. For these reasons, social support may be a valuable resource for coping with the disease and newly diagnosed people with cancer may be especially likely to experience difficulty obtaining adequate support. Different studies have shown that there may be interpersonal and communication problems between patients with cancer and their families, friends, health care providers and social situations (Wortman, 1984). A number of studies carried out in the past ten years have demonstrated that health care professionals, including nurses and physicians, are viewed as providers of emotional, informational and appraisal support for patients with cancer (e.g. Galbraith, 1995; Northouse & Peters-Golden, 1993; Grande *et al.*, 1996). Emotional support by health providers is seen as especially helpful (Dunkel-Schetter, 1984). The source of the support plays a central role in an individual's perceived satisfaction (Dunkel-Schetter, 1984). If a source of support is seen to be inappropriate then its potential value is decreased, for example, a friend giving detailed medical advice in contrast to the same advice being provided by a doctor or nurse (Keeling *et al.,* 1996). However, studies have also shown that many doctors and nurses not only fail to meet these needs of cancer patients, but are sometimes not adequately prepared to recognize psychological or social distress and therefore cannot respond with the appropriate type of support (Ford, Fallowfield & Lewis, 1996). Davis & Fallowfield (1991) state that they believe that communication and counselling form the basis of both physical and psychological care for all patients and their families.

In medical communication, two types of behaviours are considered important: instrumental and socioemotional behaviours. They correspond to the main purpose of the medical consultation; on the one hand exchanging information, including taking and giving information, which is necessary for solving clinical problems and on the other hand, creating a therapeutic relationship, which is necessary for obtaining the patient's trust (Surbone & Zwitter, 1997). As well as information exchange and creating a therapeutic relationship, Delvaux & Razavi (1997) consider that communication with cancer patients has support as a third purpose. This is because in clinical practice and during training sessions, informational and emotional support are often used without any previous information taking and assessment of patients' needs. Research suggests that most nurses and doctors do not exhibit the skills required for effective assessment, but doctors and nurses improve their skills dramatically after brief training (Maguire, 1982; Faulkner & Maguire, 1984; Faulkner, 1992).

Sociology theorists have commented that, in society, authority is effective only among those who accept or grant its legitimacy and willingly subject themselves to it (Krippendorff, 1989). However, up to recently it has been the tradition of the medical profession to approach the doctor-patient relationship from a viewpoint of authority and paternalism, with patients given little choice in physicians' attitudes towards them in the context of that relationship (Szasz & Hollender, 1956). Ehrenreich & Ehrenreich (1978) comment that to change the health system at all, much less to create a medical system which maximally utilises self-help and mutual help and which encourages an active rather than a passive role for the patient, it would be necessary to expand medical knowledge to patients and to non-physician health workers to minimise the social distance between doctors and patients (Ehrenreich & Ehrenreich, 1978). Fortunately, the rise of health consumerism has encouraged more contractual and conflictual relationships between patient and doctor (Hughes, 1994). Greater attention is now focused on more holistic approaches to medicine, and to the qualities of physician-patient interaction. Two reasons for this change are: (1) increasing concern about malpractice litigation and the possibility of further regulation of the health care industry (Engler, Saltzman, Walker & Wolf, 1981), and (2) the realization that problem-centeredness, while pragmatic in acute care, is far less effective than patient-centeredness in preventive medicine, chronic care, and rehabilitation (Moorhead & Winefield, 1991). The touchstone of the patient-centered movement is the biopsychosocial systems approach, which humanises the patient and recognises the importance of psychological, social, organisational, and even cultural and environmental factors in health care (e.g. Engel, 1980).

In a patient-centered approach to medical care, the physician attempts to ascertain the patient's agenda and to reconcile this with his or her own. The essence of this method is that the physician tries to enter the patient's world and to see the illness through the patient's eyes. This is done by behaviour that invites and facilitates openness by the patient. The doctor's goal is to understand the patient's expectations, feelings and fears (Friederichs-Fitzwater, Callahan, Flynn & Williams, 1991). Two physician communication styles, affiliation and control, are particularly relevant to health outcomes. Controlling physicians tend to be authoritarian, power-seeking, and professionally detached. Affiliative physicians, who typically rate higher in patient satisfaction and compliance, tend to convey interest in their patients' welfare, friendliness, empathy, warmth, genuineness, candor, honesty, compassion, a desire to help, devotion, sympathy, authenticity, a non-judgmental attitude, humor, and a sociable orientation (Buller & Buller, 1987). A consultative interviewing style, encouraging active patient participation, has been found to be associated with patient and doctor satisfaction, as well as positive health outcomes (Moorhead & Winefield, 1991). Good communicators, especially those with non-verbal adeptness, are more likely to engender both patient satisfaction and adherence (e.g. Waitzkin, 1984). Information needed regarding the disease of cancer indicates patients' attempts to appraise the harms implied in the nature, extent and aetiology of cancer as well as the threats and resources implied in the negative and positive implications of the treatments. Similarly, the nature of information sought in relation to personal, family and social concerns indicates patients' attempts to appraise harms, threats and resources in relation to each (Derdiarian, 1987). Information is functionally related to the process of appraisal and coping, mediating both (Derdiarian, 1987; Lazarus, 1966).

The impact of the diagnosis, prognosis and treatment of cancer on the patient leads to a series of responses by the patient. Varying degrees of sadness, fear, pain, anxiety, depression, anorexia and other physical symptoms may be present; the patient may or may not continue to work and may or may not continue to receive support from members of the health care team and from their family and friends. This array of possible outcomes and responses varies from one patient to another and the relative importance of the components of it also vary. In general, the summation of these elements can be broadly termed quality of life (Ruckdeschel *et al.,* 1994). The patient's personality and levels of anxiety will affect his or her way of responding to the diagnosis, and this response is often difficult to predict, especially if the news is unexpected and/or the doctor has not met the person before. The response may be stunned silence, anger, disbelief and/or acute distress. Most doctors find acute distress and anger especially difficult, although stunned silence or disbelief can be just as challenging (e.g. Mermelstein & Lesko, 1992; Massie & Holland, 1987; Weisman & Worden, 1976).

Background circumstances can also affect response. For example, someone with a family history of cancer or who has recently witnessed a friend or relative dying from the disease may be devastated by the diagnosis, even if he or she has a good prospect of being cured. Thus, it is important for clinicians to have some idea of the patient's social circumstances before giving bad news, so that appropriate help and support can be provided. The aspects of the interview of most concern to the clinician might not be the ones thought most significant or distressing by the patient. Hence the need to check continually how the patient is feeling and to provide opportunity for information to sink in and for questions to be asked (Fallowfield, 1993). A study by Gilhooly, Berkeley & McCann (1988), showed that in the case of terminally ill cancer patients, approximately one-third died without having discussed their diagnosis with their G.P. The wishes of the relatives was the main reason for not sharing information (Gilhooly *et al.,* 1988). Although some elderly people are emotionally frail and may find a diagnosis of cancer quite devastating, several studies have shown that many older adults cope similarly and in some instances more effectively than their younger counterparts (Redmond & Aapro, 1997).

The diagnosis and treatment of cancer constitutes an immediate confrontation with mortality. Sympathetic, but direct, examination of the patient's vulnerability and means of coping with it will reduce rather than amplify death anxiety (Spiegel, 1990). The development and pursuit of realistic goals influenced by the prognosis can help patients adjust constructively. According to Spiegel (1990) the key to enhanced physician support of patients' adjustment to cancer is captured in the word 'control.' Information is another form of control and well-informed patients are more in control of their treatment. The importance of building social networks as protection against the very common sense of isolation experienced by cancer patients is commented upon by Spiegel who considered that, as a general rule, it is wise to give the same information to all adult members of the family. Reassuring a patient and giving bad news to his or her spouse is almost certain to drive a wedge between them in terms of their ability to communicate with one another. Specific attention to disturbances of patients' cognitive understanding of the illness and its effect, to physical symptoms such as pain and nausea and to patients' social relationships can substantially improve quality of life. Patients and their families are a valuable source of support for themselves and one another. The serious problems facing each patient with cancer can be managed better with active attention and collaboration from patients, their doctors and their families (Spiegel, 1990). The general public is also demanding better communication skills from medical personnel. Dissatisfaction with medical communications remains the most prominent of patient complaints and a major factor in the move to alternative medicine with its focus on good and reassuring communications and the patient as an informed participant in treatment (Thompson, 1984).

With regard to physicians' attitudes, it has been suggested that physicians fall into three groups with regard to giving information (Razavi, Delvaux & Hopwood, 1997). The first is characterised by a tendency to actively seek an opportunity to inform the patient about cancer. The second is characterised by an active tendency to conceal all information. The third group is an intermediate one, combining the passive withholding of information with the provision of carefully chosen facts according to the circumstances. An increasing proportion of doctors has been using the third strategy in recent years (Razavi *et al.*, 1997). In the 1950s and the 1960s, approximately 90% of physicians indicated that when the diagnosis was cancer they preferred not to inform the patients. This attitude was based on the widely held view that disclosure of the true medical facts might destroy a patient's hope or motivation, and on an under-estimate of the number of patients who wanted disclosure. It is now generally held that all mentally competent patients have rights (ethical, moral and legal) to any medical information that they require or request. These rights come from three inter-related sources: the expectations of society in general, the recognition of truth-telling as part of the code of ethics of the medical profession and case precedence in law (Buckman, 1992).

Attitudes towards giving information have changed over the last twenty years (Razavi *et al.,* 1997). A 1982 survey of North American physicians' attitudes showed that more than 80% of interviewed physicians felt that the diagnosis should be communicated to patients in clear terms as quickly as possible (Greenwald & Nevitt, 1982). Few doctors in the United Kingdom or the United States admit that they actively withhold the diagnosis of cancer from patients, but from observations of patient-doctor interactions in clinics as well as audio and videotaped recordings, it is clear that clinicians are often 'economical with the truth' (Fallowfield, 1991). Fennelly (1997) stated that if all patients who have been cured of cancer had been told they had cancer at the start and were prepared to let this be known generally, then the negative aspects of cancer diagnosis would be reduced. In Ireland, attitudes to cancer tend to be negative rather than positive. Most patients accept the diagnosis of cancer as if they were being condemned to death, a death associated with major symptoms, particularly pain, which may not be subject to control. Such factors influence the attitudes of Irish physicians towards the issue of informing patients (Fennelly, 1997). A study of the needs of 200 cancer patients and their relatives in Dublin in the 1980s found that, although 82% of patients interviewed were aware of their diagnosis, almost one quarter of these said they had never been told by the consultant doctor. The vast majority of patients wished to be told by their consultant and also wanted to have an opportunity to ask questions at a later date. Over 40% of patients had some reservations regarding the way in which the diagnosis was communicated to them (Herity *et al.,* 1987). In surveys over the past few years, patients have rated poor communication as the number one cause of dissatisfaction with hospital care. Patient and consumer groups are becoming increasingly vocal about perceived shortcomings in standards of communication in a variety of services, including services for cancer patients (Cortis & Lacey,1996). Wiggers, O'Donovan, Redman & Sanson-Fisher (1990) assessed the perceptions of 232 ambulatory cancer patients about the importance of, and satisfaction with, the following aspects of care: doctors' technical competence and interpersonal and communication skills, accessibility and continuity of care, hospital and clinic care, nonmedical care, family care and financial assistance. Most patients were satisfied with the opportunities provided to discuss their needs with doctors, the interpersonal support of doctors and the technical competence of doctors. However, few were satisfied with the provision of information concerning their disease, treatment and symptom control and the provision of care in the home to family and friends (Wiggers *et al.,* 1990).

Fallowfield (1991) described how patients can feel regarding inadequacy of information and quoted a 72-year-old woman, who had discovered a breast lump after a fall. She herself was aware of the sinister implications of the lump and was most resentful and angry about the way in which the doctor discussed or rather failed to discuss the results of her mammogram and cytology report with her. The woman stated: 'The nurse who does the breast clinic was the only one I could get anything sensible out of. I don't know what I would have done without her.' This quote also demonstrates the usefulness of having a qualified specialist nurse on hand to fill in the important gaps or to correct misunderstandings which may have arisen during a medical interview (Bullen, 1997). In fairness, some of the apparent dissatisfaction with information giving is not due to the doctor avoiding a truthful consultation, it may also reflect the underlying anxiety of the patient or a patient's reluctance to accept bad news. The overly anxious patient may need more than one consultation, extra help from a trained specialist nurse counsellor (Watson, Denton, Baum & Greer, 1988), and/or supplementary material in the form of information booklets. Patient memory and concentration deficits as a result of the trauma of diagnosis (Mermelstein & Lesko, 1992; Cull, Hay, Love, Mackie, Smets & Stewart, 1996), memory and hearing deficits in the elderly (Lubinski & Welland, 1997), adult literacy problems are all factors that can impede effective doctor patient communication and patient comprehension of information.

The importance of good communication in the delivery of effective and appropriate nursing care has been well demonstrated by research and is reflected in hospital ward policy documents and nursing textbooks (Brunner & Suddarth,1991). The shock of the diagnosis often inhibits the patient's ability to comprehend fully what he or she is being told (Ruckdeschel *et al.,* 1994). Patients and families require access to accurate information that can be repeated, questioned and clarified as necessary with opportunities to interpret it and gain an accurate understanding (Northouse, Cracchiolo-Caraway & Pappas Appel, 1991). When introduced into the patient's care at this stage, health care professionals, especially nurses can not only provide clarification of information already given and ensure that additional information is available, but also begin to help the patient and family identify their anxieties and fears, dispel myths and assist in identifying and mobilizing coping strategies (Wilkinson, 1991; Northouse & Peters-Golden, 1993). Problems may arise when patients are from cultures where the family take decisions about the welfare of ill relatives or where family members insist that the patient must not be told their diagnosis of cancer before the doctor has had an opportunity to impart the news to the patient (Burton & Watson, 1998). Studies have shown that at least during the first 100 days after diagnosis, patients are concerned primarily with more existential issues related to life and death. Subsequently, a time of accommodation and mitigation occurs when patients resume work and leisure activities (Weisman & Worden, 1976). The emotional work that needs to be accomplished after the diagnosis is overwhelming, and may take many months to resolve depending upon many factors (Edgar, Rosberger & Nowlis, 1992).

Social support and coping ability in the context of cancer

The techniques used to deal with stress have been defined as coping strategies. The concepts of coping strategy and coping behaviour are often used interchangeably. Coping can be viewed as a process and, therefore, depends on the situational context in which it occurs, as well as on what meaning the individual attaches to the situation (Cronqvist, Klang & Bjorvell, 1997). Social resource factors may serve as buffers in the coping process. As previously stated, the buffer argument suggests that stress may affect some persons adversely, but that those who have social support resources are relatively resistant to the deleterious effects of stressful events. Direct effects of social support are found when health is improved, independent of stress levels. Taken together, at least three types of functions are served by interpersonal relationships. First, interpersonal relationships may contribute to health because they are a source of acceptance and intimacy, i.e. emotional support. Second, there is consensus that social support may provide useful information, advice and guidance, i.e. informational support. Third, people may assist with instrumental problems by providing financial assistance, goods or services, i.e. instrumental support. In the past, research on coping and on social support has tended to be kept conceptually and empirically separate. Recently, however, researchers have examined links between coping and social support factors and have attempted to evolve an interpersonal theory of coping with stress (e.g. Thoits, 1991; Greenglass, 1993). Social support may impact on ability to manage stressful situations and, by increasing peoples' sense of being loved and valued, may increase self-efficacy and esteem (Bandura, 1992). People with high perceived control and self-esteem exhibit better health in the face of stress. In addition, individuals with a greater sense of personal control over stressful events are more likely to use problem-focused coping (e.g. Thoits, 1991; Greenglass, 1993).

Social support viewed as a form of coping provides theoretical links between areas that had been viewed as conceptually distinct. The conceptualisation of social support as coping also broadens the concept of coping as it has traditionally been defined to include interpersonal and relational skills. This is in direct contrast to the generally held view of coping as primarily (only) individual problem-solving (Greenglass, 1993). In one community study of how coping differs between depressive and non-depressive people, coping strategies were found to have distinctly different relationships to distress and diagnosis of depression. Strategies of coping with life events were found to be more strongly related to distress than to diagnosis of depression (Wethington & Kessler, 1991). Psychosocial interventions with patients who have cancer are designed to ameliorate the emotional distress that may occur after the diagnosis of cancer and during its subsequent course. The indication is that a selective rather than a blanket service is needed, with the target for intervention being patients at high risk for psychological morbidity (Watson, 1983). In a study by Edgar, Rosberger & Nowlis, (1992) the emotional coping of 205 patients newly diagnosed with cancer was evaluated every four months during a period of one year. Patients received a psychosocial intervention either immediately or after a four month delay. No significant differences were found between the two groups, except at eight months, when the late intervention group was significantly less depressed, anxious and worried and felt more in control than the early intervention group. In a study of adult responses to 1,332 stress episodes, Folkman & Lazarus noted that both problem-focused and emotion-focused coping were used to cope with 98% of the episodes. Folkman and Lazarus (1980) found that the importance of type of coping varied with gender, with men relying more heavily than women on problem-focused coping even when the context permitted only emotion-focused coping (McCarthy & Newcomb, 1992).

Facilitating self-management and coping skills in patients with cancer

Chronic disease differs from acute disease in many ways, one being the potential for self-management by the patient. Appropriate self-management is based upon a partnership between the patient and health professionals in which each takes responsibility for portions of the management (Holman & Lorig, 1992). The chronicity of a disease creates problems beyond the specific consequences of the particular biological abnormality (e.g. pain in cancer). The additional consequences are also a result of the disease and its treatment and fall in many categories: fatigue, depression, unfavourable employment and financial circumstances, reduced social activities and family conflict. The most relevant difference between acute and chronic disease lies in the role of the patient and family, particularly in relation to management. Appropriate management of chronic disease requires development of a partnership between the patient and the physician (Holman & Lorig, 1992).

Of special relevance to self-management is the impact on health status of people's beliefs in their efficacy to exercise some control over conditions that affect their lives (Bandura, 1986). Beliefs in personal efficacy can be strengthened in four ways (Holman & Lorig, 1992). The most powerful relies on guided mastery experiences that build coping capabilities, by learning and practising the appropriate behaviours. The second approach to building personal efficacy draws upon social modelling to convey skills and a coping orientation. People who have a problem but cope with it on a day to day basis provide models of how to cope. They have good and bad days, but on the whole are able to lead full and active lives. Social persuasion provides a third type of efficacy enhancing influence. Effective persuasion usually involves urging learners to do just a little more than they are presently doing. In building self-efficacy, success leads to success. The final mode of influence is aimed at reducing aversive physiological reactions. For the person with cancer, this may mean utilising a cognitive-behavioural intervention such as relaxation alongside routine medication for pain and/or nausea (Holman & Lorig, 1992; Sloman, 1996). High and increasing levels of perceived self-efficacy to cope with the consequences of chronic disease are associated with improvement in symptoms, physical and emotional well-being and social activities. However, even in a worsening disease situation, successful use of self-management skills can reinforce and enhance perceived self-efficacy (Holman & Lorig, 1992).

Cognitive appraisal can be altered by drug therapy, treatment procedures, especially those involving anaesthesia and metabolic states. The elderly patient is particularly vulnerable in this instance, especially following illness and/or drug therapy. Elderly patients tend to ask fewer questions of the health care professional than their younger counterparts and the current attitude of a patient-professional partnership is alien to many of them (Redmond & Aapro, 1997). Patients may need help venting negative feelings, especially anger associated with cancer diagnosis and disease experience and the negative impact this has on their quality of life. In anger, the emotion may be projected, displayed or suppressed. Suppression of anger may lead to physical symptoms which may aggravate the situation. Patients may require encouragement and assistance in the expression of thoughts and feelings and may be reluctant to express inability to cope openly in an institutional setting. It is necessary to clarify what has been said, listen attentively, seek validation of interpretations and refocus the conversation, focusing on single topics to facilitate ventilation of feelings and a catharsis of emotions (McCarthy, 1990).

The provision of psychological care in a support group is likely to be increasingly popular because many people with cancer prefer this kind of help, and the group format can be cost-effective. Support groups for people with cancer tend to take one of two approaches: the psychoeducational approach or the supportive psychotherapeutic group approach, using nondirective techniques. They are not mutually exclusive because aspects of one approach can often be found in the other. Non-directive groups tend to emphasise experiential aspects with mutual support between participants a high priority (Burton & Watson, 1998). Short term psychological interventions, particularly those with cognitive behavioural components, have been found to improve the mood and quality of life of patients with a broad range of cancers (e.g. Cunningham & Edmonds, 1996). Telephone counselling may be perceived as more helpful than support groups for some patients with cancer. One feature of this intervention is the forum it provides for participants to explore and express feelings, meaning and interpretation that commonly develop in response to cancer (Marcus, Garret, Cella, Wenzel, Brady, Crane, McClatchey, Kluhman & Pate-Willig, 1998). It appears that particular subgroups of breast cancer patients may benefit more than others from this intervention. For example, younger premenopausal patients with breast cancer appear to experience greater disruptions in their quality of life than older patients, especially in the areas of social support, emotional distress, sexual functioning and body image (e.g. Wyatt & Friedman, 1996). While short term intervention studies point to improvements, much less is known about the effect of long-term psychotherapies (defined as more than three months of weekly meetings) on patients with cancer. Many of the psychological changes made by subjects in longer term interventions may elude conventional psychometric assessment. Further research of a rigorous qualitative nature is required to develop a clearer understanding of the experience of living with and eventually dying of cancer within the context of a long-term intervention (Edmonds, Lockwood & Cunningham, 1999). Research suggests that amount and quality of social support also influences the length of survival through the endogenous pathway, perhaps through changing social and psychological coping responses. Social support, measured as support from spouse, family, friends or medical care providers is associated with longer survival with cancer in general as well as survival with breast, colorectal and lung cancers (e.g. Spiegel *et al.,* 1989).

The family is the primary support system for patients with cancer (Rowland, 1989). However, the occurrence of cancer affects the entire family and generates great anxiety (e.g. Schmale, Morrow & Schmitt, 1983). Consequently, family members, especially spouses and children, may also need support (Northouse *et al.,* 1991; Northouse & Peters-Golden, 1993). Studies of the spouses of patients with cancer document the nature and duration of their stress and the concerns that they confront over the course of their partners' illness. For example, a study by Musci (1985) found that the majority of family members had a high degree of anxiety and depression and felt particular frustration with chemotherapy side effects, overwhelmed by responsibilities, work and financial problems, yet few utilised support groups or communicated their concerns to nurses. An examination of the literature shows specific concerns that appear universal to spouses of cancer patients. Chief among those are (1) dealing with the fear and threat associated with a cancer diagnosis; (2) helping partners to deal with the emotional repercussions of the cancer and (3) managing the changes and disruptions of daily life brought about by the disease (Northouse & Peters-Golden, 1993). Lewandowski & Jones (1984) commented that family needs may be different from patients' needs and may fluctuate in the various phases of illness. From their study of 62 patients with cancer and their families, they suggested that the most helpful intervention for the patient overall, was information given directly to the patient (Lewandowski & Jones, 1984). However, the importance of providing information to spouses has been repeatedly emphasised in the research literature. Many spouses report receiving little information or guidance as to how to help and support their suffering partners emotionally, or advice about how to cope with problems, caused by the illness, impacting on daily life, especially for spouses of patients with advanced cancer and those undergoing chemotherapy (Northouse & Peters-Golden, 1993). The degree to which open communication assists a couple's adjustment to breast cancer may depend on the communication patterns they used before the diagnosis, as well as on each partner's preferences for information and disclosure. It appears that communication may be most beneficial when both partners have similar needs for information. If they differ in their information requirements, forcing communication could lead to further frustration, rejection and withdrawal (Northouse *et al.,* 1991).

It has been found that access to information and knowledge of treatments seem to add to health professionals fear rather than assuage it (Box & Anderson, 1993). Doctors often avoid the use of the word cancer when discussing diagnosis with patients. Instead they use such euphemisms as tumour, growth, lump, wart or polyp which may not pose threat or stigma or evoke strong emotions in either the patient or the doctor. Doctors and nurses may be avoiding their own fears of cancer or death. It has been recognised that patients can evoke reactions in professionals that lead to various forms of indirect avoidance, so that their patients' communication and psychological needs are never appreciated or dealt with (Anstey, 1991; Dennison, 1997). It is evident from the literature that health care professionals still avoid discussing sexual issues with patients and their partners; the recent emergence of nurse specialists in cancer care and site-specific specialties such as gynaecology and breast care have gone some way to addressing the neglect (Dennison, 1997). Patients who receive a diagnosis of cancer are in a position of extreme uncertainty and vulnerability. If a patient believes that a cancer diagnosis is tantamount to a death sentence, then a profound loss of hope may result (Sardell, 1993).

Summary

Research has shown that social relationships and the coping resources they provide are essential in managing stress and influencing psychological and physical health (Cobb, 1976; Cassel, 1976). The importance of relationships with others for mental health is a key assumption underlying the idea of social support as fulfilling ongoing social needs, while a more focused definition of social support emphasises fulfillment of needs that arise as a consequence of stressful life events. Early studies focused on the quantity of significant social relationships in an individuals' social network. However, Schaefer, Coyne & Lazarus (1981) found that the adequacy of support as perceived by the recipient was a better predictor of psychological adjustment than the availability of support. Thoits (1984) suggested that the same coping methods that are utilised by individuals in response to their own stressors are also the methods that are utilised by others as assistance. Patients with cancer commonly experience uncertainty about the nature, course and prognosis of the disease (Silberfarb, Holland, Anbar, Bahna, Maurer, Chahinian & Comis, 1983), reduced ability to control their own lives (Brinkley, 1983), increased dependence on others and disruption of family, work and social life (Wortman & Dunkel-Schetter, 1979; Nerenz, Leventhal & Love, 1982). They may also have a need to find some meaning in their experiences (Weisman & Worden, 1976). The experience of having cancer pervades every area of life and presents the patient with a massive adjustment task (Silberfarb, 1984). Patients and their spouses and families require access to information that can be repeated as necessary, enhancing patients' adjustment and facilitating their sense of control. Spouses and families require support also to cope with the stressors cancer imposes upon family relationships (Spiegel, 1990; Northouse *et al.,* 1991). Health care professionals are seen as providers of informational and emotional support for patients with cancer, with the latter type of support viewed as especially helpful (e.g. Galbraith, 1995; Northouse & Peters-Golden, 1993; Grande *et al.,* 1996; Dunkel-Schetter, 1984). Adequate communication is central to the provision of support (Delvaux & Razavi, 1997; Davis & Fallowfield, 1991).

QUALITY OF LIFE IN PALLIATIVE CARE

The concept of quality of life

The phrase 'quality of life' entered the vocabulary of the United States towards the end of the Second World War and implied material affluence evidenced by possession of consumer goods, spare time and spare money. The definition of the term was widened in the early 1960s to include education, health and welfare, economic and industrial growth and the defence of the 'free' world (Fallowfield, 1990). The major political and social upheavals of the late sixties revealed a switch of emphasis from a materialistic view of quality of life towards 'personal freedom, leisure, emotion, enjoyment, simplicity and personal caring' (Ebbs, Fallowfield & Fraser, 1989). Despite the appeal of material possession, one of the primary requisites to the enjoyment of a high quality of life is good health. Efforts to measure health found importance in the 1930s when Stouman & Falk (1936) introduced the concept of health indicators and the 1970s saw an explosion of interest in quality of life during illness and treatment (Montazeri, Gillis & McEwen, 1996). Concurrent with technological advances, patients began to demand that their doctors took a more holistic view of medical problems. That quality of life is a multi-faceted phenomenon was recognised by Herophilus in 300 BC. He commented upon the way in which physical demise rendered much of the rest of life somewhat meaningless: 'to lose one's health renders science null, art inglorious, strength effortless, wealth useless and eloquence powerless' (Fallowfield, 1990).

Quality of life (QoL) has become an important issue for patients with cancer because treatments have been developed with the potential to substantially prolong life. Patients may be faced with living longer with a variety of sequelae from both the cancer and its treatment. This has forced health care providers and patients to examine not just the quantity of life but also the quality of prolonged survival (Ferrell, Wisdom & Wenzl, 1989; Loewy, Kapadia, Hsi & Davis, 1992). The success of cancer therapies has led the Food and Drug Administration in the USA to recommend that quality of life measures be included in clinical trials of cancer therapies with multiple treatment arms so that quality of life becomes one aspect on which policy decisions are made (e.g. Wells, 1997). The definition of quality of life has important implications for its measurement. The World Health Organisation (WHO) laid the foundation for measurement with their definition of health as 'a state of complete physical, mental and social well-being and not just the absence of disease and infirmity' (WHO, 1947, 1958). The WHO definition takes account of the view that QoL has multiple dimensions. Traditional measures of treatment outcomes, called clinical indicators, are familiar to most health care providers. Tumour size, biological markers of treatment response, toxicity, performance status and survival have been used for many years to evaluate patient response to treatment. These clinical indicators focus on the physical dimension of health but provide no information on the mental or social dimensions. A different approach is necessary to determine the impact of interventions on psychological, social and spiritual well-being in patients with cancer (Wells, 1997).

The concept of quality of life was included in the American Cancer Society's first conference workshop on Methodology in Behavioural and Psychosocial Research in 1984. Agreement on definition, measurement, ethical and policy issues have been elusive. However, there has been considerable progress during the past decade (Ganz, 1994). Conceptually, quality of life refers to well-being, quality of survival, human values and the satisfaction of needs, whilst operationally, it refers to patients' evaluations of their own health compared with what they expect to be possible (e.g. Montazeri *et al.* 1996; Cella & Tulsky, 1990). Definitions proposed by two research groups are (1) quality of life is the subjective evaluation of life as a whole (de Haes, 1988); and (2) quality of life refers to patients' appraisal of and satisfaction with their current level of functioning, compared to what they perceive to be possible or ideal (Cella & Cherin, 1988). Thus quality of life is a patient-centred concept that is likely to reflect the important concerns of the individual, recognise the autonomy of patients and contribute to their participation in informed decision-making (Payne, 1992). Quality of life (QoL) is a vague, multidimensional concept, theoretically incorporating all aspects of an individual's life (Bowling, 1995a). It is a term used to refer both to the degree to which a subject's present life is commensurate with his or her aspirations (de Leval, 1995) and to a composite of those aspects of life and human functioning that are considered essential for living a full life (McMillan & Mahon, 1994).

Health-related quality of life

In the palliative treatment of chronic illness, attention must extend beyond symptom control to include the overall quality of patients' lives. Medical interventions are rarely evaluated on the basis of cure or survival alone. Many interventions are deemed justifiable if they provide comfort, palliation or support of some kind. The subjective nature of the quality of life concept is reflected in the following definition: 'Health-related quality of life (HQL) refers to the extent to which a person's usual or expected physical, emotional and social well-being are affected by a medical condition or its treatment' (Cella, 1995). The concept clearly involves physical and psychosocial well-being (Selby, 1993). A fully satisfactory QoL might be regarded by some as a return to the situation before an illness began, whereas others would require the attainment of an ideal quality (de Haes & van Knippenberg, 1985). Most authors recognise that a satisfactory QoL is an individual judgment and that there are differences between individuals (e.g. O'Boyle, McGee, Hickey, O'Malley, & Joyce, 1992). Failure by health professionals to fully understand the complex nature of individual QoL could result in treatment regimens that not only fail to improve QoL but actually contribute to its deterioration (Waldron, O'Boyle, Kearney, Moriarty & Carney, 1999).

There are several useful reviews of quality of life measures (e.g. Bowling, 1995b; Patrick & Erickson, 1993; Walker & Rosser, 1993). A considerable relevant literature also exists in the area of cancer therapy (e.g. Aaronson & Beckman, 1987; Donovan, Sanson-Fisher & Redman, 1989; Selby, 1993). Some key issues have been selected for discussion here. Health related quality of life (HQL) (Patrick & Erickson, 1993) may be defined as the value assigned by individuals, groups or society to the duration of survival as modified by impairments, functional states, perceptions and social opportunities influenced by disease, injury, treatment or policy. Five broad concepts that combine the quantity and quality of life on a value scale or continuum are (1) opportunity, (2) health perceptions, (3) functional status, (4) impairment and (5) death and duration of life.

(1) *Opportunity* is defined as the potential for an optimal state of health or 'being all one can be'. Opportunity is integral to many definitions of life quality. A major social principle for people with disease, impairment or disabilities is that all aspects of life

should be accessible to them. People with a disease or disability who are denied opportunities to acquire or use the fundamental elements of living that are generally available in a community experience a disadvantage (Patrick & Erickson, 1993).

(2) When a person is asked 'How are you ?' the person's answer is a subjective evaluation, or *health perception* of their quality of life. The frequency with which such evaluations are made emphasises the saliency and importance of the concept of health perceptions, although how these overall evaluative judgements are made is not well understood. For one person the evaluation may vary in different life situations; likewise, two people may evaluate a similar life situation in very different ways. Self-assessed health status, like more comprehensive and lengthy measures of general health perceptions, include the individual's evaluation of physiological, psychological and social well-being and the effect of health on other aspects of life (Patrick & Erickson, 1993).

(3) *Functional Status.* From the precedent of the WHO definition of quality of life have come a large number of measurement efforts focused on functioning in the physical, mental and social area of life. Although the WHO definition was not accompanied by operational methods for measuring 'well-being' in these three areas, the comprehensiveness of the definition has set a standard by which many measurement efforts have been judged. It is recommended that physical, psychological, social and cognitive measures should be included in comprehensive measures of functional status (Patrick & Erickson, 1993).

(4) *Impairment.* At least six impairment domains can be distinguished: symptom or subjective complaints, signs, self-reports of disease, physiological measures, tissue alterations and diagnoses. The relative emphasis placed on each type depends on the health decision under investigation, on the assessment objectives and on how the evidence is obtained (Patrick & Erickson, 1993).

(5) *Death and duration of life.* Length of life and time of death are of intense interest to individuals as well as of considerable importance to their family, friends and caregivers.

Length of survival has long been a primary end-point in assessing disease burden and treatment effectiveness in medical effectiveness evaluations. Life expectancy is not the only criterion that patients, families and clinicians use when deciding about life-threatening treatments such as heart transplantation or chemotherapy. Quality of life (how well a person lives) is considered along with quantity of life (how long a person lives). In this instance, quality of life might be used in its broadest sense, including both health- and non-health-related aspects (Patrick & Erickson, 1993).

Domains of quality of life

Most people would agree that quality of life is not a unitary concept, but rather a complex combination of optimal functioning in psychological, social, occupational and physical domains (Fallowfield, 1990). In the domain of psychological quality of life, typical QoL indicators are a person's levels of anxiety, depression and their adjustment to illness. Patients with disrupted psychological QoL from crippling depression and anxiety are unable to enjoy, or function adequately in any of the other areas thought to contribute to life's quality. The basic rational underpinning counselling and cognitive behaviour therapy, is to help patients restructure their thinking and thereby their feelings and ability to cope with anxiety and depression and to adjust to their illness more satisfactorily. Some people are unable to face the fact of ill-health and its treatment unless they have access to a great deal of support from health professionals, family and friends. Others seem to be able to summon up enormous resources of fortitude, courage, dignity and even joyfulness, despite disability, pain and the threat of death. Frankl, for example, witnessed first hand the mental and physical privations of the Nazi concentration camps and later developed a branch of psychotherapy (logotherapy) based on his experiences and philosophy of the importance of having a reason to live (Fallowfield, 1990). Loss of physical strength and well-being is most keenly felt, even in the early stages of illness, by patients with manual jobs and those who enjoy sport or practical hobbies. When and if physical weakness becomes so marked as to cause loss of independence, almost all patients feel frustrated by their enforced inactivity. Many feel concerned or guilty about being a burden on relatives or staff, regardless of how willing these carers may be. Of all the practical deprivations, giving up driving the car is the one which comes hardest of all to many patients in the modern Western world. Loss of role can lead to boredom and perhaps cause friction with other people who have had to take over the patient's former duties (Barraclough, 1994). Longitudinal analysis of a study by Williamson & Schulz (1995) revealed that as pain increased over time, so did activity restriction, which in turn predicted increases in depressed affect.

In the social domain of quality of life, chronically ill people frequently express fears that friends and lovers will desert them. There is some evidence from anthropological work that this fear of abandonment during illness is not entirely misplaced, nor is it always demonstrative of neurosis or paranoia. Avoidance behaviour might well have served a vital function throughout evolution for both animals and prehistoric man. In the absence of any means of treating disease, avoiding the sick or abandoning them would have been an important adaptive behaviour. Such seemingly callous, selfish acts would have limited the exposure of healthy members of the species to contagious infections, thus promoting their survival (Foster & Anderson, 1978). This behaviour is still apparent in non-human primates such as chimpanzees. Sufferers of cancer and AIDS often fear abandonment. Stable support from family and friends, together with the ability to participate in social activities, are immensely important contributory factors to quality of life (Fallowfield, 1990).

With regard to the occupational domain of quality of life, a great deal of personal gratification is obtained through the achievement, social recognition and interactions provided at and by work. Forced retirement due to ill-health severely threatens self-image, self-worth and self-respect, which can produce considerable psychological distress. Dependency on others for the routine necessities of life, such as shopping, cooking and cleaning can for many people cause a fundamental role loss with a concomitant loss of self-esteem.

In considering the physical domain, it has been suggested that insight or perception of health is only possible if a person has experienced its absence. Avoidance of pain is one of the most basic human drives and one of the primary reasons for seeking medical help. Chronic pain severely restricts a person's ability to function and enjoy life and poses considerable psychological, social and economic stresses. Uncontrolled pain is one of the most feared consequences for patients with cancer. Although pain in cancer usually heralds disease progression, it is important to remember that pain perception is always subjective. Pain can mask depression and can be the result of excessive anxiety. Saunders and other pioneers in the hospice movement have shown how pain can be controlled much more effectively if anxiety and fear of pain are conquered first (Fallowfield 1990). Focusing on four patients with terminal cancer, Saunders' ideas about pain and symptom control, first put forward in a paper published while still a medical student (Saunders, 1958), subsequently became central to modern palliative care. Gradually, a new approach to the care of dying people was developed, which harnessed together medical innovation in pain and symptom management, with wider concerns for the practical and social needs of patients and families, as well as a responsiveness to spiritual matters. Good nursing care, an explicit approach to the terminal stage of disease and pain and emphasis on the need for good physical care were combined with psychological and spiritual assistance (Sheldon, 1997). Saunders later put forward the concept of total pain, a holistic view in which physical, psychological, social and spiritual pain were combined with major implications for the quality of life of the person with advanced cancer (Saunders, 1967).

The spiritual dimension of a person's life has been described as being beyond religious affiliation and having components of 'meaning, purpose and fulfilment in life, the will to live, or hope and faith in self, others and God' (Renetsky, 1979). Granstrom (1985) stated 'many individuals do not seriously search for the meaning and purpose of life, but live as if life will go on forever. Often, it is not until crisis, illness, ageing, loss, limitation or suffering occurs that the illusion is shattered. Therefore, illness, suffering, ageing, loss and ultimately death by their very nature become spiritual encounters (Tully, 1998). Spirituality may be broadly defined as the essence or life of a person (e.g. Conrad, 1985). Thus, the suffering of a person with advanced cancer may be related to a perception of his or her whole life as having deteriorated because of the experience of pain. Another aspect of the spiritual dimension in palliative care is hope. External factors that influence hope are the culture in which the person lives, and his or her current environment, which include both the physical setting and the relationships that are possible with carers and others (Sheldon, 1997). High levels of hope have been found to be linked with high levels of coping (Herth, 1989). In a series of interviews with ten adults who were aware that they were terminally ill and given a prognosis of less than six months, Herth (1990) identified a number of strategies used by patients to foster hope and other factors which hindered it. Feeling valued as a person, having meaningful relationships, relief from troublesome symptoms and realistic goals, all contributed to the increase in hope which occurred in the small group of patients studied as they came nearer to death. All these are areas which professionals can influence and which are 'embedded in the tradition of palliative care' (Lunn, 1993). Communicating that people matter by remembering what they said recently, which position they can lie most comfortably in, realism but creativity about what could be achieved during each week of their care, can contribute to their hope. The converse of enhanced hope was found to be feeling undervalued and abandoned, uncontrolled symptoms and no sense of direction (Herth, 1990; Sheldon, 1997). The attitude transmitted by health care professional needs to be empathic and genuine, with a real concern for patients' experience as currently perceived by patients themselves.

Writing of her experience as a staff psychologist in a hospice in Paris, helping patients with terminal cancer to resolve their grief and gain hope and meaning from the time they had left to live, de Hennezel (1997) described the situation relating to a patient named Patricia who had not yet learned the prognosis of her illness, although her husband, Pierre, had been informed. The dilemma imposed on the person closest to the patient is described: 'Dr. Clement tried to find out what Pierre thought of this conspiracy of silence surrounding Patricia. From what he can tell, Pierre isn't ready to break it (the news) yet; he's afraid that Patricia will collapse, that she will lose all joie de vivre and that in taking away all hope, he'll kill her'. de Hennezel comments 'It's not the first time we've heard these arguments which show just how deeply the common view of death is coloured by anguish. We think we're protecting the person who's dying, but aren't we first and foremost trying to protect ourselves?' The issues of how much information and what information is told, by whom, and when, to the person with advanced cancer are a very difficult aspects of care and require sensitive listening and communication skills to understand what the person wants to know. People who are aware that they have a limited time left to live can avail of the opportunity to say things they have never said, make preparations for their loved ones, and say goodbyes, helping to give a purpose and meaning to the time left and thus facilitating some control, dignity and hope (e.g. Faulkner, 1998).

QoL and sense of control

A sense of control is central to maintaining hope and quality of life for the person with advanced cancer (e.g. Sheldon, 1997). Lewis, Haberman & Wallhagen (1986) interviewed 57 adults with late-stage cancer (21 men and 35 women, the gender of one subject not reported) and identified four cognitive/behavioral strategies used by them to enhance feelings of personal control. Brockopp, Hayko, Davenport & Winscott (1989) pointed out that, building on the findings of Lewis *et al.* (1986) it would seem that individuals living with a life-threatening disease have two needs associated with their sense of personal control which are related to hope and to information. To monitor the progress of their disease, shift attempts to exert control to areas in which success is possible and turn to other areas of their lives when control is not possible, individuals must gather information about their condition. Waiting for a period of normality to return suggests that hoping behaviours are occurring. Brockopp *et al.* (1989) found significant correlations between perceived level of control and eight issues related to hope and information-seeking. Their study was designed because of the evidence that exists linking information-seeking to a need for control and the clinical opinion that links hopelessness to feelings of helplessness or loss of control (Seligman, 1975). Brockopp *et al.* (1989) point out that needs for personal control are highly individualised and should be assessed directly until associations with other psychological constructs are shown. Designing a plan of care that interprets needs for hope and information as relating to a need to increase control is not warranted unless data from the patient clearly defines the relationship.

An important concept for those involved with the care of patients with cancer is that of conveying care, not only for their survival but for their physical, emotional, social and vocational function. Measures must be aimed at facilitating optimal function and life satisfaction for the patient treated for cancer (Mellette, 1993). The way others relate to the patient with cancer will have major implications for that patient's sense of well-being and quality of life. Caring, or making contact, is the essential element within the nurse-patient relationship that makes a significant difference to the patient’s sense of well-being

(Benner & Wrubel, 1989). Analysis of paradigms used by Holden (1990) revealed a component of empathy which proved to be instrumental in creating the caring climate. However, Reid-Ponte (1992) stated that in nursing education and service there is inadequate knowledge concerning the specific behaviours of professional nurses that decrease the distress of patients during nurse-patient interactions. The concept of care directs attention from paternalism to participation, from linearity to holism and most importantly, from patient to person (Roy, 1995).

The division of labour between nursing and medicine demonstrates some of the tensions that are involved in achieving a balance between caring and curing. In a study of the nursing care delivered to dying patients in various settings, Field (1989) demonstrated clearly the difficulties facing nurses during the negotiation of the 'space' required for the implementation of those aspects of their work which are difficult for others to see and for nurses themselves to articulate. Field (1989) highlighted how the 'comfort' and sentimental aspects of nursing work are embedded within the more visible activities of 'machine,' 'safety' and 'articulation' work associated with the essentially medically controlled treatment of patients. The three elements of total care, teamwork and trust are central to palliative care. 'Total care' refers to the multidimensional relief of suffering (Cassell, 1991) whether experienced by ill persons or by their companions; 'teamwork' alludes to the model of interdisciplinary working required for effective palliative care and 'trust' is about the nature of the relationship between the cared-for person and his/her carers. In 1990 the World Health Organisation defined palliative care as: 'the active total care of patients whose disease is not responsive to curative treatment'. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families (Clark & Seymour, 1999).

The measurement of quality of life

As pointed out by Selby (1993), interest in direct methods for measuring QoL in cancer is a relatively recent development. Bardelli & Saracci (1978) reviewed all the clinical studies published in six major cancer journals between 1956 and 1976, and found that fewer than 5% reported attempts to measure any aspect of QoL. Since 1976 there has been a substantial increase in studies on this subject, reflecting a recognition of the limitations and potential hazards of modern treatment. In 1989 the United Kingdom Medical Research Council (MRC) Working Party carried out a review of methods available for evaluating quality of life. This review considered the function, format, scoring, structure and clinical usage of a wide range of questionnaires. Recommendations were made that any QoL assessment in patients with cancer should include physical well-being (symptoms and toxicities such as pain, fatigue, nausea, physical activity and work, recreation and self-care activities), psychological well-being (body image, self-esteem, emotional distress, anger, depression) and social well-being (effects on social activities, isolation, social support from family and friends, and sexual relationships) (Selby 1993; Maguire & Selby 1989). These suggestions are broadly similar to those of Aaronson (1986) who also included an enquiry about satisfaction with medical care as an important area requiring attention. It seems likely that the interaction with health care teams will have a major influence on a patient's perception of his or her quality of life during a period of life-threatening illness. However, patients with cancer may not readily admit to dissatisfaction (Selby, 1985). In the literature, domains of QoL for patients with cancer also include spiritual well-being (Ferrell, Hassey, Dow, Leigh, Ly & Gulasekaram, 1995).

Quality of life may suffer as a result of cancer and its treatment. As the disease progresses, QoL issues loom large (Mor, 1987). The symptoms associated with local or advanced cancer are many and varied. Although the severity of symptoms and the threat to patients' lives may not be greater for many cancers than for other common life-threatening conditions such as ischaemic heart disease, they do present special difficulties in the measurement of QoL. The difficulties arise from the multiplicity of cancer presentations and disabilities. Each cancer site is associated with a spectrum of presentations and stages. In addition to the problems presented by the multiplicity of cancer presentations, their severity can generate restrictions on the measurement of QoL. Patients with advanced and/or recurrent cancer require extensive and intensive care and it is important that the measurement of QoL in this context should not be too onerous for them. The need to restrict the length of questionnaires confounds the difficulties presented by the multiplicity of features that must be measured. The reduction of questionnaires to the minimum possible is necessary. However, if the questions are focused upon a single area they may fail to assess the impact of disease on the patient's whole life (Selby, 1993). Cancer medicine is concerned with the effect of the disease and its treatment upon the patient, the goal being to return any patient, as far as possible, to normal. The upper limit of measurement should be normality for that patient, not an ideal of perfect QoL (Selby, 1993).

Appropriate instruments are essential if outcome measures are to be valid, reliable and clinically meaningful (Fitzpatrick, Fletcher, Gore, Jones, Spiegelhalter & Cox, 1992). Reliability refers to the extent to which the measure yields consistent results. Validity is the degree to which the measure reflects what it is supposed to measure (Hays, Anderson & Revicki, 1993). During the past decade there has been rapid expansion of the pool of psychometrically evaluated quality of life instruments for use with patients with cancer, including generic measures of quality of life and health status that have been used with noncancer medical patient samples (Ganz, 1994). Generic instruments cover a broad range of quality of life dimensions in a single instrument. Well known examples include the Nottingham Health Profile (Hunt, McEwen & McKenna, 1986) and the Sickness Impact Profile (Bergner, Bobbitt, Carter & Gilson, 1981). Advantages of generic measures of quality of life are that they have undergone rigorous testing during development and standardisation and include many health-related dimensions, which removes the need to select dimensions for a particular study, allows for the detection of unexpected effects and facilitates comparisons among different disease groups and between healthy and ill populations (Fletcher, Gore, Jones, Fitzpatrick, Spiegelhalter & Cox, 1992; Wells, 1997). However, a broad approach may reduce responsiveness to effects in health care, whereas disease specific instruments reduce patient burden and increase acceptability by including only relevant dimensions, which may increase responsiveness. Disease specific measures are developed to closely match the dimensions of quality of life affected by a specific disease, such as cancer and generally are more sensitive to changes in quality of life dimensions than generic instruments. Disadvantages are the lack of comparability of results with those from other disease groups and the possibility of missing effects in dimensions that are not included (Fletcher *et al.*, 1992).

When selecting an instrument the most important issue is how well it will perform in the required situation. In brief, validity and reliability are necessary for all contexts; the importance of other psychometric properties varies with context. For example, sensitivity (false negative results) and specificity (false positive results) are important for screening and responsiveness. Instruments whose value has been proved for screening should not be assumed to be effective for other purposes (Fitzpatrick *et al.,* 1992). Instruments have been especially developed for use with patients with cancer and comprehensive lists of instruments for measuring quality of life in patients with cancer have been given by Ganz (1994) and Wells (1997). Most instruments developed during the past decade have been designed for self-administration and are relatively short, permitting their use in clinical trials. Although the use of self-administered instruments is relatively efficient, it has some limitations. Specifically, elderly or cognitively impaired patients and those with declining performance status may not be able to complete these instruments. Other limitations of current instruments include lack of translation into different languages (an exception is the EORTC Quality of Life questionnaire (Aaronson, Ahmedzai, Bergman, Bullinger, Cull, Duez, Filiberti, Flechtner, Fleishman, de Haes, 1993) and a limited number of instruments for evaluating children with cancer (Ganz, 1994).

The evaluation of cancer treatments have traditionally been made using biomedical outcomes such as duration of survival, progression of disease and control of physical symptoms. However, these criteria fail to take account of patients' subjective assessment of the impact of disease on their lifestyle. The diagnosis, course and treatment of cancer has extensive repercussions for individuals and their family. A review of health-related quality of life (HQL) as a multi-dimensional construct encompassing perceptions of both positive and negative aspects of dimensions of physical, social and cognitive functions, as well as the negative aspects of somatic discomfort and other symptoms produced by a disease or its treatment is given by Osaba (1994). Since HQL is a subjective concept, it is the patients' opinions that should be sought. Assessment of HQL by an observer is likely to be biased by the observer's own internal standard of what is a desirable HQL state. Because the observer's internal standard is actually an external standard from the patient's perspective, observers' opinions may be different to those of patients (Osaba, 1994). Slevin, Plant, Lynch, Drinkwater & Gregory (1988) examined the extent to which a doctor or health professional can make a valid assessment of a cancer patient's quality of life, anxiety and depression utilising a number of scales including the Karnofsky Performance Scale (Karnofsky & Burchenal, 1949) and the Hospital Anxiety and Depression (HAD) Scale (Zigmond & Snaith, 1983). The same questionnaires were completed by the health professionals, patients and relatives, with the exception that the Karnofsky Performance Scale was filled in only by the health professionals and HAD scales were filled in only by the patients. For the supposedly objective Karnofsky Scale, the same score was achieved on only 54% of occasions. For the other more subjective scales measuring quality of life, anxiety and depression, the range of scores was even greater and thus, the scales were even less reliable. For example, in the population of cancer patients studied, the elements of the Hospital Anxiety and Depression Scale were not the major contributors to anxiety and depression, the patients were more likely to be worried because of their future. Slevin *et al.* (1988) concluded that if a reliable and consistent method of measuring quality of life in patients with cancer is required, it must come from the patients themselves.

Research has been carried out to begin identifying lay definitions of quality of life. Hall (1976) asked subjects what they thought of when they heard the words 'quality of life'. The largest single category referred to was the family, home-life and marriage. A large number of respondents were unable to be specific and referred to being happy, contented or 'being satisfied inside yourself'. Health ranked quite highly and the longer the interval since the last visit to the doctor, the higher the rate of satisfaction with life. Factors which received least mention were 'pressures of life', consumer goods, equality and justice. More promising research on health related quality of life has involved the application of the techniques of human judgement analysis to assess health related quality of life from the perspective of the individual. Developed by O'Boyle *et al.* (1992), the technique is known as the Schedule for the Evaluation of Individual Quality of Life (SEIQoL). With this technique, respondents are asked to list the five areas of life ('cues') that they judge to be the most important to their overall quality of life. Open-ended questions are used to elicit the relevant cues. Then subjects rate their current status and global quality of life against a vertical visual analogue scale. Relative weights of importance are then attached to the items. O'Boyle *et al.* (1992) point out that a valid measure of quality of life should quantify the level of functioning of each individual in those areas of life that he or she believes to be most important. In their study of patients undergoing hip replacement, social/leisure activities and family were nominated most frequently by both patients and controls; happiness, religion, independence and finances were also nominated. Health was nominated more frequently by controls than by patients. A similarly hermeneutic approach to measuring disease specific quality of life was adopted by Guyatt and his colleagues in their development of quality of life scales for people with bowel disorders, respiratory disease and heart disease (e.g. Guyatt, Berman, Townsend, Pugsley & Chambers, 1987). Respondents were asked to list activities that were affected by their condition and then specify which were the most important in their day to day lives. Although subjective QoL measures are increasingly replacing objective measures, the content of such measures continues to be mostly selected by the investigator (Waldron *et al.*, 1999)

Cancer does not reflect a single disease entity and treatment adverse effects vary greatly, so diagnostic and treatment specific instruments, such as the Lung Cancer Symptom Scale (Hollen, Gralla, Kris & Potanovich, 1993) have been developed which are highly specific to anticipated changes related to diagnosis or treatment and therefore provide a high level of sensitivity to change in the patient's quality of life. Few instruments will contain all of the dimensions affected by cancer and cancer treatments. Therefore, an approach to the measurement of quality of life should include both a generic or disease-specific core supplemented with diagnosis or treatment specific modules. Quality of life considerations are crucial when treatments are aversive, especially when the treatment aims are palliative rather than curative (Payne, 1992). In a study of quality of life in cancer patients receiving palliative chemotherapy by Payne (1992), 53 patients with advanced breast cancer or ovarian cancer were studied prospectively for 6 months to assess whether the site and method of chemotherapy administration influenced their quality of life. Patients received palliative chemotherapy either at home or in hospital. Quality of life was operationalised as measurement of anxiety, depression, self-esteem, health locus of control, physical performance and symptoms. In addition, semi-structured interviews explored social roles, relationships and perceptions of treatment. Hospital administered chemotherapy was perceived to be most distressing. Patients treated in hospital were much less active than those treated at home. Although ability to perform domestic tasks was not directly related to quality of life, the results of this study lend support to the contention that hospital administered chemotherapy was perceived as more stressful and had a greater impact on lifestyle. Regression analysis indicated that anxiety and depression accounted for most of the variance in quality of life. Patients who died during the study (24%) experienced considerable psychological and physical distress. Recent developments in cancer palliation may have prolonged the dying process in patients with cancer, but it is important that this extra time should not be misused to prolong suffering (Stoll, 1988). A valid QoL measure for patients facing imminent death should permit assessment of QoL from the unique perspective of the individual, without imposing a predetermined external value system (e.g. Waldron *et al.*, 1999).

Social support and quality of life

Individuals who participate in social interactions and who have enduring relationships with one another cannot do without adequate information. The study of communication necessarily hinges on the role of information and it is this that is shared among individuals by the process of communicating. This information, by rendering events more predictable, gives advantages to the users of the process by enabling recipients to make appropriate choices and to facilitate further communication to influence those choices (Smith, 1972). Informative reassurance is a purposeful, conscious and deliberate attempt to restore confidence (French 1979, Teasdale 1989) and reduce uncertainty (Boyd & Munhall 1990; Morse, Bottorff, Anderson, O'Brien & Solberg, 1992). Although a range of behaviours may be used to produce a state of calmness or assurance, information giving and explanations primarily are used to produce this state. Others have argued that this type of reassurance is a complex interpersonal skill that can be enhanced by education (French 1979) and that it is prompted by knowledge of the patient's situation and evidence of his/her unmet and projected needs (Boyd & Munhall 1990). Patients with cancer may require a different empathic strategy than one of 'perceiving, feeling and listening' to help cope with the distress caused by the progression of the disease. One strategy used by patients with cancer includes active information-seeking from health care providers about ways either to help cure the cancer or to discover the most support while dealing with the progression of the disease.

A more active teaching/information-giving approach as the nurse communicates with the patient might be more distress-relieving for the patient than simply using the empathic communicating strategy of perceiving and listening (Mages & Mendelsohn, 1979). In this way, uncertainty about the disease can be reduced by providing information at a pace set by the patient and being available for emotional support (Galbraith, 1995). Empathic communication skills are at the core of effective human relations and effective communication is the core of every helping relationship. The goals of every helper include assisting the helped to (1) increase self-esteem and (2) gain control over and assume responsibility for decisions, the helper being anyone who assists others to understand, overcome or deal with problems (Okun, 1992). There is evidence that patients fail to communicate their worries to staff (Johnston, 1982). If doctors and nurses do not know what the individual is worrying about, then they are unlikely to be able to reassure the patient and give information relevant to his or her worries (Johnston, 1982) with possible major implications for quality of life.

Qol and terminal care

When it is clear that life will end in the near future, the quality of life that is left becomes a central concern for the person who is dying and those around him or her. All the previously described elements and concerns related to spirituality, hope and hopelessness, fear, loss and grief and meaning are brought into sharp focus and possible existential crisis. The existential domain of quality of life includes concerns about death and existential obliteration, freedom (the absence of external structures), isolation (the final unbridgeable gap separating self from all else) and the question of meaning (the dilemma of meaning-seeking creatures who recognise the possibility of a cosmos without meaning) (Cohen, Mount, Tomas & Mount, 1996). Only the person who is dying can define what quality of life means to them. One person may find quality of life in enjoying nature, another in relationships with friends and family. Because the needs and wishes of patients and their carers may change fast as the disease progresses, a continual review of the goals for care is required to keep pace.

People from different cultures manage emotions associated with their own death or that of their loved ones in various ways. A context provided by the culture they live tends to influence whether death will be managed according to traditional (providing complex rituals enabling the needs of the group to be reasserted in the face of death) or modern (hidden from view and managed by experts) approaches. In modernity the archetypal death is from cancer and is regarded as predictable in its course and amenable to clinical interventions. Neo- or post-modern death places greater emphasis on living with dying (rather than the control of death) (Clark & Seymour, 1999). The neo-modern approach draws on elements of both the other approaches but without acknowledging the contradictions that may arise when the roots of each are so different. Different generations, different members of the same family, men or women may feel more comfortable with one approach rather than another and this can produce considerable tension at a time of heightened emotion when someone is dying (Sheldon, 1997). With the development of specialist palliative care services against a background of economic, social and organisational change has come a far more flexible and needs led service for those who are dying and their carers. For example, part of the skill of the nurse involved with the care of the dying person is to facilitate helpful family interactions and to ensure that space is available for relatives to rest and take refreshment as well as to talk amongst themselves. Nurses need to be sensitive and to be emotionally available, giving time to listen if required, while the services of a bereavement counsellor may be very appropriate at some future time for the bereaved. An appreciation of the individual's response to their own death and their view of what constitutes quality of life for them is central to quality care. Saunders' (1967) thesis of the lack of necessity for the dying person to experience pain is central to ensuring that the dying person experiences the best possible quality of life which is the over-arching goal of palliative care.

Ahmedzai (1993) suggested three theoretical components to quality of life: the absence or presence of subjective feelings of pleasure or happiness, normative ideals of activity or performance and the preference of the individual. The greater the gap between the person's present state and wished for state, the less satisfactory is their quality of life (Calman, 1984). In one study, inpatients admitted in a seven month period to a voluntary hospice were asked to identify and grade problems as they perceived them and to grade problems previously identified by the medical and nursing staff. Doctors and nurses successfully identified pain and immobility as problems but were less successful in relation to psychosocial problems, reinforcing the importance of ascertaining the dying patient's views (Rathbone, Horsley & Goacher, 1994).

Spiritual distress characterised by loneliness, despair, grief and loss of the future may affect the quality of life of patients with advanced cancer (e.g. Ferrell *et al.,* 1995; Kahn & Steeves, 1993). People's ability to adequately meet their own needs can be inhibited in certain situations, such as illness and hospitalisation, with a subsequent loss of control. The importance of the family setting as a possible enhancement to perceived control and quality of life for patients with advanced cancer is highlighted in a study by Dessloch, Maiworm, Florin & Schulze (1992) who investigated quality of life in 41 terminally-ill cancer patients, 21 of whom received hospital care and another 20, home-bound hospice care. Both groups were comparable with respect to the patients' physical condition. The following variables were chosen as indicators of quality of life: perceived social support and social distress, coping with illness, perceived positive environmental factors, perceived control over daily activities and caring routines, contentedness with medical care and nursing and physical well-being. Assessment was made by means of a semi-structured interview. Results indicated that the home-bound care was superior with respect to perceived positive environmental factors, perceived control over daily activities and caring routines and contentedness with nursing. As there was no difference in perceived social support and social distress between the groups, results of the study suggested that control factors other than support and empathy were involved in raising the quality of life rating for the home-care group. These factors may be linked to perceived control and role loss and increased dependency on others for the hospice patients and higher levels of contendedness/happiness for the home-based group.

A serious illness like cancer often results in temporary or permanent loss of functions or roles. Several tasks can no longer be performed and have to be taken over by other people, thereby increasing dependency on others. According to exchange theory, this imbalance may lead to loss of social contacts and support because the patient is less capable of meeting other people's needs, resulting in a decreased social network and amount of experienced social support over the disease course. A study by Dawson (1991) compared the ability of hospice and conventional settings to meet the basic emotional needs of families during a member's dying and death from cancer. In addition, the relationship of basic needs satisfaction, perceptions about the nurse and overall satisfaction with the programme of care were explored. Results showed that the conventional care group demonstrated the lowest levels of basic needs satisfaction, satisfaction with the psychosocial support of the nurse and overall programme satisfaction, while home hospice care provided the highest quality of basic needs satisfaction and the highest level of satisfaction with the nurse, with the home care group revealing the lowest unmet need scores, the greatest satisfaction with the psychosocial support from nurses and the greatest overall satisfaction with their programme of care. Dawson (1991) questioned whether satisfaction in the home setting was higher because the home setting itself was more satisfying. However, nothing in the analysis of the study's data supported this possibility. The data evaluation indicated that a programme of care intervention, particularly psychosocial support by the nurse, played a strong role in overall satisfaction. Dawson (1991) concluded that the home care staff simply provided a consistently higher quality of basic needs support to familial care givers.

Applying QoL issues to caregivers

There are many reasons why it is not possible or practicable for some people to remain at home when they are dying. In a review of the literature, Hunt (1997) identified haematological malignancy, disease of rapid progression; older age; low socio-economic status and lack of access to palliative care services as variables which are associated with institutional death. Cultural beliefs about the role of the family and of the value of hospital care versus home care will also influence where people die (Hunt, 1997). Most significantly, the degree to which palliative care needs can be met successfully in the home environment is shown to depend upon the close involvement and availability of an informal carer for the dying person, whether a family member or a close friend. The provision of adequate support for informal carers, together with appropriate medical and nursing intervention appears to increase both the length of time that dying people remain in their own homes and the proportion of deaths that occur at home (Hunt, 1997). Issues related to quality of life also apply to the carers and partners of people with cancer. Frequently, carers are overwhelmed with the difficulties they have to endure, which may include loneliness, financial difficulties, reduced sleep and for some people the distress of seeing their loved one undergo changes in personality due to the ravages of brain tumour or metastatic disease. Practical help from the social services, friends and neighbours can do much to alleviate psychological and emotional distress and may contribute to reducing the social and psychological pain of both the carer and the dying person. One of the principles of palliative care is that carers should be treated as of equal importance (Sheldon, 1997). Understanding the dilemmas, needs and circumstances of the dying person is intricately bound up with those who are providing care. These 'informal carers' have often been overlooked in social and policy analysis. Two factors have increased the visibility of informal carers. First, feminist scholars have pointed to the importance of understanding the gendered nature of informal care and the ways in which it relates to assumptions and expectations of women's roles in families. Second, within social policy, there has been a growing interest in the activities of informal carers, rooted in their potential contribution to wider aspects of 'care in the community' as a policy goal (Twigg & Atkin, 1994). New patterns of family life, prolonged ageing and rapidly changing employment patterns have resulted in a lack of availability of care-givers and an increased awareness of the difficulties of care-giving. While inadequate symptom control is clearly a major factor involved in the experience of dying for the patients themselves, it also is highly likely to contribute to the experience of extreme stress among their informal care-givers. This has been found to be one mechanism which results in the emergency admission of dying people to hospital during the last week of their lives (Thorpe, 1993).

Summary

The considerations required to maximise quality of life for the person with cancer are numerous and complex, especially as the disease of cancer advances and symptom control assumes major importance. It is clear that cancer can impact severely on all aspects of a person's quality of life and frequently upon the life of their families and loved ones. The disease trajectory is marked by loss, grief, uncertainty, anxiety, pain, activity restriction, in short, a potential devastation of quality of life. Morris & Sherwood (1987) suggested that through an unspecified process, patients with cancer experience a major loss of quality of life at a period prior to the last twelve weeks of life, followed by another major loss during the last few weeks of life. Many patients with terminal cancer have residual capacities that enable them to participate in activities and meaningful social relationships during their last weeks of life, while most retain cognitive ability up until death. In keeping with the philosophy put forward by Saunders (1967), the care of the person who is suffering from advanced cancer or who is terminally ill requires detailed, frequent assessment on a patient-centered holistic basis in order to maximise quality of life.

LIFESPAN, SOCIOECONOMIC STATUS AND CANCER

Stages of adulthood and cancer

A diagnosis of cancer has implications for undermining or delaying an optimal developmental outcome for a person, depending upon their stage of maturity when faced with that diagnosis and also depending upon the type and stage of cancer that is diagnosed. For example, a young man diagnosed with stage 1 Hodgkin's Disease will face a different prognosis and possible related life crises compared with either a peer of the same age or an elderly person diagnosed with metastatic bowel or lung cancer (cf. Barr, Cowan & Nicolson, 1997; Strain, 1998; Souhami & Tobias, 1998).

People in early adulthood are usually focused on the development tasks of the acquisition of the new roles of worker, spouse and partner up to the age of thirty years. The years from thirty onwards are typified by establishment in work, usually reached by 40 years, increasing self confidence, assertiveness and independence. From approximately age fifty, with wide individual differences, women experience the onset of the menopause, which may be followed by increased bone loss and loss of muscle tissue. For some people work roles become less prominent with preparation for retirement. Couples may experience heightened marital satisfaction (Bee, 1998). The major single factor influencing the individual experience of middle adulthood is health. For the minority who experience significant ill-health the sense of choice or control is far less apparent. One study found that the two events likely to shift a man in mid-life from good to poor psychological adjustment were either a significant deterioration of health or alcoholism (Vailant & Vailant, 1990). Late adulthood brings decline in most measures related to physical performance, with some possible decline on cognitive ability related to reduced cognitive function and hearing loss, with wide individual differences. Degree of social involvement is related to life satisfaction and health, with decline in social involvement for those with physical and cognitive impairment, along with increased risk of disability and frailty. Currently it is estimated that older persons have a risk of developing cancer ten times greater than that for individuals younger than 65 years of age. By the year 2030, 70% of patients with cancer in the US will be 65 years of age or older (Havlik, Yancik, Long, Ries & Edwards, 1994).

It is likely that the onset of a severe and chronic disease such as cancer is one of the most traumatic events for a person, particularly when it occurs non-normatively in the earliest parts of the lifespan, the psychological effects possibly exacerbated by social and cultural factors. Although a substantial number of people may experience psychological distress in response to the knowledge that they have cancer, where possible, they may also continue life's trajectory without overt manifestations of functional or psychological maladaptation or impairment (Strain, 1998). In general, people tend to hold strong beliefs in their personal invulnerability and there is little anticipatory socialisation for issues related to chronic illness such as being educated to deal with death. Death in modern times tends to be dealt with in a more hidden way than it was traditionally (e.g. Clark & Seymour, 1999). By comparison, negative life events such as loss of a loved one, may be at least partially embedded into culturally shaped ways of responding (Stroebe & Stroebe, 1987). People diagnosed with advanced cancer that cannot be cured are faced with the double burden of fearing death and grieving for their own loss of life. To suffer from cancer usually implies the loss of hopes, goals and plans, possibly never to be replaced, depending upon the type of cancer and stage at diagnosis. For example, breast and prostate cancer have better treatment options and likely survival time than lung cancer (e.g. Balfour & Kaplan, 1998; Souhami & Tobias, 1998). However, prostate cancer is significantly associated with older age and fitness is one of a number of factors that require consideration with regard to its radical treatment, thereby possibly affecting prognosis (Souhami & Tobias, 1998).

Regardless of SES, almost all families confronted with cancer and its treatment will have financial problems. Poor people are more likely to be diagnosed with cancer when the disease is advanced and treatment options significantly more limited. For the middle class family with insurance, as medication costs increase, financial deprivations accumulate because of out of pocket expenditures, and lost earnings because of aspects of the treatment. Therefore, even those who are insured can be financially devastated by substantial gaps in coverage. Thus, the total experience of cancer is usually more disruptive to patients and their families than that of other diseases and the economic issues are a significant part of the disruption. If financial needs are not met, a patient's treatment, overall functioning and quality of life may be compromised (Christ, 1991; Berkman & Sampson, 1993).

Cancer and SES

The risks of developing and dying from cancer vary across levels of SES and the experience of living with cancer and fighting the disease also changes with SES (Balfour & Kaplan, 1998). For example, poorer people with cancer experience increased mortality rates from that disease compared to people in higher income brackets (Balfour & Kaplan, 1998; Berkman & Sampson, 1993; American Cancer Society, 1989). An inverse gradient between SES and poor health has been documented for many diseases across the lifespan and in many different populations and places (e.g. Haan, Kaplan & Syme, 1989). Explanations for the association between SES and ill-health include (1) experience of maternal deprivation by the poorest populations; (2) poorer access to medical prevention, diagnosis and treatment; (3) a higher prevalence of specific risk factors in lower social classes (e.g. occupational hazards and diet); (4) selection of people with poorer health into the lower classes through illness; and (5) a general susceptibility to disease that increases as SES decreases (e.g. Balfour & Kaplan, 1998). Depending on the site of the cancer, SES is associated both directly and inversely with cancer incidence. However, the pattern of association between SES and cancer survival is consistent across site; as SES decreases, so does the rate of survival from cancer (Balfour & Kaplan, 1998). SES might influence these patterns of cancer onset and progression by both exogenous and endogenous pathways. The former include influences on life-style, health behaviours and medical care. The latter hypothesise that SES, through stress, or other systemic changes, has direct physiological effects on the host (e.g. Holland, 1998).

Across different world populations, incidence rates of many sites of cancer, especially lung, oral and esophageal, stomach, uterine, cervix and pancreas, crudely termed cancers of poverty, increase with decreasing health (e.g. Faggioni, Zanetti & Costa, 1994; Balfour & Kaplan, 1998). In contrast, cancer sites for which there is a direct association with SES, termed cancers of affluence, include colon, rectum, breast, uterine corpus and skin. Also, patterns of direct and inverse association between SES and cancer site may change over time, the most logical explanation being that risk factors for cause at a given site are patterned directly or indirectly with SES. Thus it is necessary to consider risk factors for the different cancer sites and how these relate to SES (Balfour & Kaplan, 1998). For example, tobacco smoking is the major risk factor for lung cancer (e.g. Holland, 1998; Souhami & Tobias, 1998) and alongside other risk factors such as occupational exposure and air pollution, shows evidence of an inverse gradient with SES (Balfour & Kaplan, 1998; Souhami & Tobias, 1998). It is considered likely that a person of lower SES has a greater chance of beginning smoking earlier, smoking for a longer period of his or her life and smoking more cigarettes per day, while having less chance of quitting compared to individuals of higher SES. For persons of lower SES, this risk behaviour may be coupled with higher exposure to occupational hazards and air pollution (Balfour & Kaplan, 1998).

The situation is somewhat different and more diverse with regard to breast cancer. Epidemiological analyses indicate that breast cancer incidence is related to a group of reproductive factors: nullparity, age at first childbirth, earlier menarche and later menopause, which suggests that endocrine factors play a role in breast cancer (Kesley & Horn-Ross, 1993). Social factors, including SES, profoundly influence reproductive behaviour, with poorer women more likely to have children at a younger age and to have more children (e.g. Freidman, 1992). In addition, it is possible for factors such as nutrition to influence the age at menarche and menopause, with good nutrition prolonging the fertile period. Because of socially mediated reproductive patterns, women in higher SES groups experience an increased dose of sex hormones and a higher rate of breast cancer. However, other hypothesised risk factors for breast cancer including high dietary fat intake, smoking and low levels of physical exercise, are currently inversely associated with SES and would not account for the pattern of breast cancer incidence (Balfour & Kaplan, 1998).

The primary risk factors for colon cancer are a diet low in fibre and high in protein and fat and a history of low physical activity (e.g. Doll & Peto, 1981). These risk factors, measured in the 1980s and 1990s, all show an inverse association with SES, whereas the incidence of colon cancer has a direct association which may reflect a changing temporal trend. For example, in the early decades of this century, white collar jobs were associated with higher rates of sedentary behaviour and a diet high in protein and animal fat and low in fibre. Since colon cancer is hypothesised to develop over a very long time, the excess incidence of colon cancer found in white-collar workers as compared to blue-collar workers is a result of behaviours occurring much earlier. In the latter part of this century, high consumption of meat, dairy and starch foods and low consumption of fruits and vegetables has become more frequent in the lower SES groups, while the pattern is the opposite in higher SES groups. The same reversal is occurring for physical exercise. While higher SES groups still hold sedentary jobs, as a group they have adopted a higher rate of leisure time physical activity than have lower social classes. In addition, many low-paying service and manufacturing jobs are now sedentary. A trend of diminishing or reversal in the association of colon cancer incidence and SES has been reported in analyses from the United Kingdom (e.g. Smith, 1979; Balfour & Kaplan, 1998).

Black people with colon cancer have lower survival rates than white people, possibly related to more advanced stages of disease at diagnosis and to socioeconomic differences between blacks and whites (Mayberry, Coates, Hill, Click, Chen, Austen, Redmond, Fenoglio-Preiser, Hunter & Haynes 1995). A prospective study by Mayberry *et al.* (1995) which included 454 black people and 521 white people aged 20-79 years found that stage at diagnosis accounted for more than half the excess cancer mortality observed among black persons. Cancer of the cervix is the most common malignancy in developing countries and ranks second only after breast cancer in incidence in the female population worldwide, with an annual incidence of 500,000. The peak age for invasive carcinoma is 50-60 years and for in situ disease approximately 30-40 years. It is more common in women of lower SES and is associated with cigarette smoking. In addition, the survival rate in developing countries from this disease is very low because of late presentation and inadequate treatment facilities and it therefore represents a major public health problem (Barr, Cowan & Nicolson, 1997; Slevin & Tate, 1998).

SES and mortality

Regardless of the pattern of cancer incidence, SES has an inverse relationship with cancer mortality. The poorer a person is, the greater the risk of death and the shorter the survival time (e.g. Berg, Ross & Latourette, 1977). One prospective study reported that men in the lowest occupational grade had a 50% higher overall mortality from cancer of all sites than had men in the highest (Smith 1979). In general, cancers with low survival rates exhibit little survival differences by level of SES, while cancers with the highest survival rates tend to have the greatest relative social class differences in survival. Cancers with the best survival times are possibly more amenable to intervention, suggesting that medical treatment factors may play a role in forming the SES differences in survival. The potential differences in medical care can be separated into many aspects of seeking and receiving care: access to regular cancer screening and preventive medicine, symptom recognition, delay in seeking diagnosis, medical treatment offered, medical procedure accepted and treatment efficacy and adherence. Evidence from several studies suggests that income and social class play a role in tumour stage at diagnosis (Balfour & Kaplan, 1998). Numerous studies have reported differences in cancer staging at diagnosis and in survival between black and white patients with breast cancer (Hunter, Redmond, Chen, Austen, Greenberg, Correa, Muss, Forman, Wesley, Blacklow, 1993). Hypotheses about what causes the differences in time and stage at diagnosis include differences in symptom recognition, delay in seeking diagnosis or difficulty accessing treatment. Roberts, French & Duffy (1984) found that the knowledge of the signs and symptoms of breast cancer differed by social class.

Symptom recognition and delay in seeking treatment are factors in which the responsibility rests on the individual patient. Contextual hypotheses for SES associated differences in stage at diagnosis include differences in access to medical care, lack of a personal provider and feelings of mistrust about medical intervention (American Cancer Society, 1989; Balfour & Kaplan, 1998). Once cancer has been diagnosed, treatment differences are a potential risk for survival differences across SES groups. Since SES is associated inversely with many other health problems, lower SES groups may have serious co-morbidity conditions besides the incident cancer, contraindicating optimal treatment options (Satariano & Ragland, 1994). Co-morbidity may also be one of several factors which influence progression of tumours through a decrease in host resistance, especially with cancers which have better treatment options and prognosis and thus longer survival times (Balfour & Kaplan, 1998).

Lifespan and QoL

It is obvious that a person in early or middle adulthood who suffers a major loss is placed in a crisis situation; lack of perceived support and difficult family interactions may impact on that person's well-being, sense of self-efficacy and coping ability (Bandura, 1992). If cancer is subsequently diagnosed, this may represent a severe compounding of an already difficult life situation, depending on the type of loss experienced and family interactions already present, possibly exacerbating existing anxiety, sense of loss of control and hopelessness/helplessness (Burton & Watson, 1998). Some people blame themselves for getting cancer and for the suffering they feel they have inflicted upon their families. Their sense of guilt may be compounded by shame, leading to social and emotional isolation. People with advanced disease may bear an additional frustration of feeling unfulfilled in their life's hopes and plans, along with a sense that cancer is denying or cheating them of opportunities. For younger patients there is a special poignancy to the often expressed regret that they will not see their children grow up to adulthood (Burton & Watson, 1998).

Cancer often brings a loss of dignity because of surgical changes such as mastectomy, colostomy or limb amputation brought about by the disease or its treatment. In this way the loss and grief inflicted by the diagnosis of cancer may be deepened by loss of self-esteem, self-image and fear of loss of sexual attractiveness, as is expressed in the following statement by one woman:

> *I wish it (the operation scar) wasn't there, that's all...I wouldn't let anybody see me without my clothes on. I just look at myself in the mirror and I think...Oh God! Men wouldn't find me attractive...not with this scar...I don't think so anyway (Burton & Watson, 1998).*

Impact on body image may be severe due to non-surgical treatments for cancer such as the use of indwelling urine catheters, effects of radiation and chemotherapy and hormonal therapy. Treatments for cancer may have a profound effect on all phases of the sexual response, including libido, arousal and orgasm. Removal of the breast and catastrophic surgery for genital malignancies is the most obvious cause of dysfunction. The impact of chronic pain and of anxiety and depression on sexual function must also be considered and disruption in sexual activity by chemotherapy is very common (Burton & Watson, 1998).

Self-care involves activities undertaken to maintain life, health and well-being. Three types of self-care tasks have been identified, described as universal, developmental and health deviation (tasks occurring as a function of the illness/treatment). Universal tasks which involve activities to meet needs for air, water, food, elimination, activity and rest, solitude and social interaction, safety and normalcy may be profoundly affected by illness. The symptoms accompanying treatment for cancer at any stage of the disease can lead to marked disruption of self-care activities if they are not controlled adequately, with influence upon emotional responses and possible severe disruption for quality of life (Munkres, Oberst & Hughes, 1992). Appraisal has been reported to be the best predictor of affective mood and to mediate the direct effects of symptom distress on mood in a sample of patients receiving radiation therapy (Oberst, Hughes, Chang & McCubbin, 1991). A study by Oberst *et al.* (1991) of 72 adults with cancer in treatment for an average of four weeks found that fatigue was the most distressing symptom, coming for treatment was the most demanding and self-treatment, such as administering medications, was the most difficult. Universal self-care activities most disrupted by treatment were social and recreational activities. In a study of patients being treated for initial or recurrent cancer, those with recurrence had higher symptom distress and health deviation self-burden scores and more stressful appraisals. Economic status, symptom distress and recurrence status predicted 49% of appraisal variance (Munkres *et al.,* 1992).

Thus, the overall scenario brought about by cancer, especially if recurrent or advanced, is one of frequent distress and disruption to daily and long-term life plans. The disease of cancer has many possible disruptive outcomes. For example, the person with cancer of the throat who has removal of all the organs involved in speech production, may then require retraining with a speech therapist to learn how to use an electro-larynx. The fatigue induced by advanced cancer and compounded by chemotherapy and radiation treatment for many patients results in an inability to cope with employment whether in the short or the long term, such that patients will need much psychological support and encouragement to regain their confidence and self-esteem (Greenberg, 1998).

It is clear that family dynamics will be drastically challenged when a family member suffers ongoing illness due to cancer. Loved ones and carers will themselves require support and guidance to enhance their own coping skills and to facilitate the coping skills of their relative with cancer. Up to the 1980s little systematic investigation had focused on problems for family members of patients with cancer from their own perspectives (Cook Gotay, 1984). A recent Irish study on male attitudes to breast cancer showed that three out of four men wanted more information about breast cancer and its side effects, with almost nine in ten married men and those in the middle age range requiring most information. For the group of men surveyed the prime areas of concern following their partner's diagnosis of cancer were supporting their partner through the illness, coping financially and with children and maintaining work commitments (ARC Cancer Support Centre, Dublin, 1998).

The greatest risk factor for developing cancer is age. Developmental considerations that must be addressed in the elderly are decreasing strength, health and vigour, sensory loss, adjustment to retirement and reduced income, adjustment to a spouse's death or death of siblings, other family members or friends, establishing an affiliation with their own group, adjusting to new roles and loss of status and establishing satisfactory living arrangements (Luckenotte, 1996). Many of these are changes encountered by an individual as they reach retirement-time often viewed by the rest of the population as marking transition into old age. As the individual grows older these circumstances change, so that a 90-year-old will have different problems to cope with from a 65-year-old (Redmond & Aapro, 1997). Human cancer incidences increase exponentially with advancing age (Miller, 1980; Newell, Spitz & Sider, 1989), as does the number of disorders and chronic diseases. The presence of comorbidities, or simply the fact that the individual is elderly, may mean that they are referred to other treatment units and are never properly diagnosed as having cancer. Older people are prone to altered protective mechanisms and thus endure age related deficits and more severe cancer-related aetiologies. Pain control presents a major problem in the elderly with cancer and the assessment of pain may be complicated by failing sight, hearing, cognitive impairment, confusion or dementia, coupled with a fear of addiction to opioids. A comprehensive overview of the effects of cancer in elderly patients is available elsewhere (cf. Redmond & Aapro, 1997). Once in palliative care, the dying elderly may have problems substantially different from younger patients due to communication difficulties in understanding and speaking and the existence of comorbidity confusing the status of the patient's health (Redmond & Aapro, 1997; Lubinski & Welland, 1997; Stein, 1996).

The final stage of life, death, is a very complex psychosocial issue and beyond the scope of the present thesis. The major issue for patients with advanced cancer is maximisation of the quality of life they are presently enjoying, through the use of optimal symptom control and relevant support and psychosocial interventions, so that patients can discuss and prepare for their own death with their loved ones, make plans and take time to do the things they want to do while they have the strength and, as much as possible, enjoy life to the full on a day to day basis.

Summary

Depending upon a person's age, the diagnosis of cancer has implications for affecting their developmental outcome. Lifespan interacts with SES to disrupt normal life and relationships (Balfour & Kaplan, 1998). The type of cancer will also affect chances of survival. For example, breast and, in general, prostate cancers have better treatment options than lung cancer (Holland, 1998; Souhami & Tobias, 1998). Some cancers, such as skin, colon and breast, are more associated with high SES, while others, such as cervical and lung, have an inverse relationship to SES. The risks of developing cancer and dying from cancer vary across levels of SES, as does the experience of living with cancer and fighting the disease (Balfour & Kaplan, 1998). The consequences of a diagnosis for people in their early and middle adulthood can include financial disruption, with reduced activity and social contacts. Disruptions to family dynamics induced by the changes to lifestyle such as financial burden and loss of roles can further compound the psychological distress induced by cancer (Burton & Watson, 1998). Human cancer incidences increase exponentially with advancing age (Miller, 1980; Newell, Spitz & Sider, 1989). The elderly will have different problems to cope with to the middle-aged (Redmond & Aapro, 1997). For the young, middle-aged and elderly, having cancer can mean having to endure major disruptions to lifestyle and quality of life.

RATIONALE FOR THE SELECTION OF INSTRUMENTS TO MEASURE PERCEIVED PAIN, SOCIAL SUPPORT, PSYCHOLOGICAL DISTRESS, COPING AND QUALITY OF LIFE IN PATIENTS WITH ADVANCED CANCER

Rationale for the study

As mentioned in the foreword, the initial idea for the study was the consideration of the effect of a cognitive-behavioural intervention of AT on the enhancement of the sense of self-efficacy of people with cancer (Bandura, 1992). The implication is that if people with cancer experience an increased sense of control and reduced feelings of helplessness and hopelessness, along with a reduction in psychological distress and experience of pain as a consequence of participating in a cognitive-behavioural intervention, they may be motivated to be more active in participating in their own health care. Patients wish to participate responsibly in decisions made about their lives. The challenge to that power comes from the doctor. In the exercise of their professional role, doctors may act in a paternalistic manner and infantilise patients, to undermine their power of self-determination.

Many health professionals are concerned with the psychological well-being of people who are physically ill. They must deal with the fact that an institution-centered rather than a client-centered care regime is less likely to give absolute priority to patients' interests. Hospital-induced stresses (as opposed to illness-induced stresses) figure to a large extent in the experience of the ill and injured. This especially so in the neglect of management of patients' needs for informational and emotional support in the context of illness (Nichols, 1995). A major need on the part of most seriously ill people and their partners is for good, clear, frequent and honest information. Waitzkin (1984) reported studies indicating that between 69% and 90% of doctors actively withheld information. In contrast, a similar percentage of people with advanced cancer wanted to have information. Similarly, Reynolds (1978) confirmed that 97% of a group of patients with cancer wanted full information. Coles (1990) illustrated how people can emerge from even a well-intentioned interview with a doctor or nurse still little the wiser, the problem being that the person ends up being told what the professional assumes they need to know. The absence of true client-centeredness in hospital care can be very damaging (Nichols, 1995).

Pain experienced by patients with cancer has severe physiological and psychological effects. Knowledge of the effectiveness of various cognitive and behavioural coping strategies on pain perception and pain control would assist nurses in planning and implementing effective nursing interventions for patients with cancer suffering from pain. Effective nursing interventions could enhance quality of life for patients with cancer (Arathuzik, 1994). The concepts underlying the use of cognitive-behavioural interventions for people with cancer are congruent with Orem's (1985) self-care theory of nursing practice, which emphasises the supportive-educative role of the nurse in helping the patient to gain therapeutic self-care skills (Sloman, 1995). The improvement to quality of life brought about by cognitive-behavioural interventions needs to be sustained by adequate informational and emotional support provided in a hospital context, to remove the problem of hospital induced stresses for patients undermining the effect of beneficial psychological interventions (Nichols, 1995; Sloman, 1995). This has implications for the development of adequate clinical nurse specialist back-up services to help to meet the information and counselling requirements of persons with cancer.

Watson, Denton, Baum & Greer (1988a) suggested that a nurse-counselling service can be of value in helping to reduce the amount of distress experienced as a result of the diagnosis and treatment of breast cancer. Bloom (1979) found that psychological intervention helped cancel out fatalistic attitudes among mastectomy patients and concluded that 'by providing informational and emotional support, it was possible to decrease patients' feelings that their health was influenced primarily by factors outside of their control'. In the service described by Watson *et al.* (1988a) information was provided in order to help reduce misconceptions about cancer and the uncertainties associated with the side and after-effects of treatment and this may have contributed to the greater feelings of personal control reported by counselled patients. Watson *et al.* (1988a) commented that this type of service may be appropriate for those patients who need help at particular crisis points (i.e. at time of diagnosis, during treatment and at point of recurrence) but for more profoundly disturbed patients the traditional psychiatric service is probably the most appropriate.

The present study aimed to find out which support variables are considered most helpful to people with advanced cancer and with cancer pain and whether certain types of support, or specific people providing support, are beneficial in mediating psychological distress and facilitating effective coping. The idea underlying the study was to determine whether there are support variables that might help to maximise quality of life for patients with cancer. Effective social support might help to reduce the psychological distress evoked by having cancer which might be further compounded by institution-centered attitudes by health care professionals. A comprehensive review of the literature and study of the available psychological instruments for measuring the various constructs in this context, verified that, for the purposes of this study, it would be appropriate to focus upon the measurement of the psychological variables of perceived pain, social support, psychological distress and quality of life of patients with advanced cancer and to determine the relationships among these variables. This chapter will outline the method of selection of the instruments utilised to measure these variables. It was necessary to select instruments that might facilitate accurate measurement of participants' experiences in the context of cancer and allow statistical analysis to examine the different relationships between variables, i.e. correlational analysis. Thus, where possible, instruments were selected that had already been validated with an adequate sample of people with cancer, as one major problem in conducting research in Ireland is obtaining a sufficiently large homogeneous sample.

The measurement of pain

As discussed in chapter two, it is only recently acknowledged that the concepts of pain and quality of life are closely related (e.g. WHO, 1986). Pain has evolved from a philosophical to a scientific concept that is measurable. However, pain must be approached as a fundamentally subjective state because no satisfactory objective indicators of pain exist (Bonica, 1990). The most valid and reliable assessment of pain is that provided by the patient with pain: 'Pain is what the patient says hurts' (Twycross, 1994).

Therefore, it is necessary to use methods of measurement that are clear, accurate, not too time consuming and readily understood by the patient with pain.

The selection of instruments to measure perceived pain. Pain in cancer can be grouped into four causal categories: caused by cancer itself, caused by treatment, related to cancer and/or debility, or caused by a concurrent disorder (Grond, Zech, Diefenbach, Radbruch & Lehmann, 1996). Cancer patients who do experience pain may have multiple problems associated with pain (McMillan, Williams, Chatfield & Camp, 1988). Clinical pain is a complex phenomenon in which physical sensations, affective factors and cognitive components interact to determine the totality of individual experience (Melzack, 1975). Previous work on pain assessment has been generally restricted to investigations involving the single parameter of perceived pain intensity. Recognition of limitations of this approach has contributed to the long-term goal of developing assessment instruments which tap major pain dimensions and provide adequate between-subject comparison data (Graham, Bond, Gerkovich. & Cook, 1980). During the past decade, and particularly following the introduction and refinement of the Gate Control Theory of Pain (Melzack & Wall, 1965, 1982, 1988), a conceptualisation of pain as a multidimensional, subjective and uniquely personal experience has emerged. Current theories of pain and clinical experience support a multidimensional framework for the experience of pain that has implications for assessment and management in any setting. Six major dimensions have been identified: physiological, sensory, affective, cognitive, behavioural and sociocultural (McGuire, 1992).

The best known multidimensional pain measurement instrument is the McGill Pain Questionnaire (MPQ), the procedures and techniques for which were described initially by Melzack & Torgerson (1971). In the first part of their study, subjects were asked to classify 102 words, obtained from the clinical literature relating to pain, into smaller groups that described different aspects of pain experience. On the basis of the data, the words were categorised into three major classes that described the sensory, affective and evaluative dimensions to the pain experience (Kremer, Hampton Atkinson & Ignelszi, 1981). The second part of the study was an attempt to determine the pain intensities implied by the words within each sub-class. Groups of doctors, patients and students were asked to assign an intensity value to each word, using a numerical scale ranging from mild to excruciating pain. The high degree of agreement on the intensity relationships among pain descriptors by subjects who had different cultural, socio-economic and educational backgrounds, facilitated the development of a pain questionnaire. Major measures derived from the MPQ are the Present Pain Intensity Index and the Pain Rating Index (Graham *et al.*, 1980). The Present Pain Intensity Index is a numerical (1-5) scale, to rate the current intensity of pain. The Pain Rating Index consists of a set of 78 verbal descriptors presented on one page in 20 lists (sub-classes) of 2-6 words each. Each list is arranged in a continuum from low to high intensity. The subject's task is to select one word from each sub-class which is applicable to his or her pain.

In a study by Graham *et al.* (1980), the MPQ was administered to 36 cancer outpatient volunteers to evaluate the efficacy of biofeedback and hypnosis as adjunct training techniques for the management of chronic pain associated with cancer. In examining the statistical relationship between internal MPQ measures, Melzack (1975) reported significant correlations between Present Pain Intensity and all components of the Pain Rating Index. In the study by Graham *et al.* (1980) only the 'affective' and 'evaluative' components of the index significantly correlated with intensity. Attempts by Graham *et al.* (1980) to use the MPQ as a weekly summary measure of pain were not successful. When subjects were divided into high and low pain groups on the basis of their daily home ratings of pain intensity, summary MPQ indices did not reflect this differentiation over two replications. Individual correlational analysis, computed between daily pain intensity and the Total Pain Rating Index measure of the summary MPQ for each week of participation, also failed to show a significant relationship. Finally, when daily home pain intensity was tracked over time for each subject and divided into high and low pain weeks, a significant relationship with summary MPQ measures was found for less than half the group assessed. These results supported Melzack's (1975) contention that the MPQ is best used as a measure of immediate pain. Difficulties were apparent in attempts by subjects to summarise their pain over weekly periods. Firstly, the immediate level of pain experienced by a subject at the time of MPQ administration tended to colour his or her perception of past pain. Secondly, although these subjects were designated as 'chronic pain patients' the pattern in which such pain was manifested differed from subject to subject. A study by

Daut, Cleeland & Flanery (1983) found that the MPQ required more detailed explanation for patient use and some patients were unable to complete it. Melzack's (1975) study demonstrated that perceived pain intensity is multidimensional. (Kremer *et al.*, 1981). Chronic cancer pain is also multidimensional in origin (Twycross, 1997). Cancer pain intensity changes with time and patients' perception of its quality and their ability to endure it also vary (McMillan *et al.*, 1988). Pain is a key component in the quality of life of cancer patients (Morris, Suissa, Sherwood, Wright & Greer, 1986). Therefore, the measurement of pain is essential for the evaluation of methods to control pain (Melzack, 1975) if optimal quality of life is to be achieved.

The length of the McGill Pain Questionnaire and its intended presentation in an interview format led Daut *et al.*, (1983) to design a new pain questionnaire specifically for cancer patients, which incorporated the content areas sampled by the McGill survey and other tools. Originally called the Wisconsin Brief Pain Questionnaire, it is now known as the Brief Pain Inventory (BPI) (Cleeland, 1985). The development of the BPI was guided by several considerations. Since it was to be used to obtain estimates of pain prevalence and severity, it had to be easily administered to large numbers of patients. Thus, it had to be brief, self-administered and easily understood. A competing necessity was that it was able to assess relevant aspects of pain, namely, history, intensity, location, quality, interference with activities and cause. In the BPI, patients are asked to circle a number from zero to ten that signifies the severity of their pain, with zero labelled as 'no pain' and ten labelled 'pain as bad as you can imagine.' Following the pain ratings, patients are asked to report the medications or treatments they receive for pain, the percent relief these medications or treatments provide and patients' belief about the cause of their pain. Finally, patients are asked to rate how much pain interferes with mood, relations with other people, walking ability, sleep, normal work, and enjoyment of life, using a 0 to 4 rating scale. The BPI has demonstrated respectable test-retest item correlation over short intervals of time following administration to two groups of cancer patients: the first group of 20 inpatients with cancer was retested within a week, the second group of 56 patients was retested over several months (Cleeland, 1985). Higher reliabilities were obtained for the pain items when the test-retest interval was short than when the interval was long. Evidence for the validity of the BPI comes from ratings of pain interference with various activities which increased with ratings of pain severity at its worst. In addition, the proportion of patients receiving narcotic analgesics increased as pain ratings increased (Cleeland, 1985).

Pain intensity measurement of any individual patient ideally would address each variable known to influence pain intensity (Kremer *et al.*, 1981). Although such efforts have been made (e.g. Duncan, Gregg. & Ghia, 1978), more often simple measurement devices that are psychometrically sound and not obviously confounded by psychosocial variables are used. The visual analogue scale (VAS) is acknowledged as the best paper and pencil instrument for assessing clinical pain intensity, based on the following findings: (1) patients produce a uniform distribution of pain intensity estimates on a VAS (Huskisson, 1974; Ohnhaus & Adler, 1975); (2) pain estimates on a VAS are reliable over time (Revill, Robinson, Rosen, & Hogg, 1976); (3) variance due to psychomotor factors is small (Revill *et al.*, 1976); (4) the VAS is sensitive to pain change (Clarke & Spear, 1964); and (5) the VAS does not force quantum changes in pain intensity as occur with category scales (Ohnhaus & Adler, 1975). A visual analogue scale becomes a numeric, or equal interval rating scale when numbers are attached. There are several advantages to using an equal interval rating scale, including clearer understanding of the patient's experience, consistency in interpretation and ease of communication between health care professional and patient, as well as among health care professionals (McCaffrey *et al.*, 1994).

Patient-completed visual analogue scales can lead to under-reporting of severity and duration of pain and distress compared to interviewer-completed five-point scales (Lunt, 1984). However, visual analogue scales have been found to be superior to categorical scales in their discriminatory ability (Lunt, 1984). In a study by Kremer *et al.*, (1981) 11% of a chronic pain patient population could not complete a VAS. In their study, patients with chronic pain reported pain intensity on each of three pain intensity scales, the visual analogue, numerical and adjectival scales and then ranked the scales in order of best communication of pain intensity. All patients were able to complete an adjectival scale but 11% were unable to complete a visual analogue scale and 2% failed to complete a numerical scale. The intensity of the pain ratings on the three scales were significantly correlated and there were no reliable differences in reported intensity as a function of preference for scale type. Pain intensity was reliably higher on each scale for depressed-anxious patients as compared to non-depressed/non-anxious patients. Patients completing all three scales indicated a significant preference for the adjectival scale but the basis for this preference did not appear to be related to sex, etiology of pain, affective variables, nor selected psychological variables. These data indicate that pain scale preference does not influence pain intensity reports. A second important finding was that a large and statistically significant percentage of the study population preferred an adjectival scale. The basis for this preference was that patients felt that the adjectival scale best allowed them to express accurately their perceived pain experience.

Pain in the hospice setting is receiving increasing attention from researchers (e.g. Dobratz, Burns, Oden, 1989; Dobratz, Wade, Herbst & Ryndes, 1991) whose collective work has supported the six dimensions of the pain experience. There are two major approaches to the assessment of pain. A unidimensional approach is adopted if the clinician wishes to assess components of only a single dimension such as pain intensity, location or relief, involving physiological and sensory dimensions of pain. Common instruments for this purpose include visual analogue scales, graphic and behavioural scales and verbal descriptor scales. However, in chronic care settings, the affective, cognitive and behavioural dimensions might assume priority, requiring the use of multidimensional instruments in which two or more dimensions of the pain experience can be measured simultaneously, giving more comprehensive information (McGuire, 1992).

An important distinction for measurement purposes is that between affect and cognition (e.g. Veenhoven, 1984). Affect refers to an emotional phenomenon (e.g. positive/negative feeling) and cognition refers to rational appraisal (e.g. evaluation). Cognition may be more stable than affect and less sensitive to changes in life circumstances (Headey, Holmstrom, & Wearing, 1984; de Haes, de Ruiter, Tempelaar & Pennink, 1992); both are impaired in patients with cancer (de Haes *et al.*, 1992). Factors contributing to cognitive deficit in cancer patients are memory deficits as a result of the trauma of diagnosis, high pain levels and associated anxiety and depression (Mermelstein, & Lesko, 1992; Breitbart, 1994; Cull, Hay, Love, Mackie, Smets & Stewart, 1996). These deficits are exacerbated by the existence of a high percentage of elderly people in this patient population (Yancik

& Ries, 1994; Redmond & Aapro, 1997), with accompanying cognitive and neurological deficits as a consequence of ageing (Lubinski & Welland, 1997).

Brevity and accuracy of pain measurement were important considerations in the present study which utilised a lengthy questionnaire with participants, approximately 30% of whom were receiving chemotherapy, approximately 50% of whom were receiving radiotherapy and approximately 5% receiving a combination of both when interviewed. Both treatments are likely to result in patients experiencing physical discomfort at some level (e.g. Selby, 1993; Skeel & Lachant, 1995). In an attempt to get an accurate evaluation of pain intensity together with an affective assessment of pain experience, a shortened version of the BPI was chosen and combined with an adjectival scale as used in the MPQ. As noted above, intensity estimates with this combination have been shown to be significantly correlated (Kremer *et al.*, 1981). The aim of this combination was to allow an evaluation of participants' present and average pain intensities using equal interval rating scales, and an estimate of their global pain experience by using an adjectival scale. Participants were asked to relate their average and global pain experience in terms of that experienced in the month prior to the study. An important factor in the present study, with regard to the experience and measurement of present pain, is that participants were in the advanced stage of their disease. Many were receiving chemotherapy and/or radiotherapy as methods of tumour reduction and pain control. Therefore, at the stage where any given participant completed the questionnaire, frequently, but not always, the participant's present experience of pain would be less than that experienced in his or her very recent past.

The measurement of psychological distress and perceived loss

As discussed in chapter five, spirituality may be broadly defined as the essence or life of a person (e.g. Conrad, 1985). Crisis often prompts a search for meaning and purpose in life (Granstrom, 1985). Saunders (1967) put forward the concept of total pain, a holistic view in which physical, psychological, social and spiritual pain were combined with major implications for the quality of life of the person with advanced cancer. Spiritual distress characterised by loneliness, despair, grief and loss of the future may affect the quality of life of patients with advanced cancer (Kahn & Steeves, 1993; O'Connor, Wicker &

Germino, 1990, Ferrell *et al.*, 1995). As described in chapter three, for many people the diagnosis of cancer or the discovery of recurrence is a catastrophic event and individuals may respond with symptoms of severe anxiety and depression. The etiology of psychological distress results from a combination of medical, social and psychological factors (Mermelstein & Lesko, 1992). As outlined in chapter two, Zimmerman *et al.*, (1996) found that cancer patients with pain had higher anxiety and depression scores than cancer patients without pain. The psychological effects of pain include anxiety, depression, a sense of loss and a feeling of diminished usefulness, increased fear and diminished coping (e.g. Ferrell, 1995).

The experience of loss. Many of cancer's psychological effects can be understood in terms of reactions to loss, or the threat of loss in the future. The types of losses experienced by patients with cancer include losses related to: well-being, physical strength, independence, role, activity, interpersonal relationships, sexual function, physical integrity, life expectancy, control and mental integrity (Barraclough, 1994). Associations are reported frequently among pain, functional disability and symptoms of depression (Williamson & Schulz, 1995). A study by Mor (1987) suggested that the dominant factor constraining the range of human psychosocial functioning was physical condition.

Loss of physical strength and well-being causes greatest disruption, even in the early stages of illness, to patients with manual jobs, those who need strength for day to day activities such as parents with young families, as well as those who practice physical fitness and other energy-requiring activities. Loss of independence brought about by enforced inactivity results in severe frustration for most patients with cancer, with anxiety or guilt about being a burden to relatives or staff, compounding distress. Not being able to drive the car is perceived as a loss and increases the sense of enforced restriction of activity already imposed by the symptoms of cancer. Loss of role can lead to boredom and perhaps cause friction with other people who have had to take over the patient's former duties (Barraclough, 1994). Longitudinal analysis of a study by Williamson & Schulz (1995) revealed that, as pain increased over time, so did activity restriction, which in turn predicted increases in depressed affect. As the present study aimed to examine the effects of perceived pain on psychological distress and quality of life, and these variables are inclusive of spiritual well-being (e.g. Ferrell *et al.*, 1995), it was decided to focus on losses perceived as most salient by the participants in the present study. Participants were asked to rate how each loss variable affected them, in the context of their having cancer, according to a Likert-type scale, i.e 'not at all,' 'a little', 'quite a bit 'or 'very much'.

Selection of instruments to measure psychological distress. A large range of quantitative questionnaires is available for measuring some aspects of the quality of life of patients and a much smaller number of methods which have been developed specifically for QoL measurement in cancer patients. The Medical Research Council Working Party (Maguire & Selby, 1989) evaluated global measures, performance indices, scales measuring several dimensions and scales measuring a single psychological dimension. Conclusions of this group were that the current 'best-bet' for tapping key dimensions of quality of life is the Rotterdam Symptom Checklist (RSCL) which is considered to be a good, clear and simple questionnaire which has been validated against independent interviews and found to have high sensitivity and specificity in measuring the psychological dimensions of QoL. The Hospital Anxiety and Depression Scale (HAD Scale) appears to be particularly useful in assessing levels of anxiety and depression in cancer patients (Selby, 1993).

As the present study already includes measures of aspects of three main domains of quality of life, i.e. physical (perceived pain), social (support of family friends and health care professionals) (e.g. Selby, 1993; Ferrell *et al.*, 1995) and spiritual well-being (loss and meaning in cancer (Barraclough, 1994), the HAD Scale (Zigmond & Snaith, 1983) and the psychological sub-scale of the RSCL (de Haes, van Knippenberg & Neijt, 1990) were selected as measures of psychological distress (e.g. Ferrell, 1995; Holland, 1997). Emotional well-being is an independent factor determining quality of life for patients with cancer (Bliss, Selby, Robertson & Powles, 1992). The screening of patients with cancer for psychiatric morbidity by using psychometric questionnaires is more difficult than for other diseases because many methods draw upon the somatic symptoms of psychiatric illnesses to identify the diagnosis and quantify severity. A good example is the weight loss commonly associated with depression. Somatic symptoms are frequently manifestations of the physical disorders associated with cancer when it is advanced. The value of many psychometric questionnaires is therefore limited in patients with cancer and those which, like the HAD Scale (Zigmond & Snaith, 1983) seek to avoid the use of somatic symptoms are especially valuable (Selby, 1993). The most commonly encountered emotional disorders in patients are anxiety and depression which frequently co-exist. The HAD Scale is a brief self-administered rating scale which has been specifically designed for patients with physical illness (Zigmond & Snaith, 1983). It consists of 14 items, seven regarding depression and seven related to anxiety. The depression sub-scale has been constructed so that somatic items are largely excluded. The sub-scale heavily emphasises anhedonia, which is considered by some to be the symptom of depression characteristic of the endogenous subtype and predictive of response to antidepressant medication (Klein, 1974). The items on the anxiety sub-scale were chosen by Snaith, Baugh, Clayden, Hussain & Sipple (1982) from anxiety items in the Present State Examination (Wing, Cooper & Sartorius, 1974) and from Snaith's own research.

Reliability for the sub-scales was established by Zigmond & Snaith (1983). Following the accumulation of data on 50 patients, the internal consistency of the two sub-scales was examined by calculating correlations (Spearman) between each item and the total score of the remaining items in the sub-scale. For the anxiety items the correlations ranged from 0.41 to 0.76 and the significance of these was $p < 0.01$. Items in the depression scale had correlations ranging from 0.30 to 0.60, all significant beyond $p < 0.02$. For the depression and anxiety sub-scales, it was found that a score of 7 or less for non-cases, scores of 8-10 for doubtful cases and scores of 11 or more for definite cases, produced the best results. In order to test the reliability of these findings, the same criteria were applied to the data of the next fifty patients yielding similar results. In order to determine whether scores on the two sub-scales could also be used as indications of the severity of depression and anxiety respectively, correlations (Spearman) of the sub-scale scores and the psychiatric ratings were calculated; the results of this were $r = 0.70$ for depression and $r = 0.74$ for anxiety, $p < 0.001$.

Evidence for the concurrent validity of the HAD Scale has been established in a number of studies including that by Bramley, Easton & Morley & Snaith (1988) which differentiated between anxiety and depression in a group of patients with psychiatric morbidity. Clinical experience of patients and physical illness suggests that it is frequently difficult to distinguish between anxiety and depression. On the basis of factor analysis of the data in a study of Belgian cancer patients, Razavi, Delvaux, Farvacques & Robaye (1990) concluded that the HAD Scale was a unidimensional measure of emotional distress. However, Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss (1991) described the factor structure of the HAD Scale in a study of 568 cancer patients, which was the first detailed analysis of the scale to be reported with any substantial group of patients. Factor analyses were performed on the full 14-item HAD Scale and on the two seven-item sub-scales separately. Using the BioMedical Data Package (BMDP, 1988), Pearson product-moment correlation coefficients were computed and a principal-component procedure used to extract the initial factors, prior to rotation. Because of the considerable debate over whether anxiety and depression exist as separate entities, it was considered important to compare the two rotation procedures. Complete sets of HAD Scale scores were available for 568 patients and factor analyses were carried out on these. Following an orthogonal rotation, the anxiety and depression items loaded on separate factors, but there was a finding of 0.50 when an oblique rotation was performed. This method of rotation was used for the rest of the study to test the stability of the factor structure. In order to test the stability of the factor structure obtained, further analyses of two subsamples were carried out. The sample was split into two halves and factor analyses were then performed on these two subsamples. Separate factor analyses were performed on the data from male and female subjects to establish the factor stability across sexes. Principle-component analysis consistently extracted two factors in both the full sample of 568 patients and in the subsample, supporting the view that in the group of cancer patients studied, the HAD Scale is bidimensional, tapping the separate but related constructs of anxiety and depression.

The Rotterdam Symptom Checklist (RSCL) (de Haes, van Knippenberg & Neijt, 1990) is a self-rating scale developed for assessing QoL among cancer patients. It may also be used to monitor levels of patient anxiety and depression, reflecting the presence of psychological illness (Trew & Maguire, 1982). It has one psychological and four physical symptom sub-scales on a four-point Likert scale, from ‘not at all’ to ‘very much’. Watson, Law, Maguire, Greer, Bliss, & Ibbotson. (1992) tested the validity of the RSCL with a group of patients with cancer selected because they showed evidence of psychological morbidity. Alpha coefficients were calculated in this sample for the psychological and combined physical sub-scales and were 0.86 and 0.77 respectively, confirming good overall reliability. The ability of the RSCL to pick up psychological symptoms was tested by examining for any correlations with scores on the HAD Scale. The validity of the RSCL was indicated by a highly significant positive association between RSCL psychological symptoms and HAD Scale anxiety (0.74, $p < 0.001$) and HAD Scale depression (0.52, $p < 0.001$) sub-scales. The RSCL physical symptoms scores were also significantly positively associated with HAD Scale depression (0.40, $p < 0.001$) scores. Some of this overlap may be accounted for by physical symptoms of cancer which are sometimes also evident in depressed patients (e.g. insomnia and lack of energy) (Watson *et al.*, 1992).

The structure of the RSCL and its stability had been investigated by de Haes, van Knippenberg & Neijt (1990) in three studies involving cancer patients. Following the first two studies of patients with cancer four factors were found. The first factor included psychological items in the RSCL, the second factor concerned somatic pain experience, the third referred to gastrointestinal symptoms and the fourth to the experience of fatigue and malaise. Based on these results, sub-scales were defined in relation to psychological distress, pain, gastrointestinal symptoms and fatigue and proved to have good reliabilities as indicated by Cronbach's alphas of 0.94, 0.81, 0.88 and 0.72, respectively. Following the findings in the first two studies, the RSCL was revised and after a third principal component analysis, psychological and physical distress sub-scales were constructed which showed good reliability as indicated by Cronbach's alphas of 0.88 and 0.82, respectively.

Plumb & Holland (1977) suggest that the physical symptoms that usually accompany psychological morbidity have a different meaning for patients with cancer as these symptoms are probably related to the disease or are an effect of the cancer treatment. Therefore, they should not be included in instruments designed to measure anxiety and depression. Thus, only purely psychological items should be included in the psychological distress sub-scale of the RSCL. These are irritability, worrying, depressed mood, nervousness, desperate feelings about the future, tension, anxiety and difficulty in concentrating. Reliability analysis indicated that the alpha of this scale in the third study was 0.89 (de Haes *et al.*, 1990).

In a study by Hopwood, Howell & Maguire (1991), two hundred and four patients with advanced breast cancer completed the HAD Scale and the RSCL. Eighty-one of these patients were recruited to determine how well the two questionnaires identified depressive illness and anxiety states in patients with advanced cancer of the breast. The order in which these questionnaires were completed by patients was balanced so that they were equally represented in first and second positions. In total, 44 patients out of the 81 recruited had a high score on either the HAD Scale or the RSCL or both. Consecutive patients with a high score on either questionnaire were asked if they were willing to be interviewed for the research by a psychiatrist for a comparative assessment. The interviews were conducted by a psychiatrist who was blind to the questionnaire scores, using the Clinical Interview Schedule (Goldberg, Cooper, Eastwood, Kedward & Shepherd, 1970) with additional questions, in order to apply standardised psychiatric diagnostic criteria for anxiety and depression (DSM III). The sensitivity (false negatives) and specificity (false positives) were calculated for the HAD Scale anxiety and depression sub-scales and the RSCL psychological distress sub-scale, using both the recommended threshold score (11) and a range of alternative cut off scores (Hopwood *et al.*, 1991). Sensitivity and specificity values were then recalculated using weighted values in the 204 out-patient attendees who completed both questionnaires. Whilst the specificity remained relatively unchanged, the sensitivity of the HAD Scale improved from 75% to 81% and that of the RSCL fell from 75% to 71%.

The accuracy of a screening instrument is also dependent upon its positive predictive value (Vecchio, 1966), that is, the probability of an individual with a high score being a true psychiatric case (Hopwood *et al.*, 1991). The positive predictive value for the RSCL was 55.6% and for the HAD Scale it was 49.6%. The positive predictive value for the anxiety sub-scale was 56.3% and that for the depression sub-scale 42.9%. The negative predictive values were also calculated, the RSCL being 80.3% and the HAD Scale 82.7%. In other words, both questionnaires, used as screening instruments, would correctly identify one in every two high scores as a case and have a relatively low risk of misclassifying a low score as a case. The ability of the HAD Scale to accurately detect anxiety cases is high but its ability to detect depression more modest (Hopwood *et al.*, 1991). This is important because, as Chapman (1979) states, depression is the most common emotion found in cancer patients.

When screening for illness, it is desirable to achieve a 100% detection rate. Whilst this can be achieved with the HAD Scale and RSCL, it is only at the expense of including a high proportion of false positives which could create an unacceptable interview load. In clinical practice, patients with high scores warrant further assessment by a brief interview, as it is possible to discriminate true cases from false positives on this basis. The optimal sensitivity is aimed at identifying an acceptable balance in terms of accuracy and clinical feasibility. An instrument with good predictive power is very valuable, since it will reduce the interview load. The RSCL was superior to the HAD Scale in this regard. Whilst the HAD Scale is short and capable to an extent of discriminating between anxiety and depression, the RSCL is also short, taking less than 10 minutes to administer and has demonstrated itself to be more useful in reducing interview time (Hopwood *et al.*, 1991).

The Courtauld Emotional Control Scale (CECS) (Watson. & Greer, 1983) was developed to evaluate the extent to which an individual reports controlling anger, anxiety and depressed mood. Scale items were derived from responses to semi-structured clinical interviews with patients who were awaiting breast biopsy. In order to comprise three sub-scales, each with the same number of items, the seven items with the highest loadings on each sub-scale were included in the final version of the questionnaire. The internal consistency of the scale was measured by examining item remainder and item total correlations for the 21 items making up the three sub-scales. The item remainder correlations indicated that each sub-scale had good internal consistency. There were significant inter-correlations between items on different sub-scales, suggesting that the dimensions measured by the sub-scales were not entirely independent but that a total emotional control score summing across the sub-scales could be obtained. The stability of subjects' responses were evaluated by correlating the scores on the initial administration with those obtained in re-administering the scales three to four weeks later. These correlations were: anger $r=.86$, $p<0.001$; anxiety $r=.84$, $p<0.01$; depressed mood $r=.89$,

$p<0.001$ and total CECS score $r=.95$, $p<0.001$. Thus the questionnaire has relatively good test-retest reliability. The final 21-item form of the CECS was administered to two separate samples along with other widely used personality measures, in order to test its concurrent validity and demonstrated that as a whole it measures a general tendency to report controlling emotional responses. Face validity for the CECS was provided by significant inverse associations with the Bortner Scale, the latter measuring type A behaviour, a component of which is the inability to control emotional outbursts. These correlations were anger $r=-.34$, $p<0.05$, anxiety $r=-.42$, $p<0.01$, depressed mood $r=-.57$, $p<0.001$, total score$=-52$, $p<0.01$, indicating that subjects low on emotional control were high on type A behaviour (Watson & Greer, 1983). The CECS includes a measure of control of anger and was included in the study to investigate whether age and gender of participants might influence their control of emotion which, in turn, might possibly impact upon their experience of psychological distress. Feelings of anger may be associated with the trauma of a diagnosis of cancer, and as a consequence of a sense of loss of control and associated feelings of vulnerability and loss of self-esteem (Mermelstein & Lesko, 1992; Burton & Watson, 1988).

The measurement of coping in the context of cancer

As outlined in chapter three, Lazarus & Folkman's (1984) process model of coping has implications for behaviour change because people who employ so-called negative coping mechanisms can be helped to change maladaptive behaviour by changing their way of thinking (Watson, 1999). In the context of illness, this has implications for quality of life which may be partly determined by the way in which a person copes with illness (Weisman, 1979). de Haes *et al.*, (1992) reported that patients with cancer who are able to adjust are best able to maintain their quality of life (Bowling, 1995a).

The selection of an instrument to measure coping. The Mental Adjustment to Cancer scale (MAC) (Watson, Greer, Young, Inayat, Burgess, Robertson, 1988b) was utilised as a measure of coping attitudes in the present study. The MAC scale (Watson *et al.*, 1988b) assesses psychological adjustment to cancer and consists of 40 items scored on 4-point Likert scales. There are five factor-analytically-derived sub-scales:

(1) Fighting Spirit (sixteen items): assesses an optimistic attitude in which the patient views the disease as a challenge.

(2) Helplessness/hopelessness (six items): the patient feels engulfed by the disease and thoughts of dying from the disease.

(3) Anxious Preoccupation (nine items): a reaction of persistent anxiety marked by a monitoring of physical sensations as probable signs of recurrence.

(4) Fatalism (eight items): the diagnosis is acknowledged by the patient but with a resigned or fatalistic attitude.

(5) Avoidance (one item): the patient is eager to put the disease behind him or her and to get on with life by minimising or denying the seriousness of the disease (Edmonds, Lockwood & Cunningham, 1999).

The MAC scale was developed by Watson *et al.* (1988b) as a measure of responses to cancer which could be used to help clarify the relationship between types of coping responses and attitudes, and level of psychological distress (e.g. Seligman, 1975; Lazarus, 1981; Lazarus & Folkman, 1984; Watson *et al.*, 1988b). The MAC scale was developed from interviews with patients with breast cancer and lymphomas. Items were selected which focused on four response categories. These were described as fighting spirit, stoic acceptance, helpless/hopeless and denial. A total of 58 items were selected and these were balanced, as far as possible, over the four dimensions mentioned. All items were based directly on statements made by patients and were rephrased, where necessary, to make them appropriate to the questionnaire format. The aim was to select from the pool of 58 questionnaire items those which best determined the response categories previously described, resulting in a questionnaire which could be given to patients with any type or stage of cancer, the only constraint being that the patient should have been informed of his or her diagnosis. This was necessary to be able to refer to their diagnosis of cancer, as their reactions to cancer were of main interest and also because denial or avoidance responses could not be measured in those patients where there was any degree of uncertainty about their knowledge or diagnosis. The internal consistency of the sub-scales was measured by examining item remainder and item total correlations. The results showed that each sub-scale was homogeneous with significant correlations between items and the following sub-scale totals: fighting spirit, 0.84; anxious preoccupation, 0.65;

fatalistic, 0.65 and helpless, 0.79. Watson *et al.* (1988b) considered that a rating by the patient's spouse or partner would provide some evidence on the validity of the MAC scale. Intercorrelations between partner and spouse ratings were all highly significant, except avoidance which consisted of only one item (fighting spirit, 0.76, p<0.001; anxious preoccupation, 0.63, p<0.01; fatalism, 0.63, p<0.01; helpless, 0.66, p<0.001 and avoidance, 0.34). Stability of responses was tested on a small sub-sample who completed the scale on two occasions, when they were out of active treatment for their cancer. The results indicated that all MAC scale scores were consistent across the two occasions and were significantly correlated (fighting spirit, 0.52, p<0.001; anxious preoccupation, 0.56, p<0.001; fatalism, 0.38, p<0.02; helpless/hopelessness, 0.65, p<0.001 and avoidance, 0.41, p<0.02).

The measurement of social support

As stated in chapter four, the conceptualisation of social support both as fulfilment of on-going social needs and as assistance when faced with life stressors, emphasises the importance of relationships with others for emotional and psychological well-being. In the literature a core set of functions served by relationships appears recurrently, which includes emotional, esteem, information support and tangible assistance.

Social support as a multidimensional construct. At present the concept of social support is considered multidimensional and both functional and network properties are important (Norbeck *et al.*, 1981; Neuling & Winefield, 1988). Thus, social support can be defined as either the fulfilment by others of basic ongoing requirements for well-being or, the fulfilment of more specific time-limited needs that arise as the result of adverse life events or circumstances (Cutrona, 1996).

The selection of an instrument to measure social support. The Multi-Dimensional Support Scale (MDSS) (Neuling & Winefield, 1988) specifies the source, type and frequency of support received from family members, close friends and health care professional and includes, as a measure of subjects' satisfaction, recipients' rating of adequacy of each behaviour from each person. In order to encompass the multidimensionality of social support, the MDSS includes four aspects. The first is emotional support, which involves closeness with others in an environment of acceptance or love (the MDSS includes four relevant items: encouraging a person to talk about his or her illness, illness experience, listening carefully to a person and [family and friends only] making him or her feel loved). The second is informational support, which allows for organisation of thoughts and provides a framework for appraisal (the MDSS includes four relevant items: offering advice about how a person can help themselves, suggesting ways of a person looking at his or her illness, offering advice about treatments available and what to expect). The third aspect is tangible support, which involves direct aid (family and friends only) (the MDSS includes two relevant items: provision of help with child-care, transport and household chores, as well as taking over the duties of the ill person and doing everything for them. A third item was added for the present study: help with arrangements that are required as a consequence of a person's illness). The fourth aspect is reassurance, which leads to increased confidence (the MDSS includes two relevant items: trying to reduce a person's anxiety by telling him or her everything would be all right and telling jokes and chatting as distraction). The MDSS measures the frequency with which each type of support is given, i.e. 'never,' 'sometimes' or 'often', by each source and, on a separate scale, perceived recipient satisfaction with frequency as 'less often,' 'more often, or 'satisfied'. This enables a distinction to be made between quantity and quality of social support, so that it can be determined how much of each type of support is seen as supportive from each source.

In the initial preparation of the MDSS by Neuling & Winefield (1988), as a validity check, a significant other, usually the patient's spouse and always someone living in the same house, was asked for his or her opinion of the subject's physical and social adjustment one month after surgery for breast cancer, using the same questions and scales as given to the subjects 2-7 days, one month and three months post-surgery. The SPSSx program 'Reliability' was utilised to calculate Cronbach's alphas which demonstrated high internal reliability of the MDSS. It was not appropriate to do test-retest reliability, as it was expected that subjects' emotional and physical state would change considerably between hospitalisation and the follow-up interview a month later.

The MDSS was selected as a measure of social support for the present study for the following reasons. Firstly, it has been validated for use with patients with cancer. Secondly, it measures both received and perceived social support. In general, measures of received support correlate less strongly with physical and mental health outcomes than do measures of perceived social support (Wethington & Kessler, 1986). Thirdly, both prevalent concepts of social support as (1) pertaining to ongoing relationships, and (2) as transactions that occur after the onset of adverse circumstances, are of significance in the oncology setting. This is because a significant percentage of cancer patients suffer prolonged anxiety and depression as a consequence of the uncertainty, trauma and pain that is associated with cancer as an illness, especially in the advanced stages of the illness (Mermelstein & Lesko, 1992). The MDSS is able to determine the level of satisfaction and dissatisfaction with ongoing long-term support relationships and the level of satisfaction and dissatisfaction with the amount of support afforded by health care professionals, presently caring for the patient during his or her cancer illness. This is central to the main hypothesis of the present study which states that patients with high pain experience are more likely to perceive a support deficit somewhere in their social network compared with patients with low pain, regardless of the level of actual support received. The study by Neuling and Winefield (1988) utilised the MDSS to evaluate received and perceived support the month preceding and three months following surgery for breast cancer. The present study utilised the MDSS to evaluate received and perceived support in the month prior to the study.

Summary

In total, seven scales were selected as shown in the summary below. A major advantage for the present study is that all the scales selected had been validated with populations of people with cancer. The issues involved in the measurement of the various domains of quality of life for people with cancer are complex and varied. Ideally, a more individually oriented quality of life assessment tool such as the SEIQoL developed by O'Boyle *et al.* (1992) would permit a detailed analysis of each participant's experience of cancer, but was impracticable for the present study. The Cancer Locus of Control Scale (Watson, Greer, Pruyn & van den Borne, 1990) was considered but subsequently not used. One reason for this was that the questionnaire was found to be too long during the pilot study. The length of the finished questionnaire was considered as possibly problematic for some participants and this point required consideration when deciding which measures were to be used in the study.

Summary of scales selected for the study.

Scale	Abbrev.	Authors	Variables Measured
The Brief Pain Inventory; Equal Interval Rating Scales	BPI	Daut, Cleeland & Flanery	present & average pain; percentage pain relief
The McGill Pain Questionnaire; Adjectival Scale	MPQ	Melzack	overall evaluated pain
The Multi-Dimensional Support Scale	MDSS	Neuling & Winefield	received and perceived informational, emotional, tangible and reassurance support
The Mental Adjustment to Cancer Scale	MAC scale	Watson *et al.*	coping attitudes
The Hospital Anxiety and Depression Scale	HAD Scale	Zigmond & Snaith, Moorey *et al.*	anxiety and depression
Courtauld Emotional Control Scale	CECS	Watson & Greer	control of anger, anxiety and depressed mood.
The Rotterdam Symptom Checklist	RSCL	de Haes *et al.* Watson *et al.*	psychological distress

METHODOLOGY

Aim. The study aimed to explore the relationships between perceived pain, social support, psychological distress, coping and quality of life in a group of patients with advanced cancer who were receiving palliative treatment and/or care. It was hypothesised that, as a function of perceived pain, the coping ability of patients with advanced cancer would be impaired, resulting in increased psychological distress and a perception of inadequate social support.

Design. The study was a cross-sectional survey, using an adventitious sample. The researcher employed a structured questionnaire with quantitative elements, permitting correlational analysis of ordinal variables, as well as a qualitative element.

Participants. To meet ethical requirements, explicit approval to proceed with the study was obtained from the Medical and Nursing Directors of an oncology centre and a hospice located in Dublin. Permission to interview patients with advanced cancer was sought through each patient's consultant or senior registrar in the oncology centre and the sister-in-charge of the day-care centre at the hospice. The researcher sought, through the nursing staff, to interview patients receiving palliative care who were either (1) attending the hospice day-care centre; (2) who were inpatients in the oncology centre, or (3) who were attending the palliative care clinic, radiotherapy centre or chemotherapy day-ward as outpatients at the oncology centre. The researcher was permitted to read patients' medical notes, and each potential participant was carefully screened to ensure that patients with a known medical history of severe depression prior to being diagnosed with cancer and patients with cerebral tumours and known cerebral metastases were not included in the study. The researcher requested the participation of adult male and female patients, aged over 18 years, who were undergoing palliative treatment and/or care and who were aware of their cancer diagnosis, but not necessarily of their prognosis. The decision about a participant's inclusion in the study depended upon an initial selection by the researcher, by reading patients' medical records. This was followed by the researcher checking with a senior member of each patient's medical team to ensure that the patient's medical status was palliative and that he or she was aware of his or her diagnosis. The researcher strove to convey the (true) impression that she was independent of all other teams or disciplines within the two locations of the study.

Procedure: Patients were approached individually by the researcher and the purpose of the study was briefly explained to them in the following manner:

> *My name is Shelagh. I'm a nurse doing a research project about the kind of support people who have cancer at an advanced stage feel would be most helpful to them. I'll just explain very briefly what the study is about and then I will ask you if you would like to participate. The project aim is to find out how nurses can best help people with advanced cancer to feel supported and help lower their feelings of distress. As you know, it can be extremely helpful to talk to someone caring and understanding when you are sad or distressed. The object is to try to find out if there are certain types or ways of giving support to persons with advanced cancer that could be more meaningful for people, which would help them to feel that their situation is really appreciated and help to reduce their feelings of distress.*

Care was taken by the researcher to ensure that patients who were approached were reassured that participation was strictly optional and that they had a right to withdraw from the study at any time. Approximately 60% of patients approached, a total of 98 patients, consented verbally to participate. A large proportion of the 40% who did not take part felt too unwell to do so. It is not possible at this stage to state whether the 40% who declined to participate differed from the study population on socio-demographic variables. However, it seems likely that it was the severity of their illness that mainly differentiated the two groups.

The initial intention of the researcher to obtain a study sample of a minimum of 100 participants was modified by a number of circumstances. Firstly, many participants fitting the inclusion criteria were not feeling well enough to participate, and some were too distressed to do so. Secondly, at the time the study was carried out, limited counselling services were available to patients with cancer at the oncology centre. The researcher found that administration of the questionnaire frequently prompted participants to begin to release pent-up distress and to seek emotional support. At times this resulted in interviews that were much longer than the researcher had anticipated. The researcher allowed time to establish rapport with, and to be sensitive to the needs of, each participant. Thirdly, some families were reluctant to allow their close relative, especially an older parent, to be told he or she had cancer; and at times some consultants were also reluctant to disclose the truth, lest the patient be very distressed and unable to cope. Thus, the screening process required much time and communication between the researcher, hospital health professionals and participants. As a result of these factors, not more than three participants could be interviewed each week during a nine-month period commencing in September1995. In June 1996, the researcher found the time allowed for the study curtailed by factors beyond her control in the oncology centre. Recruitment of patients to the study during the early summer period had also slowed down considerably. Following consultation with the director and supervisor of the project it was agreed to terminate the research data collection at the end of June 1996.

Measures. The following instruments were used to measure perceived pain, social support, coping attitudes, psychological distress and emotional control:

(1) Equal interval rating scales were used to rate perceived present and average (in the past month) pain intensity on a scale from zero (no pain) to ten (pain as bad as you can imagine), as in the Brief Pain Inventory (Daut, Cleeland & Flanery, 1983; Cleeland, 1985). An adjectival scale, as used in the McGill Pain Questionnaire (Melzack, 1975), evaluated global, overall pain experienced in the past month from 'no pain' to 'excruciating pain.' Participants were asked what medication/treatment they were currently receiving for pain and to indicate, on an equal interval rating scale, with zero representing 'no relief' and one hundred representing 'complete relief', what percentage pain relief their present pain medication/treatment provided for them. Other elements of the Brief Pain Inventory were excluded as they were not specific to the present study.

(2) The Multi-Dimensional Support Scale measured received and perceived informational, emotional, tangible and reassurance support given by each participant's family, friends and health care professionals (Neuling & Winefield, 1988).

(3) The Mental Adjustment to Cancer Scale measured each participant's coping attitudes (Watson, Greer, Young, Inayat, Burgess & Robertson, 1988b).

(4) The Rotterdam Symptom Checklist sub-scale (de Haes, Van Knippenberg & Neijt, 1990; Watson, Law, Maguire, Greer, Bliss & Ibbotson, 1992) measured psychological distress.

(5) The Hospital Anxiety and Depression Scale measured anxiety and depression as a measure of psychological distress (Zigmond & Snaith, 1983; Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss, 1991).

(6) The Courtauld Emotional Control Scale (CECS) evaluated the extent to which an individual reported controlling anger, anxiety and depressed mood (Watson. & Greer, 1983).

(7) Each participant was asked to describe his or her sense of physical restriction, social deficit, loss of physical strength, role and independence and overall perceived loss since learning of his or her diagnosis of cancer (Barraclough, 1994). These were the loss variables most frequently selected by participants when asked during a pilot study (cf. page 183) to describe the most salient losses experienced by them as a result of having cancer. Participants were asked to rate, according to a Likert-type scale, their perception of each type of loss, i.e. either 'not at all', 'a little', 'quite a bit' or 'very much'.

The rationale for the selection of these instruments was fully discussed in Chapter 7.

The questionnaire included the following qualitative section in which participants were asked:

(1) which type of social support they found most meaningful.

(2) to describe what changes having cancer had made to their lives; their comments were recorded verbatim by the researcher.

Hypotheses. In pursuit of the already stated aim of the study, the following hypotheses were generated:

(1) Average pain intensity is positively associated with (a) received support, (b) psychological distress, (c) perceived loss, and (d) coping deficit, and negatively associated with (e) perceived support in patients with advanced cancer.

(2) Average pain intensity rated as moderate to high is positively associated with (a) received support, (b) psychological distress, (c) perceived loss, and (d) coping deficit, and negatively associated with (e) perceived support in patients with advanced cancer.

(3) Present pain intensity is positively associated with (a) received support, (b) psychological distress, (c) perceived loss, and (d) coping deficit, and negatively associated with (e) perceived support in patients with advanced cancer.

(4) Overall evaluated pain experience is positively associated with (a) received support, (b) psychological distress, (c) perceived loss, and (d) coping deficit, and negatively associated with (e) perceived support in patients with advanced cancer.

(5) Within the over-59-years old group, the older patients are, the more likely they will be to (a) receive insufficient support from their social network, (b) perceive a support deficit, (c) experience psychological distress, (d) perceive loss, (e) report coping deficit, and (f) report that they suppress emotions.

(6) Within the under-60-years old group, the younger patients are, the more likely they will be to (a) receive insufficient support from their social network, (b) perceive a support deficit, (c) experience psychological distress, (d) perceive loss, (e) report coping deficit, and (f) report that they do not suppress emotions.

(7) Gender will influence (a) the provision and (b) the perception of social support, (c) the experience of psychological distress and (d) the perception of loss, (e) coping attitudes and (f) suppression of emotions in people with advanced cancer.

(8) Satisfaction with overall perceived support from (a) family, (b) friends and (c) health care professionals is associated with the use of positive coping mechanisms by patients with advanced cancer.

(9) Satisfaction with overall perceived support from (a) family, (b) friends and (c) health care professionals is negatively associated with (i) psychological distress and (ii) perceived loss in patients with advanced cancer.

It was hoped that the findings related to the above nine hypotheses might clarify the following issues:

(a) Does the person with advanced cancer who is experiencing pain perceive a support deficit?

(b) If yes, is a perceived support deficit specific?

(c) Does the person with advanced cancer who is experiencing pain also experience psychological distress and loss?

(d) Can psychological distress be mediated by social support?

(e) If yes, is a specific type of support required?

(f) Is the support required from a specific person in the social network of the person?

(g) Does the person with advanced cancer who is experiencing pain also experience a coping deficit?

(h) Can coping be mediated by social support?

(i) If yes, is a specific type of support required?

(j) Is the support required from a specific person in the social network of the person?

(k) Are answers to the above questions modified in the context of the experience of high pain by patients with advanced cancer?

(l) Do age and gender influence the provision and perception of social support, and the experience of psychological distress, loss and coping deficits?

(m) Does satisfaction with overall perceived support from family, friends and health care professionals facilitate coping, and mitigate psychological distress and loss in patients with advanced cancer?

Procedure. As a pilot study, a questionnaire comprised of the scales and qualitative section previously described was administered to six participants, utilising the same procedure as outlined below. However, the questionnaire was too time consuming for the comfort of the participants. The Cancer Locus of Control Scale (Watson *et al.*, 1990) was, therefore, not included in the main study on the basis that, although relevant to the study, some items in it were disliked by participants and the other measures appeared more essential for the major research questions. Participants were asked to clarify how cancer had contributed to their experience of a range of loss items frequently experienced by people with cancer (Barraclough, 1994). Loss items that appeared to be the most salient and meaningful to participants in their day-to-day experience with the disease of cancer were physical restriction and loss of: (i) physical strength, (ii) independence and (iii) role, as well as social deficit. Therefore, these items were included into the main study and rated according to a Likert-type scale from 'not at all' to 'very much'. Data from the pilot study were incorporated into the main study as no further changes needed to be made to the questionnaire design.

Main study. The researcher administered the questionnaire personally to each participant. The first page of the questionnaire contained questions pertaining to socio-demographic information. The researcher sought information about each participant's diagnosis and stage of disease from his or her medical records in the oncology centre. Information regarding each participant's site of diagnosis of primary cancer was conveyed to the researcher verbally by a member of the nursing staff in the hospice. Some participants chose to fill in the questionnaire themselves in the researcher's presence while for others the researcher elicited and noted the responses of the participants. Most participants received some assistance. Some participants required help either due to lack of energy or because some people in the over 60 years age group had poor eyesight or were not sufficiently literate. Every effort was made to keep the questionnaire administration as standard as possible to avoid introducing bias. Questionnaire administration took a minimum of 40 minutes. As previously mentioned, it was sometimes necessary to extend the interview time if the participant wished to discuss his or her personal situation in detail, as there were limited back-up services immediately available.

Difficulties encountered. Participants could relate to the content of most of the scales very well. However, as already mentioned, during the pilot study, some participants seemed uncomfortable with the content of some of the questions in the Cancer Locus of Control Scale (Watson *et al.*, 1990) such as, for example, the item 'by taking extra care of myself (i.e through exercise and diet) I can influence the course of my illness.'

Another problem encountered was with the 'decreased sexual interest' item on the Rotterdam Symptom Checklist (de Haes *et al.*, 1990). At times it was not appropriate to ask participants this question, as they were already so distressed about other problems. It was the only item in this questionnaire that was not consistently presented. Other problems encountered related to participants' fatigue and level of illness, time limitations, or the arrival of transport to take the participant home in the case of those who had travelled long distances for treatment, so occasionally some participants were not able to complete the full questionnaire. In relation to some of the results this explains why n is < 98.

Statistical methods. Data were entered, stored and analysed by the researcher on an IBM PC, using Statistical Package for the Social Sciences for Windows, Version 8.0. Most of the data collected for the present study were at nominal or ordinal rather than interval or ratio level of measurement and were not normally distributed, so did not lend themselves to parametric analysis. Therefore, nonparametric tests which make less stringent assumptions about the shape of the population, and about the level of measurement, were employed to analyse the data. Data were largely ordinal in nature and measures were frequently tied. Thus Kendall's tau-b was considered the most appropriate method of correlational analysis. Analysis of data pertaining to gender required a two-sample test appropriate for ordinal measures to test whether two independent groups had been drawn from the same population (Healey, 1999; Siegel & Castellan, 1988). The Mann-Whitney U Test was selected as it requires no assumption about population distribution and may be considered as an alternative to differences-between-means tests (Healey, 1999). In the relatively few cases where directional hypotheses were formulated, the controversy in the literature is such that the opposite result could not be ruled out. Hence two-tailed tests were used in all cases (Siegel & Castellan, 1988). Stepwise regression analysis was also performed on the principal variables.

Analysis. All selected scales were scored as recommended by the authors. Thus, each item in the Hospital Anxiety and Depression scale (Zigmond & Snaith, 1983) was scored from zero to three, a zero score indicating no anxiety or depression and a score of three indicating maximum anxiety or depression on any given item. The Mental Adjustment to Cancer (MAC) Scale was scored using the MAC scoring key (Watson *et al.*, 1988b; Johnston, Wright & Weinman, 1995). Scores on the sub-scales of the Courtauld Emotional Control Scale (CECS) were summed, items being scored in reverse where appropriate (Watson & Greer, 1983).

Pain perception was divided into categories of (1) average pain intensity, that is, the perception of pain intensity on average in the month prior to the study, as measured on an equal interval rating scale and (2) present pain perception, the perception of pain intensity at the time of the study interview, also measured by an equal interval rating scale. Participants were asked to circle a number on the two equal interval rating scales; zero represented 'no pain' and ten represented 'pain as bad as you can imagine.' A rating of 'no pain' was scored and analysed as zero. Scores obtained on the equal interval rating scales were classified as indicative of pain as 'low' (1-4), 'moderate' (5-6) or 'high' (severe) (7-10) (Skeel and Lachant, 1995; McCaffrey *et al.,* 1994). Participants were asked to describe their impression of their overall pain intensity experience in the month prior to the study on a Likert-type adjectival scale from 'no pain,' scored as zero, to 'excruciating pain,' scored as six.

Items from the Multi-Dimensional Support Scale (MDSS) were scored from zero (never) to three (often) (Neuling & Winefield, 1988). During administration of the questionnaire, participants were asked to think of one family member, friend and health care professional who had been the most supportive in the month prior to the study, in order that they could then concentrate more directly on the support received, rather than giving a global estimate of it (Neuling & Winefield, 1988). Participants rated how frequently they experienced each behaviour from each source. Participants were asked to rate whether they were satisfied or not with the frequency of expression of each type of support form each source. Type of support was divided into emotional, informational, tangible and reassurance categories. Emotional, informational, tangible and reassurance support was measured as received and perceived support from family and friends while emotional, informational, and reassurance support was measured as received and perceived support from health care professionals. Scores for different variables for each type of support were grouped together in the section examining participants' perception of support (but not in participants' assessment of received support) for ease of administration, as the researcher found that participants found the second section of the MDSS somewhat long if the same questions were once again posed individually.

The Rotterdam Symptom Checklist psychological sub-scale (de Haes *et al.*, 1990) was rated on a four-point scale from 'not at all' (zero) to 'very much' (three). Although the full questionnaire was administered, it was decided to utilise only the data from the psychological sub-scale of the RSCL (de Haes *et al.*, 1990) for the purposes of the present thesis, as that information was most relevant to the research questions. Loss variables were scored on a Likert scale and thus were quantified.

Qualitative data were scrutinised for key terms and themes, together with their frequency of occurrence and importance for the participating subjects (Burns & Grove, 1997). Classification according to each participant's primary or overall response was done by two raters working independently.

In order to study age effects, since there is evidence that the relationship between age and social support may change as a person grows older (e.g. Redmond & Aapro, 1997), it was decided to dichotomise the group at 59.5 years (a point close to the median) as this yielded two subgroups of approximately equal size. This facilitated a study of the relationships in the cases who were below median age and, separately, in the cases who were above median age.

RESULTS

Descriptive statistics

Age and education. There was a total of 98 participants in the study. Table 1 shows that over half of the males and of the females were in the 51-70 year age range. The age distributions of participants is illustrated in Figure 1.

Table 1. Percentages of participants in different age ranges (n=98)

Age *n=*	Male *42*	Female *56*	Total *98*
21-30	1.0%		1.0%
31-40	4.1%	3.1%	7.2%
41-50	2.0%	14.3%	16.3%
51-60	15.3%	19.4%	34.7%
61-70	10.2%	12.2%	22.4%
71-80	6.1%	8.2%	14.3%
81-90	4.1%		4.1%
Total	42.8%	57.2%	100.0%

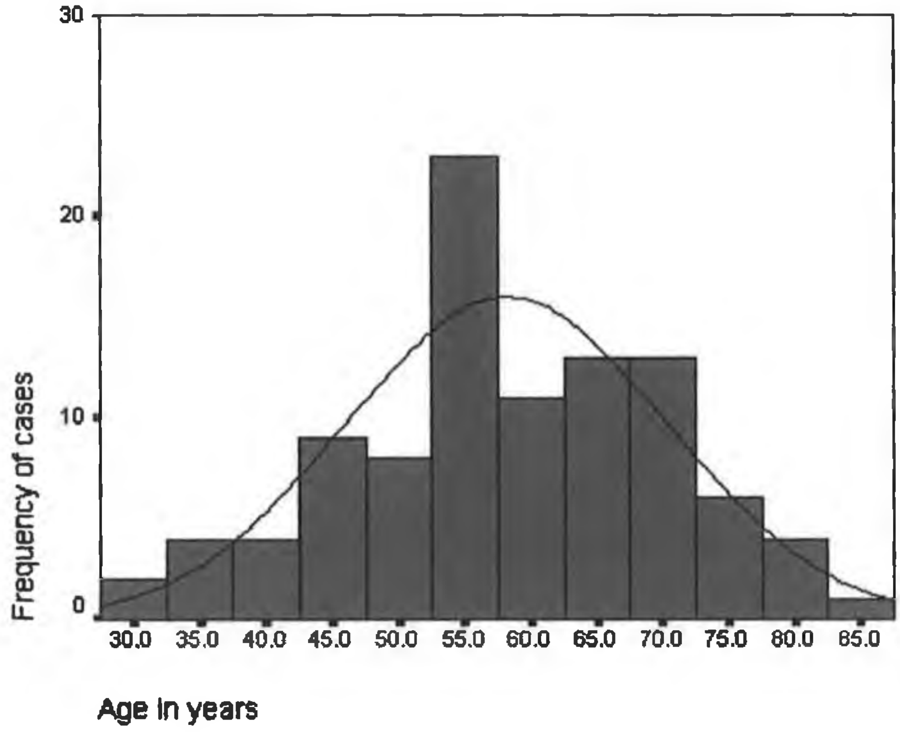


Figure 1. Age in years of study participants

The youngest subject was aged 28 years, and the oldest 83 years, giving a range of 55 years.

As shown in Table 2, participants' mean age was just over 58 years, with a standard deviation of 12.19 years. Participants' median age was 57 years.

Table 2. Measures of central tendency and dispersion of age of study participants (n=98)

	Age in Years
Mean	58.15
Median	57.00
Std. Deviation	12.19
Range	55
Minimum	28
Maximum	83

Close to half, 48%, of the study participants had completed primary, 40.8% secondary and 11.2% of participants third-level education as shown in Table 3.

Table 3.Education level of participants (n=98)

Education Level	Male	Female	Total
n=	*42*	*56*	*98*
Primary	21.5%	26.5%	48.0%
Secondary	15.3%	25.5%	40.8%
Third-Level	6.1%	5.1%	11.2%
Total	42.9%	57.1%	100%

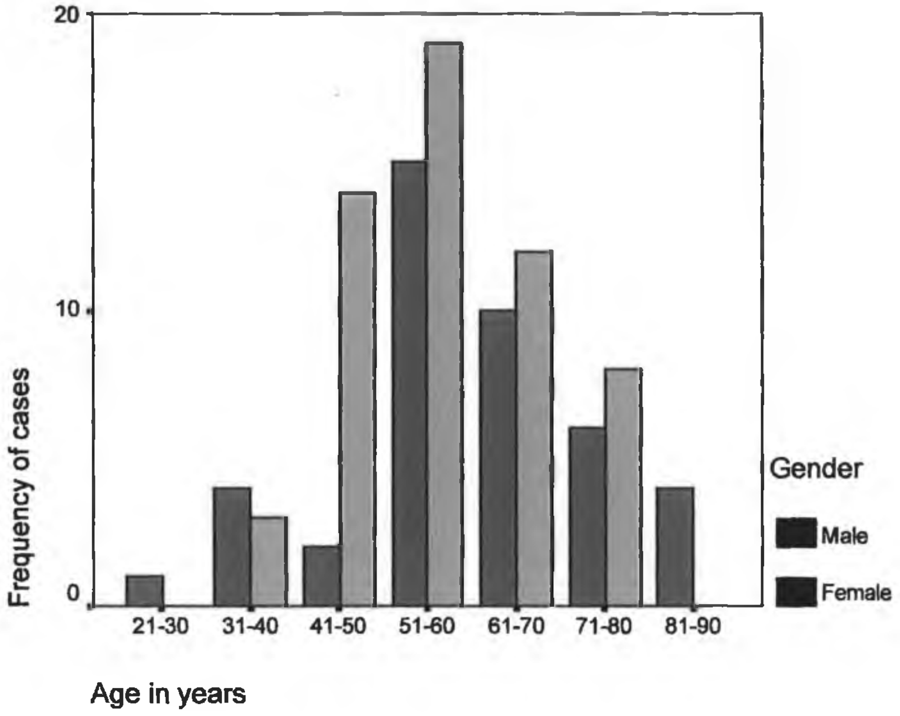


Figure 2. Distribution of sample of participants by age and gender

More female than male participants were in each ten-year age category from 41-80 years. The age categories of 21-30 and 81-90 years comprised only male participants, as shown in Figure 2.

Sociodemographic variables. As can be seen from Table 4, just over a third of the study sample (36.2%), belonged to socioeconomic class 1V, as defined by Goldthorpe (1987) and the British Registrar-General (Blane, Brunner & Wilkinson, 1996), i.e. they were skilled or semi-skilled manual workers. Over a fifth (22%) were unskilled manual workers (class V).

Table 4. Socio-economic class of participants

Socio-Economic Class	Male	Female	Total
n=	*42*	*52*	*94*
1	6.4%	6.4%	12.8%
II	4.3%	11.7%	16.0%
III	5.3%	7.4%	12.7%
IV	18.1%	18.1%	36.2%
V	10.6%	11.7%	22.3%
Total	44.7%	55.3%	100.0%

Table 5. Marital status of participants

Marital Status	Male	Female	Total
n=	*42*	*56*	*98*
Single	10.2%	3.1%	13.3%
Married	28.6%	40.8%	69.4%
Divorced		1.0%	1.0%
Widowed	4.1%	9.2%	13.3%
Separated		3.0%	3.0%
Total	42.9%	57.1%	100.0%

Table 6. Religious affiliation of participants

Religious Affiliation	Male	Female	Total
n=	*30*	*45*	*75*
Roman Catholic	36.1%	52.0%	88.1%
Church of Ireland	1.3%	4.0%	5.3%
Other	1.3%	4.0%	5.3%
No Affiliation	1.3%		1.3%
Total	40.0%	60.0%	100.0%

Table 7. Place of residence of participants

Address	Male	Female	Total
n=	*42*	*56*	*98*
Dublin	17.3%	28.6%	45.9%
Other	25.5%	28.6%	54.1%
Total	42.8%	57.2%	100.0%

Of the single participants, about three times as many were males as females. Nearly 70% of the study population were married, as shown in Table 5. Of the married participants, 58.8% were female and 41.2% were male. Where stated, religious affiliation of participants was primarily Roman Catholic (88%), as indicated in Table 6. Fewer than half the participants (45.9%) resided in Dublin, as shown in Table 7.

Diagnosis.

Table 8. Length of time since study participants learned of their diagnosis

Length of Time Since Learned Diagnosis	Male	Female	Total
n=	*42*	*56*	*98*
<1year	22.4%	15.3%	37.7%
1-5 Years	13.3%	20.4%	33.7%
>5 Years	7.2%	21.4%	28.6%
Total	42.9%	57.1%	100.0%

Table 9. Primary diagnoses of study participants

Primary Diagnosis	Male	Female	Total
n=	*42*	*55*	*97*
Colon	4.1%	1.1%	5.2%
Neck	1.0%		1.0%
Unknown Primary	1.0%	2.1%	3.1%
Breast	1.0%	29.9%	30.9%
Pancreas	1.0%		1.0%
Breast And Lung		1.0%	1.0%
Lung	10.3%	4.1%	14.4%
Oesophagus	1.1%	1.0%	2.1%
Testicular	1.0%		1.0%
Other	4.1%	4.1%	8.2%
Hodgkin's Disease	1.0%		1.0%
Larynx	1.1%	1.0%	2.1%
NHL	2.1%		2.1%
Mouth	3.1%		3.1%
Melanoma	1.1%	4.1%	5.2%
Bowel	6.2%	4.1%	10.3%
Ovarian		2.1%	2.1%
Prostate	3.1%		3.1%
Cervix		2.1%	2.1%
Myeloma	1.0%		1.0%
Total	43.3%	56.7%	100.0%

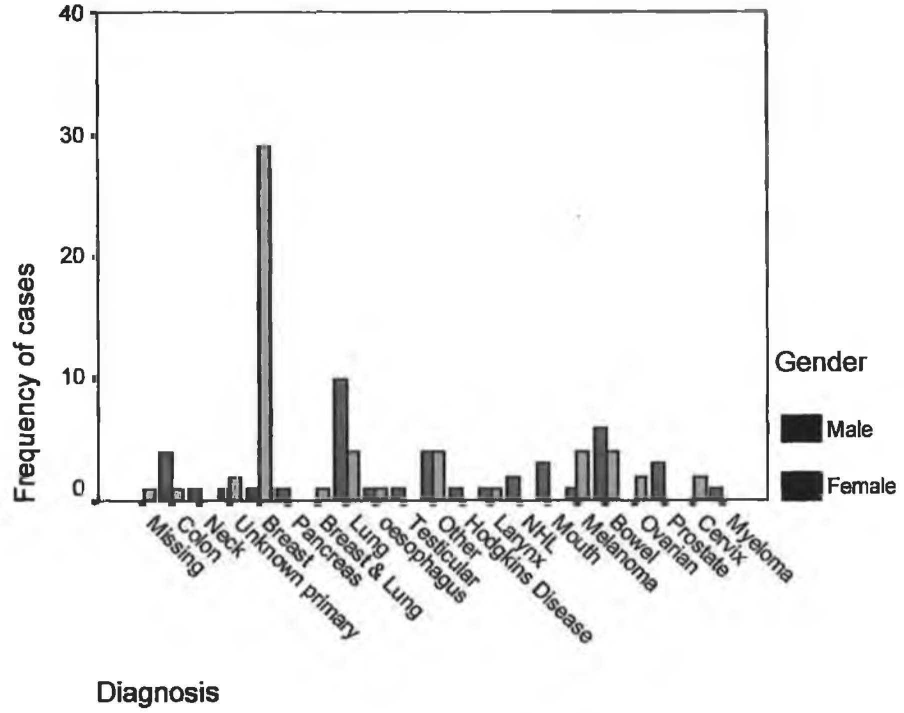


Figure 3. Relative incidence of primary diagnoses of study participants as specified in their medical case notes

Just over a third (37.7%) of participants in the study had learned of their diagnosis during the previous twelve months, as shown in Table 8. As can be seen in Table 9 and Figure 3, breast (30.9%) lung (14.4%) and bowel (10.3%) cancer were the most frequently diagnosed carcinomas and accounted for over 50% of cancers diagnosed in this sample of patients receiving palliative care. More males than females were diagnosed with lung cancer and bowel cancer (cf. Table 9). In 1995, the main causes of cancer deaths in Ireland were recorded as cancers of the breast, lung and bowel. In data collected by the Irish National Cancer Registry from January 1994 to March 1997 (1) breast cancer was the most common cancer in women after non-melanoma skin cancer, (2) colorectal cancers combined formed the largest group of non-cutaneous cancers, exceeding the number of breast and lung cancers, and (3) lung cancer was the third most frequent cancer in men and the fifth most common in women (excluding skin cancer) (National Cancer Registry, 1998).

Table 10. Age of study participants crosstabulated with their cancer diagnoses (n=98)

Diagnosis	21-30	31-40	41-50	51-60	61-70	71-80	81-90	Total
Colon				3.2%	1.0%	1.0%		5.2%
Neck							1.0%	1.0%
Unknown Primary		1.1%	1.0%	1.0%				3.1%
Breast		1.0%	8.2%	14.4%	5.2%	2.1%		30.9%
Pancreas					1.0%			1.0%
Breast and Lung		1.0%						1.0%
Lung			1.0%	5.1%	3.1%	5.2%		14.4%
Oesophagus			1.0%	1.1%				2.1%
Testicular	1.0%							1.0%
Other		1.0%	1.1%	1.0%	4.1%	1.0%		8.2%
Hodgkin's Disease		1.0%						1.0%
Larynx					1.0%		1.1%	2.1%
NHL		1.1%	1.0%					2.1%
Mouth				1.1%	1.0%	1.0%		3.1%
Melanoma			3.1%	1.1%		1.0%		5.2%
Bowel				4.1%	2.1%	3.1%	1.0%	10.3%
Ovarian				1.1%	1.0%			2.1%
Prostate					2.1%		1.0%	3.1%
Cervix		1.0%	1.1%					2.1%
Myeloma				1.0%				1.0%
Total	1.0%	7.2%	17.5%	34.2%	21.6%	14.4%	4.1%	100.0

Participants in the 51-60 years age range had a higher overall incidence of cancer (34.2%) than any other age group, breast, lung and bowel being particularly prevalent amongst them, as shown in Table 10.

Treatment. As shown in Table 11, 11.3% of the sample had undergone surgery in the past year. No participant interviewed had undergone surgery within the six weeks preceding completion of the questionnaire.

Table 11. Percentage of study participants who had undergone surgery in the past year

Surgery *n=*	Male *41*	Female *56*	Total *97*
Yes	6.2%	5.1%	11.3%
No	36.1%	52.6%	88.7%
Total	42.3%	57.7%	100.0%

Fifty per cent of participants were receiving palliative radiotherapy, while 30.2% of participants were receiving chemotherapy, as shown in Table 12. Just under a sixth of the study sample were receiving neither chemotherapy nor radiotherapy at the time of the study.

Table 12. Percentage of study participants who were receiving chemotherapy or radiotherapy at the time of the study

Therapy *n=*	Male *40*	Female *56*	Total *96*
Chemotherapy	11.5%	18.7%	30.2%
Radiotherapy	25.0%	25.0%	50.0%
Neither at present	4.2%	11.5%	15.6%
Chemo/Radiotherapy	1.0%	3.1%	4.2%
Total	41.7%	58.3%	100.0%

Pain experience. At the time of questionnaire completion 59.2% of study participants stated they were pain free; see Table 13. There were no significant differences in levels of present pain reported by male and female study participants (X^2 =.713; df=3; not significant).

Table 13. Levels of present pain experienced by participants

Present pain *n=*	Male *42*	Female *56*	Total *98*
Nil	25.5%	33.7%	59.2%
Low	13.3%	14.3%	27.6%
Moderate	2.0%	3.1%	5.1%
Severe	2.0%	6.1%	8.1%
Total	42.8%	57.2%	100.0%

Average pain intensity for the month prior to the study was described as severe by 37.7% of study participants, as shown in Table 14. There were no significant differences in levels of average pain intensity for male and female participants (X^2=.140; df=3; not significant).

Table 14. Levels of average pain experienced by participants

Average pain *n=*	Male *42*	Female *56*	Total *98*
Nil	7.1%	9.2%	16.3%
Low	14.3%	15.3%	29.6%
Moderate	10.2%	6.1%	16.3%
Severe	11.3%	26.5%	37.8%
Total	42.9%	57.1%	100.0%

There was a reduction in the number of participants who perceived pain as severe or moderate when present pain was compared with average pain, as well as an increase in the number of participants who were pain free. More female than male participants reported their pain as being severe, both in the context of present and average pain intensity and on the adjectival scale utilised to subjectively evaluate pain experience; see Tables 13, 14 and 15. There were no significant differences in levels of overall evaluated pain experience for male and female participants (X^2=.175; df=5; not significant).

Table 15. Levels of overall evaluated pain experienced by participants

Overall evaluated pain *n=*	Male *42*	Female *56*	Total *98*
No pain	5.1%	8.2%	13.3%
Mild pain	7.1%	6.2%	13.3%
Discomfort	14.3%	8.1%	22.4%
Distressing pain	8.2%	13.2%	21.4%
Horrible pain	4.1%	9.2%	13.3%
Excruciating pain	4.1%	12.2%	16.3%
Total	42.9%	57.1%	100.0%

As Table 16 shows, study participants were receiving a wide range and combination of analgesic medication. Strong opioids alone were prescribed for 41.3 % of the study participants. However, a percentage of participants were also receiving opioid medication either as weak opioid (i.e. codeine) or in combination with a tricyclic antidepressant and/or steroid and/or a non-steroidal anti-inflammatory drug (NSAID).

Table 16. Analgesic medication prescribed for study participants

Pain medication *n=*	Male *42*	Female *55*	Total *98*
Strong opioid	18.6%	22.7%	41.3%
NSAIDs		5.2%	5.2%
Weak opioid	2.1%	4.1%	6.2%
Steroids	2.1%	4.1%	6.2%
Non opioid	2.1%	3.1%	5.2%
Nil	12.4%	7.2%	19.6%
Non Opioid/Trycyclic	1.0%		1.0%
NSAID/W.Opioid	1.0%		1.0%
NSAID/S.Opioid	1.0%	6.2%	7.2%
S.Opioid/Trycyclic		1.0%	1.0%
NSAID/Trycyclic/Steroid		1.0%	1.0%
W.Opioid/Trycyclic		1.0%	1.0%
NSAID/S.Opioid/Steroid	1.0%		1.0%
Steroids/S.Opioid	1.0%	1.1%	2.1%
Steroids/NSAID	1.0%		1.0%
Total	43.3%	56.7%	100.0%

Prescribed medication afforded 100% pain relief to 33% of the study participants, but more than 10% of participants were obtaining 50% or less relief from their medication as indicated in Table 17.

Table 17. Percentage pain relief afforded by analgesic medication prescribed for study participants

% Pain Relief	Male	Female	Total
n=	*42*	*55*	*97*
Not relevant*	10.3%	8.2%	18.5%
20		1.0%	1.0%
30			
40	1.0%	1.0%	2.0%
50	5.2%	3.1%	8.3%
60	2.1%	2.1%	4.2%
70	2.1%	6.1%	8.2%
80	7.2%	8.3%	15.5%
90	3.1%	6.2%	9.3%
100	12.4%	20.6%	33.0%
Total	43.4%	56.6%	100.0%

* percentage of participants not prescribed analgesia at the time of the study

Table 18. Socio-demographic variables and diagnostic categories cross-tabulated with overall evaluated pain (n=98)

		No Pain	Mild Pain	Discomfort	Distressing Pain	Horrible Pain	Excruciating Pain	Total
Gender	Male	5.1%	7.1%	14.3%	8.2%	4.1%	4.1%	42.9%
	Female	8.2%	6.1%	8.2%	13.2%	9.2%	12.2%	57.1%
	Total	13.3%	13.2%	22.5%	21.4%	13.3%	16.3%	100.0%
Age	21-30			1.0%				1.0%
	31-40	1.1%	1.0%	1.0%	2.0%	1.0%	1.0%	7.1%
	41-50	4.1%	1.0%	2.0%	3.1%	2.0%	4.1%	16.3%
	51-60	4.1%	5.1%	7.1%	8.2%	7.2%	3.1%	34.8%
	61-70	2.0%	3.1%	5.1%	6.1%	2.0%	4.1%	22.4%
	71-80	1.0%	3.1%	4.1%	1.0%	1.0%	4.1%	14.3%
	81-90	1.0%		2.1%	1.0%			4.1%
	Total	13.3%	13.3%	22.4%	21.4%	13.2%	16.4%	100.0%
Marital Status	Single	1.0%	3.1%	4.1%	4.1%		1.0%	13.3%
	Married	9.2%	7.1%	14.3%	14.3%	12.2%	12.2%	69.3%
	Divorced		1.0%					1.0%
	Widowed	1.0%	2.0%	3.1%	3.1%	1.0%	3.1%	13.3%
	Separated	2.1%		1.0%				3.1%
	Total	13.3%	13.2%	22.5%	21.5%	13.2%	16.3%	100.0%
Primary Diagnosis	Colon	1.1%	1.0%	1.0%	1.0%	1.1%		5.2%
	Neck	1.0%						1.0%
	Unknown			1.0%		1.0%	1.1%	3.1%
	Breast	3.1%	3.1%	4.1%	6.2%	6.2%	8.2%	30.9%
	Pancreas						1.0%	1.0%
	Breast/Lung	1.0%						1.0%
	Lung	2.1%	3.1%	4.1%	1.0%	1.0%	3.1%	14.4%
	Oesophagus					1.1%	1.0%	2.1%
	Testicular			1.0%				1.0%
	Other	1.0%	2.1%	2.1%	2.0%	1.0%		8.2%
	Hodgkin's				1.0%			1.0%
	Larynx			2.1%				2.1%
	NHL		2.1%					2.1%
	Mouth		1.0%	1.1%	1.0%			3.1%
	Melanoma	3.1%	1.0%		1.1%			5.2%
	Bowel	1.0%		4.1%	4.1%		1.1%	10.3%
	Ovarian				1.1%	1.0%		2.1%
	Prostate				2.1%	1.0%		3.1%
	Cervix			1.1%			1.0%	2.1%
	Myeloma			1.0%				1.0%
	Total	13.4%	13.4%	22.7%	20.6%	13.4%	16.5%	100.0%

Half of the study participants, 51%, experienced distressing to excruciating pain. Participants with breast cancer, who comprised the largest diagnostic category (30.9%) of the study, reported the most pain. Distressing to excruciating pain was experienced by 38% of male and 60.7% of female participants as shown in Figure 4

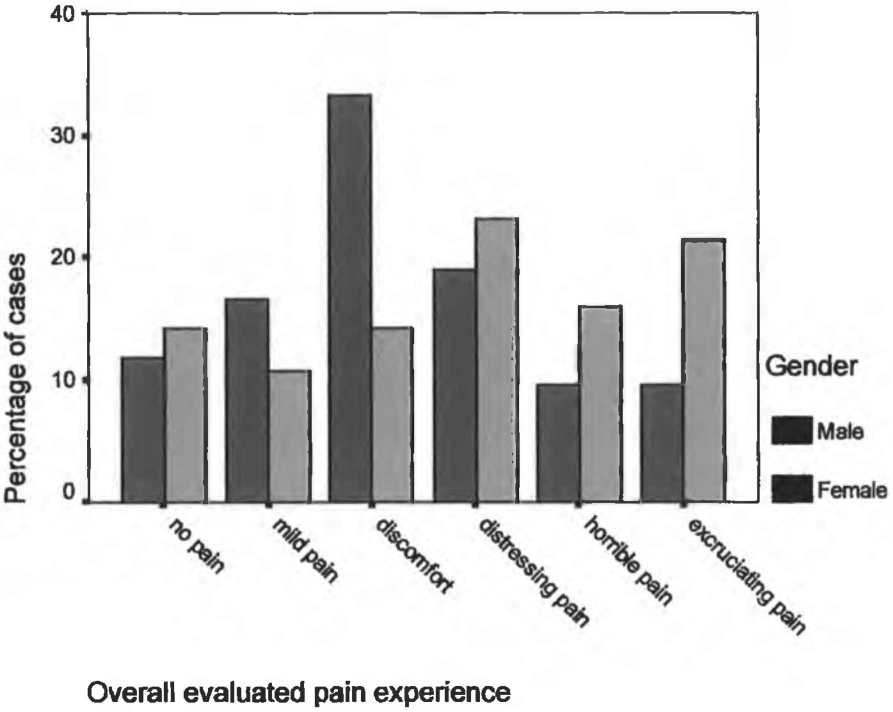


Figure 4. Percentages of male and female participants in the various categories of overall evaluated pain experience.

Less than half of the study sample, 46.4%, attributed their pain primarily to cancer. While 17.6% of participants stated that they did not know what caused their pain, another 36% of participants attributed their pain to a variety of causes; see Table 19.

Table 19. Study participants' attributions of the causes of their pain

Cause of Pain *n=*	Male *42*	Female *55*	Total *97*
Don't know	9.4%	8.2%	17.6%
Cancer	17.5%	28.9%	46.4%
Arthritis		2.1%	2.1%
Not relevant	5.2%	7.3%	12.5%
Sudden movement		1.0%	1.0%
Nerve pain	1.1%	1.0%	2.1%
Post surgery		1.0%	1.0%
Breathing		1.0%	1.0%
Treatment		2.1%	2.1%
Constipation	1.0%		1.0%
Physical activity		1.0%	1.0%
Cancer/constipation	1.0%		1.0%
Ulcer	1.0%		1.0%
Obstruction	1.0%		1.0%
Undermedication	1.0%		1.0%
Back problems	1.0%		1.0%
Multiple causes (including cancer)	4.1%	3.1%	7.2%
Total	43.3%	56.7%	100.0%

Family support. Table 20 shows that whereas 51.5% of participants found their spouses were the most supportive family member, 10.3% of participants, nine tenths of them female, found their daughters most supportive, whereas 5.2% of participants, exclusively males, found their brothers the most supportive family member. A Chi-square test revealed a gender difference in perception of family support (X^2=18.425, df 6, $p<0.005$).

Table 20. Study participants' perception of family support

Most supportive family member *n*=	Male *41*	Female *56*	Total *97*
Spouse	24.7%	26.8%	51.5%
Son(s)	1.0%	2.1%	3.1%
Daughter(s)	1.0%	9.3%	10.3%
Sister(s)	4.1%	6.2%	10.3%
Brother(s)	5.2%		5.2%
All/other	6.2%	5.2%	11.4%
Adult children		8.2%	8.2%
Total	42.2%	57.8%	100.0%

Emotional support from family members was more appreciated by 35% of participants, of whom seven tenths were female, than other types of support. Tangible support was most appreciated by 18.6% of participants, of whom nearly three quarters were female as shown in Table 21.

Table 21. Type of family support most appreciated by participants

Type of family support most appreciated *n*=	Male *41*	Female *56*	Total *97*
Emotional	10.3%	24.7%	35.0%
Informational	1.0%		1.0%
Tangible	5.2%	13.4%	18.6%
Reassurance	5.2%	4.1%	9.3%
Emotional/Tangible	1.0%	1.1%	2.1%
All	16.5%	11.3%	27.8%
Emotional/Tangible/Reassurance	3.1%	3.1%	6.2%
Total	42.3%	57.7%	100.0%

Friend support. Emotional support from friends was most appreciated by female participants, while tangible support from friends was most appreciated by male participants, as indicated in Table 22.

Table 22. Type of friend support most appreciated by study participants

Type of friend support most appreciated *n*=	Male *32*	Female *51*	Total *84*
Emotional	9.7%	34.9%	44.6%
Informational	1.2%		1.2%
Tangible	12.1%	4.8%	16.9%
Reassurance	2.4%	7.3%	9.7%
All	4.8%	7.2%	12.0%
Emotional/tangible/reassurance	4.8%	1.2%	6.0%
Tangible/reassurance	2.4%	1.2%	3.6%
Emotional/tangible	1.2%	2.4%	3.6%
Emotional/reassurance		2.4%	2.4%
Total	38.6%	61.4%	100.0%

Health care professional support. Nurses were regarded as the most supportive health care professionals by 27.3% of participants, three quarters of whom were female and 25% of whom were male. Hospital doctors were seen as most supportive by 30.1% of participants, of whom 54.5% were males and 45.5% females, as shown in Table 23.

Table 23. Health care professionals (HCPs) considered most supportive by study participants

Most supportive health care professional *n*=	Male *30*	Female *43*	Total *73*
Hospital doctor(s)	16.4%	13.7%	30.1%
Nurse(s)	6.8%	20.5%	27.3%
GP	1.4%	9.6%	11.0%
All Drs.	5.5%	1.4%	6.9%
All HCPs	11.0%	13.7%	24.7%
Total	41.1%	58.9%	100.0%

A combination of all types of support from health care professionals was most appreciated by 56.8% of participants, 46.3% of whom were males and 53.7% females. Informational support from health care professionals was the next most appreciated type of support by 26.3% of participants, 48% of whom were male and 52% female, as indicated by Table 24.

Table 24. Type of health care most appreciated by study participants

Type of health care most appreciated *n*=	Male *41*	Female *54*	Total *95*
Emotional	1.1%	4.2%	5.3%
Informational	12.6%	13.7%	26.3%
Reassurance	3.2%	3.1%	6.3%
All	26.3%	30.5%	56.8%
Informational/reassurance		2.1%	2.1%
Emotional/reassurance		1.1%	1.1%
Emotional/informational		2.1%	2.1%
Total	43.2%	56.8%	100.0%

Table 25. Categories of overall evaluated pain experience cross-tabulated with type of social support most appreciated (n=98)

Type of support most appreciated		Overall evaluated pain experience						
		No Pain	Mild Pain	Discomfort	Distressing Pain	Horrible Pain	Excruciating Pain	Total
Type of Family Support most Appreciated	Emotional	5.2%	3.1%	6.2%	8.1%	6.2%	6.2%	35.0%
	Informational		1.0%					1.0%
	Tangible	2.1%		5.2%	7.2%	1.0%	3.1%	18.6%
	Reassurance	1.0%	1.0%	2.1%	2.1%	2.1%	1.0%	9.3%
	Emot/Tang			2.1%				2.1%
	All	4.1%	6.2%	7.2%	2.1%	4.1%	4.1%	27.8%
	Emot/Tang/Reassur	1.0%	1.0%		2.1%		2.1%	6.2%
	Total	13.4%	12.3%	22.8%	21.6%	13.4%	16.5%	100.00
Type of Friend Support most Appreciated	Emotional	6.1%	4.8%	8.4%	12.1%	7.2%	6.1%	44.7%
	Informational	1.2%						1.2%
	Tangible		3.6%	6.1%	3.6%	2.4%	1.2%	16.9%
	Reassurance		1.2%	1.2%	3.6%	2.4%	1.2%	9.6%
	All	2.4%	2.4%	3.6%		1.2%	2.4%	12.0%
	Emot/Tang/Reassur	1.2%		1.2%	1.2%		2.4%	6.0%
	Tang/Reassurance	1.2%	1.2%				1.2%	3.6%
	Emot/Tangible			1.2%	1.2%		1.2%	3.6%
	Emot/Reassurance	1.2%	1.2%					2.4%
	Total	13.3%	14.4%	21.7%	21.7%	13.2%	15.7%	100.0
Type of HCP Support most Appreciated	Emotional		1.1%	3.1%	1.1%			5.3%
	Informational	3.2%	5.2%	5.3%	5.2%	4.2%	3.2%	26.3%
	Reassurance		1.1%	2.1%	1.0%	1.0%	1.1%	6.3%
	All	8.4%	6.3%	11.6%	11.6%	7.4%	11.5%	56.8%
	Inform/Reassur/	1.0%				1.1%		2.1%
	Emot/Reassur	1.1%						1.1%
	Emot/Information				1.1%		1.0%	2.1.%
	Total	13.7%	13.7%	22.1%	20.0%	13.7%	16.8%	100.0

Across all categories of pain, emotional support from family and friends was the type of support most frequently appreciated by participants, whilst a combination of all types of support was most appreciated from health care professionals (HCPs) as shown in Table 25.

As shown in Table 26, there were significant and positive associations between present and average pain (.355, $p<0.0001$) and between present and overall evaluated pain experience (.284, $p<0.001$). Average pain also correlated with overall evaluated pain experience (.784, $p<0.0001$).

Table 26a. Correlations of present, average and evaluative pain measures

			Present Pain	Average Pain	Evaluated Pain Experience
Kendall's tau_b	Present Pain	Correlation Coefficient	1.000	.355	.284
		Sig. (2-tailed)	.	.000	.001
		N	98	98	98
	Average Pain	Correlation Coefficient	.355	1.000	.784
		Sig. (2-tailed)	.000	.	.000
		N	98	98	98
	Evaluated Pain Experience	Correlation Coefficient	.284	.784	1.000
		Sig. (2-tailed)	.001	.000	.
		N	98	98	98

Table 26b. Mean, standard deviations and non, borderline and definite cases produced by the HAD Anxiety and Depression subscales.

	HAD Anxiety	HAD Depression
N	92	92
Mean	5.55	4.60
Std. Deviation	4.51	3.98
Non-cases	63	70
Borderline cases	18	13
Cases	11	9

NB The means and standard deviations in respect of the various rating scales employed are set out in Appendix iv.

RESULTS RELATING TO HYPOTHESES

In the following sections the results of analyses in relation to each hypothesis in the study will be presented

Hypothesis 1a. Average pain intensity is positively associated with received support within the social networks of patients with advanced cancer.

Scores for participants' average pain intensity were correlated with scores for all received emotional, informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

As shown in Table 27, average pain intensity scores demonstrated significant positive associations with received emotional support (.223, p<0.01) and received overall support (.155, p<0.05) from health care professionals. There were no other significant associations between participants' average pain intensity and any of the other received social support variables examined in the study.

Table 27. Associations of average pain intensity scores with scores of received social support

Type of social support	Correlations with average pain intensity
Received emotional support from health care professionals	.223, p=.007
Received overall support from health care professionals	.155, p=.048
All 12 other received support scores	Not significant

Kendall's tau-b, 2-tailed. n=98

Hypotheses 1b and 1c. Average pain intensity is positively associated with psychological distress and perceived loss in patients with advanced cancer.

Scores for participants' average pain intensity were correlated, using Kendall's tau-b, 2-tailed, with scores for variables associated with psychological distress (i.e. RSCL items irritability, worrying, depressed mood, nervousness, desperate feelings about the future, tension, anxiety and difficulty in concentrating; and HAD items anxiety and depression) as well as perceived loss (i.e. physical strength, independence, role, physical restriction, social deficit and overall perceived loss).

As can be seen in Table 28, physical restriction was the single psychological distress/loss variable significantly and positively associated with participants' average pain intensity (.199, p<0.025).

Table 28. Associations of average pain intensity scores with scores of psychological distress (RSCL & HAD) and perceived loss

Type of psychological distress/perceived loss	Correlations with average pain intensity
Physical restriction	.199, p=.024
All 15 other scores of psychological distress and perceived loss	Not significant

Kendall's tau-b, 2-tailed. n=98

Hypothesis 1d. Average pain intensity is positively associated with coping deficit in patients with advanced cancer.

Kendall's tau-b, 2-tailed, was employed to correlate scores for participants' average pain intensity with scores for coping attitudes of anxious preoccupation, fatalism, helplessness/hopelessness, fighting spirit and avoidance as measured by the Mental Adjustment to Cancer scale (MAC).

As shown in Table 29, avoidance was the single coping attitude positively associated with participants' average pain intensity (.243, p<0.025).

Table 29. Associations of scores of average pain intensity with scores for the Mental Adjustment to Cancer scale (MAC)

Type of coping attitude	Correlations with average pain intensity
Avoidance	.243, p=.013
All 4 other MAC scores	Not significant

Kendall's tau-b, 2-tailed. n=80.

Hypothesis 1e. Average pain intensity is negatively associated with perceived support within the social networks of patients with advanced cancer.

Scores for participants' average pain intensity were correlated with scores for all perceived emotional, informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

As shown in Table 30, there was a significant and positive association between average pain intensity and perceived reassurance support from health care professionals (.192, $p<0.05$). There were no significant associations between participants' average pain intensity and the other perceived social support variables examined in the study.

Table 30. Associations of average pain intensity scores with scores of perceived social support

Type of social support	Correlations with average pain intensity
Perceived reassurance support from health care professionals	.192, p=.039
All 13 other perceived support scores	Not significant

Kendall's tau-b, 2-tailed. n=98

Hypothesis 2a. Average pain intensity rated as moderate to high is positively associated with received support within the social networks of patients with advanced cancer.

Participants' average pain intensity scores rated as moderate to high were correlated with scores of received emotional informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

Table 31 shows that participants' average pain intensity rated as moderate to high was significantly and positively associated with received emotional support from health care professionals (.245, $p<0.05$). As noted in Table 31, there were no other significant associations with received support variables.

Table 31. Associations of scores for average pain intensity rated as moderate to high with scores for received social support

Type of social support	Correlations with average pain intensity rated as moderate to high
Received emotional support from health care professionals	.245, p=.047
All 13 other received support scores	Not significant

Kendall's tau-b, 2-tailed. n=53

Hypotheses 2b and 2c. Average pain intensity rated as moderate to high is positively associated with psychological distress and perceived loss in patients with advanced cancer.

Scores for participants' average pain intensity rated as moderate to high were correlated, using Kendall's tau-b, 2-tailed, with scores for variables associated with psychological distress (i.e. RSCL items irritability, worrying, depressed mood, nervousness, desperate feelings about the future, tension, anxiety and difficulty in concentrating; and HAD Scale items anxiety and depression) as well as perceived loss (i.e. physical strength, independence, role, physical restriction, social deficit and overall perceived loss).

As noted in Table 32, no significant associations were found between average pain intensity rated as moderate to high and psychological distress or perceived loss.

Table 32. Correlations of average pain intensity rated as moderate to high with scores of psychological distress (RSCL & HAD Scale) and perceived loss

Type of psychological distress/perceived loss	Correlations with average pain intensity rated as moderate to high
All 16 psychological distress and perceived loss scores	Not significant

Kendall's tau-b, 2-tailed. n=53

Hypothesis 2d. Average pain intensity rated as moderate to high is positively associated with coping deficit in patients with advanced cancer.

Kendall's tau-b, 2-tailed, was employed to correlate scores for participants' average pain intensity rated as moderate to high, with scores of coping attitudes of anxious preoccupation, fatalism, helplessness/hopelessness, fighting spirit and avoidance as measured by the Mental Adjustment to Cancer scale (MAC).

As shown in Table 33, average pain intensity rated as moderate to high demonstrated a significant and negative association with fatalism (-.296, p<0.05).

Table 33. Significant associations of participants average pain intensity scores rated as moderate to high with Mental Adjustment to Cancer scale (MAC) scores

Type of coping attitude	Correlations with average pain intensity rated as moderate to high
Fatalism (MAC)	-.296, p=.027
All 4 other MAC scores	Not significant

Kendall's tau-b, 2-tailed. n=41

Hypothesis 2e. Average pain intensity rated as moderate to high is negatively associated with perceived support within the social networks of patients with advanced cancer.

Scores for participants' average pain intensity rated as moderate to high were correlated with scores of perceived emotional, informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

Table 34 shows that participants' average pain intensity rated as moderate to high was significantly and negatively associated with perceived emotional support (-.284, $p<0.05$), perceived informational support (-.279, $p<0.05$) and perceived tangible support (-.284, $p<0.05$) from friends. No other significant associations were demonstrated between scores for average pain intensity rated as moderate to high and perceived support scores as indicated by Table 34.

Table 34. Associations of scores for average pain intensity rated as moderate to high with scores for perceived social support

Type of social support	Correlations with average pain intensity rated as moderate to high
Perceived emotional support from friends	-.284, p=.041
Perceived informational support from friends	-.279, p=.044
Perceived tangible support from friends	-.284, p=.041
All 11 other perceived support scores	Not significant

Kendall's tau-b, 2-tailed. n=53

*Hypothesis 3a. **Present pain intensity is positively associated with received support within the social networks of patients with advanced cancer.***

Scores for participants' present pain intensity were correlated with scores for all received emotional, informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

As shown in Table 35, present pain scores demonstrated significant and positive associations with scores for received tangible support from family (.233, $p<0.025$) and friends (.189, $p<0.05$).

Table 35. Associations of present pain intensity scores with scores of received social support

Type of social support	Correlations with present pain intensity
Received tangible support from family	.233, p=.012
Received tangible support from friends	.189, p=.033
All 12 other received support scores	Not significant

Kendall's tau-b, 2-tailed. n=98

Hypotheses 3b and 3c. Present pain intensity is positively associated with psychological distress and perceived loss in patients with advanced cancer.

Scores for participants' present pain intensity were correlated, using Kendall's tau-b, 2-tailed, with scores for variables associated with psychological distress (i.e. RSCL items irritability, worrying, depressed mood, nervousness, desperate feelings about the future, tension, anxiety and difficulty in concentrating; and HAD Scale items anxiety and depression) as well as with perceived loss (i.e. physical strength, independence, role, physical restriction, social deficit and overall perceived loss).

As shown in Table 36, anxiety, as measured by the HAD sub-scale, was the single psychological distress/perceived loss variable significantly and positively associated with participants' present pain intensity (.248, p<0.005).

Table 36. Associations of present pain intensity scores with scores of psychological distress (RSCL & HAD Scale) and perceived loss

Type of psychological distress/perceived loss	Correlations with present pain intensity
HAD Anxiety	.248, p=.003
All 15 other measures of psychological distress and perceived loss	Not significant

Kendall's tau-b, 2-tailed. n=98

Hypothesis 3d. Present pain intensity is positively associated with coping deficit in patients with advanced cancer.

Kendall's tau-b, 2-tailed, was employed to correlate scores of participants' present pain intensity with scores for coping attitudes of anxious preoccupation, fatalism, helplessness/hopelessness, fighting spirit and avoidance, as measured by the Mental Adjustment to Cancer scale (MAC).

As Table 37 shows, no significant associations were found between scores of participants' present pain intensity and scores on the Mental Adjustment to Cancer scale (MAC) as a measure of coping attitude in study participants.

Table 37. Associations of present pain intensity scores with scores of Mental Adjustment to Cancer scale (MAC)

Type of coping attitude	Correlations with present pain intensity
All 5 MAC scores	Not significant

Kendall's tau-b, 2-tailed. n=80

Hypothesis 3e. Present pain intensity is negatively associated with perceived support within the social networks of patients with advanced cancer.

Scores for participants' present pain intensity were correlated with scores for all perceived emotional, informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

As shown in Table 38, present pain scores demonstrated no significant associations with scores of perceived support from family, friends and health care professionals.

Table 38. Associations of present pain intensity scores with scores of perceived social support

Type of social support	Correlations with present pain intensity
All 14 perceived support scores	Not significant

Kendall's tau-b, 2-tailed. n=98

Hypothesis 4a. Overall evaluated pain experience is positively associated with received support within the social networks of patients with advanced cancer.

Scores for participants' evaluated pain experience were correlated with scores for all received emotional, informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

As shown in Table 39, there was a significant, positive association between participants' overall evaluated pain experience and received emotional support from health care professionals (.165, $p<0.05$). No other received support variables were significantly associated with participants' overall evaluated pain experience.

Table 39. Associations of scores of evaluated pain experience with scores of received social support

Type of social support	Correlations with overall evaluated pain experience
Received emotional support from health care professionals	.165, p=.037
All 13 other received support scores	Not significant

Kendall's tau-b, 2-tailed. n=98

Hypotheses 4b and 4c. Overall evaluated pain experience is positively associated with psychological distress and perceived loss in patients with advanced cancer.

Scores for participants' evaluated pain experience were correlated, using Kendall's tau-b, 2-tailed, with scores for variables associated with psychological distress (i.e. RSCL items irritability, worrying, depressed mood, nervousness, desperate feelings about the future, tension, anxiety and difficulty in concentrating; and HAD Scale items anxiety and depression), as well as with perceived loss (i.e. physical strength, independence, role, physical restriction, social deficit and overall perceived loss).

As can be seen in Table 40, there were significant positive associations between participants' overall evaluated pain experience and RSCL psychological distress measures of desperate feelings about the future (.186, $p<0.05$) and anxiety (.167, $p<0.05$), and with the HAD anxiety sub-scale (.186, $p<0.05$), as well as with perceived loss items physical strength (.181, $p<0.05$), physical restriction (.200, $p<0.025$) and overall perceived loss (.197, $p<0.025$).

Table 40. Associations of scores of overall evaluated pain experience with scores of psychological distress (RSCL & HAD Scale) and perceived loss

Type of distress/loss	Correlations with overall evaluated pain experience
Desperate feelings about the future (RSCL)	.186, p=.027
Anxiety (RSCL)	.167, p=.044
Anxiety (HAD)	.186, p=.018
Physical strength	.181, p=.027
Physical restriction	.200, p=.018
Overall perceived loss	.197, p=.014
All 10 other psychological distress/loss scores	Not significant

Kendall's tau-b, 2-tailed. n=98

Hypothesis 4d. Overall evaluated pain experience is positively associated with coping deficit in patients with advanced cancer.

Kendall's tau-b, 2-tailed, was employed to correlate scores for participants' evaluated pain experience with scores for coping attitudes of anxious preoccupation, fatalism, helplessness/hopelessness, fighting spirit and avoidance as measured by the Mental Adjustment to Cancer scale (MAC).

Table 41 shows that participants' overall evaluated pain experience was significantly and positively associated with helplessness/hopelessness (.172, $p<0.05$) and significantly and negatively associated with fighting spirit (-.279, $p<0.001$) as measured by the MAC scale.

Table 41. Associations of scores of overall evaluated pain experience with scores of the Mental Adjustment to Cancer scale (MAC)

Type of coping attitude	Correlations with overall evaluated pain experience
Helplessness/hopelessness (MAC)	.172, p=.047
Fighting spirit (MAC)	-279, p=.001
All 3 other MAC scores	Not significant

Kendall's tau-b, 2-tailed. n=80

Hypothesis 4e. Overall evaluated pain experience is negatively associated with perceived support within the social networks of patients with advanced cancer.

Scores for participants' overall evaluated pain experience were correlated with scores for all perceived emotional, informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

As shown in Table 42, there were significant positive associations between scores for participants' overall evaluated pain experience and perceived tangible support from family members (.221, p<0.025). However, participants' overall evaluated pain experience was significantly and negatively associated with perceived overall family support (-.204, p<0.025).

Table 42. Associations of scores of overall evaluated pain experience with scores of perceived social support

Type of social support	Correlations with overall evaluated pain experience
Perceived tangible support from family	.221, p=.013
Perceived overall support from family	-.204, p=.019
All 12 other perceived support scores	Not significant

Kendall's tau-b, 2-tailed. n=98

Hypothesis 5a. Within the over-59-years old group, the older patients are, the more likely they will be to receive insufficient support from their social networks.

Ages of participants who were over-59-years old were correlated with all received emotional, informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

As shown in Table 43, ages of participants who were over-59-years old were significantly and negatively associated with received tangible support from friends (-.308, p = 0.01).

Table 43. Associations of ages of participants who were over-59-years old with scores of received social support

Type of received support	Correlations with age in over-59-year olds
Received tangible support from friends	-.308, p=.010
All 13 other received support scores	Not significant

Kendall's tau-b, 2-tailed. n=43

Hypothesis 5b. Within the over-59-years old group, the older patients are, the more likely they will be to perceive a support deficit from their social networks.

Ages of participants who were over-59-years old were correlated with all perceived emotional, informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

As shown in Table 44, ages of participants who were 60 years or more were associated negatively and significantly with perceived emotional support (-.294, $p<0.025$) and perceived informational support (-.286, $p<0.05$) from health care professionals. No other significant associations were found between perceived support variables and ages of participants over-59-years.

Table 44. Associations of ages of participants over-59-years old with scores of perceived social support

Type of perceived support	Correlations with age in over-59-year olds
Perceived emotional support from health care professionals	-.294, p=.024
Perceived informational support form health care professionals	-.286, p=.028
All 12 other perceived support scores	Not significant

Kendall's tau-b, 2-tailed. n=43

Hypotheses 5c and 5d. Within the over-59-years old group, the older patients are, the more likely they will be to experience psychological distress, and to perceive loss.

Ages of participants who were 60 years or more were correlated, using Kendall's tau-b, 2-tailed, with scores for variables associated with psychological distress (i.e. RSCL items irritability, worrying, depressed mood, nervousness, desperate feelings about the future, tension, anxiety and difficulty in concentrating; and HAD Scale items anxiety and depression), as well as with perceived loss (i.e. physical strength, independence, role, physical restriction, social deficit and overall perceived loss).

As shown in Table 45, no significant associations were found between ages of participants 60 years or more and scores for variables associated with psychological distress or perceived loss.

Table 45. Associations of ages of participants who were 60 years or more with measures of psychological distress (RSCL & HAD Scale) and perceived loss

Type of psychological distress/ perceived loss	Correlations with age 60 years or more
All 16 scores of psychological distress and perceived loss	Not significant

Kendall's tau-b, 2-tailed. n=43

Hypothesis 5e. Within the over-59-years old group, the older patients are, the more likely they will be to report a coping deficit.

Kendall's tau-b, 2-tailed, was employed to correlate ages of participants who were 60 years or more with scores for coping attitudes of anxious preoccupation, fatalism, helplessness/hopelessness, fighting spirit and avoidance as measured by the Mental Adjustment to Cancer scale (MAC).

As shown in Table 46, there were no significant associations between ages of participants who were over-59-years and scores for coping attitudes as measured by the MAC scale.

Table 46. Associations of age of 60 years or more with scores for the Mental Adjustment to Cancer scale (MAC)

Type of coping attitude	Correlations with age in over-59-year olds
All 5 MAC scores	Not significant

Kendall's tau-b, 2-tailed. n=35

Hypothesis 5f. Within the over-59-years old group, the older patients are, the more likely they will be to report that they suppress emotions.

Kendall's tau-b, 2-tailed, was employed to correlate ages of participants who were 60 years or more with scores for control of the expression of anger, anxiety and depressed mood as measured by the CECS.

As indicated in Table 47, there were no significant associations between ages of participants who were 60 years or more and CECS scores for control of the expression of anger, anxiety and depressed mood.

Table 47. Associations of ages of participants who were 60 years or more with scores of indices of emotional control

Type of emotional control	Correlations with age in over-59-year olds
All 3 emotional control indices	Not significant

Kendall's tau-b, 2-tailed, n=43

Hypothesis 6a. Within the under-60-year old group, the younger patients are, the more likely they will be to receive insufficient support from their social networks.

Ages of participants who were under-60-years old were correlated with all received emotional, informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

Ages of participants who were under-60-years old were significantly and negatively associated with received emotional support from health care professionals (-.207, $p<0.05$) as shown in Table 48.

Table 48. Associations of ages of participants who were under-60-years old with scores of received social support

Type of support	Correlations with age in under-60-year olds
Received emotional support from health care professionals	-.207, $p=.041$
All 13 other received support scores	Not significant

Kendall's tau-b, 2-tailed. $n=55$

Hypothesis 6b. Within the under-60-year old group, the younger patients are, the more likely they will be to perceive a support deficit from their social networks.

Ages of participants who were under-60-years old were correlated with all perceived emotional, informational, tangible and reassurance support variables investigated in the study, using Kendall's tau-b, 2-tailed.

As shown in Table 49, there were no significant associations of ages of participants who were under 60 years old with perceived support variables investigated in the study.

Table 49. Associations of ages of participants who were under-60-years old with scores of perceived social support

Type of perceived support	Correlations with age in under-60-year olds
All 14 perceived support scores	Not significant

Kendall's tau-b, 2-tailed. n=55

Hypotheses 6c and 6d. Within the under-60-years old group, the younger patients are, the more likely they will be to experience psychological distress and to perceive loss.

Ages of participants who were under-60-years old were correlated using Kendall's tau-b, 2-tailed, with scores for variables associated with psychological distress (i.e. RSCL items irritability, worrying, depressed mood, nervousness, desperate feelings about the future, tension, anxiety and difficulty in concentrating; and HAD Scale items anxiety and depression), as well as with perceived loss (i.e. physical strength, independence, role, physical restriction, social deficit and overall perceived loss).

As shown in Table 50, no significant associations were found between ages of participants under-60-years old and scores for variables associated with psychological distress or perceived loss.

Table 50. Associations of ages of participants who were under-60-years old with measures of psychological distress (RSCL & HAD Scale) and of perceived loss

Type of psychological distress/perceived loss	Correlations with age in under-60-year olds
All 16 scores of psychological distress and perceived loss	Not significant

Kendall's tau-b, 2-tailed. n=55

Hypothesis 6e. Within the under-60-years old group, the younger patients are, the more likely they will be to report a coping deficit.

Kendall's tau-b, 2-tailed, was employed to correlate ages of participants who were under-60-years old with scores for coping attitudes of anxious preoccupation, fatalism, helplessness/hopelessness, fighting spirit and avoidance as measured by the Mental Adjustment to Cancer scale (MAC).

As seen in Table 51, ages of participants under-60-years old were associated positively and significantly with scores for the coping attitude of fatalism (.216, p<0.05).

Table 51. Associations of ages of participants who were under-60-years old with scores on the Mental Adjustment to Cancer scale (MAC)

Type of coping attitude	Correlations with age in under-60-year olds
Fatalism	.216, p=.045
All 4 other MAC scores	Not significant

Kendall's tau-b, 2-tailed. n=45

Hypothesis 6f. Within the under-60-years old group, the younger patients are, the more likely they will be to report that they do not suppress emotions.

Kendall's tau-b, 2-tailed, was employed to correlate ages of participants who were under-60-years old with scores of control of the expression of anger, anxiety and depressed mood as measured by the CECS.

As indicated in Table 52, there were no significant associations between ages of participants under-60-years of age and scores for control of the expression of anger, anxiety and depressed mood as measured by the CECS.

Table 52. Associations of ages of participants who were under-60-years old with scores of emotional control as measured by the CECS

Type of emotional control	Correlations with age under-60-years old
All 3 emotional control indices	Not significant

Kendall's tau-b, 2-tailed. n=55

Hypothesis 7a. Gender will influence the provision of social support for patients with advanced cancer.

Since the scores for social support were not normally distributed, the non-parametric Mann-Whitney U Test was employed to determine whether gender of participants would influence reception of emotional, informational, tangible and reassurance support variables investigated in the study.

As shown in Table 53, there were significant differences in gender in the reception of emotional support from health care professionals ($Z= -2.112$, $p<0.05$), overall support from health care professionals ($Z=-2.007$, $p<0.05$), and informational support from family members ($Z=-3.070$, $p< 0.01$). Scores for female participants were higher for both received emotional and overall support from health care professionals. From a possible score of 12 for emotional support, 10 male and 25 female participants had scores of 9. Female participants had higher scores on 50% of the higher range of scores for overall support from health care professionals. Of the 51% of participants who received no informational support from family members, 7 out of 10 were female.

Table 53. Scores of gender with scores of received social support

Type of support	Z Score
Received emotional support from health care professionals	-2.122, p=.035
Received informational support from family	-3.070, p=.002
Received overall support from health care professionals	-2.007 p=.045
All 11 other received support scores	Not significant

Mann-Whitney U Test n=98

Hypothesis 7b. Gender will influence the perception of social support for patients with advanced cancer.

A Mann-Whitney U Test was employed to determine any differences due to gender in scores for the perception of emotional, informational, tangible and reassurance support variables investigated in the study.

No significant differences were found between gender and scores of perceived support in the social networks of participants, see Table 54.

Table 54. Scores of gender with scores of perceived social support

Type of perceived support	Z Scores
All 14 support variables	Not significant

Mann-Whitney U Test, n=98

Hypotheses 7c and 7d. The gender of patients with advanced cancer will influence their experience of psychological distress and perception of loss.

A Mann-Whitney U Test was employed to determine whether there would be significant differences due to gender for scores for variables associated with psychological distress (i.e. RSCL items irritability, worrying, depressed mood, nervousness, desperate feelings about the future, tension, anxiety and difficulty in concentrating; and HAD Scale items anxiety and depression), as well as with perceived loss (i.e. physical strength, independence, role, physical restriction, social deficit and overall perceived loss).

As Table 55 shows, female participants complained of irritability ($Z = -2.582$, $p < 0.01$) significantly more than male participants, felt loss of independence to a greater extent ($Z = -2.298$, $p < 0.025$) and experienced greater overall perceived loss ($Z = -1.922$, $p < 0.05$).

Table 55. Scores of gender with measures of psychological distress (RSCL & HAD Scale) and perceived loss

Type of psychological distress/perceived loss	Z Scores
Irritability	-2.582, p=.010
Independence	-2.298, p=.022
Overall perceived loss	-1.922, p=0.05
All 14 other psychological distress and loss items	Not significant

Mann-Whitney U Test n=93.

Hypothesis 7e. The gender of patients with advanced cancer will influence their coping attitudes.

A Mann-Whitney U test was employed to determine if gender of participants would show significant differences for coping attitudes of anxious preoccupation, fatalism, helplessness/hopelessness, fighting spirit and avoidance as measured by the Mental Adjustment to Cancer scale (MAC).

There were no significant differences between genders on scores for the Mental Adjustment to Cancer scale (MAC) of participants in the present study; see Table 56.

Table 56. Scores of gender for the Mental Adjustment to Cancer scale (MAC)

Type of coping attitude	Z Scores
All 5 MAC scores	Not significant

Mann-Whitney U Test n=80

Hypothesis 7f. Gender will influence the control of emotion in patients with advanced cancer.

A Mann-Whitney U test was employed to determine whether there would be differences determined by gender in control of the expression of anger, anxiety and depressed mood as measured by the CECS.

Table 57 shows that there were no significant differences between gender on scores of emotional control as measured by the CECS.

Table 57. Scores of gender of participants with scores of emotional control as measured by the CECS

Type of emotional control	Z Scores
All 3 emotional control indices	Not significant

Mann-Whitney U Test n=80

Hypothesis 8a. Satisfaction with overall support given by their family is associated with the use of positive coping mechanisms by patients with advanced cancer.

Kendall's tau-b, 2-tailed, was employed to correlate scores for participants' satisfaction with overall support given by their family with scores for coping attitudes of anxious preoccupation, fatalism, helplessness/hopelessness, fighting spirit and avoidance as measured by the Mental Adjustment to Cancer scale (MAC).

As can be seen in Table 58, MAC scale items anxious preoccupation (-.245, $p<0.01$) and helplessness/hopelessness (-.282, $p<0.005$) showed significant and negative associations, whilst fighting spirit (.196, $p< 0.05$) showed a significant and positive association with participants' satisfaction with overall support given by their family.

Table 58. Associations of scores of overall satisfaction with family support with scores of the Mental Adjustment to Cancer scale (MAC)

Type of coping attitude	Correlations with satisfaction with family support
Anxious preoccupation (MAC)	-245, p=.008
Helplessness/hopelessness (MAC)	-282, p=.003
Fighting spirit (MAC)	.196, p=.034
2 other scores for coping attitudes	Not significant

Kendall's tau-b, 2-tailed. n=80

Hypothesis 8b. Satisfaction with overall support given by their friend(s) is associated with the use of positive coping mechanisms by patients with advanced cancer.

Kendall's tau-b, 2-tailed, was employed to correlate scores for participants' satisfaction with overall support given by their friends with scores for coping attitudes of anxious preoccupation, fatalism, helplessness/hopelessness, fighting spirit and avoidance as measured by the Mental Adjustment to Cancer scale (MAC).

The single MAC scale item fatalism demonstrated a significant and positive association with participants' satisfaction with overall support given by their friends (.193, $p<0.05$), as indicated in Table 59.

Table 59. Associations of scores for overall satisfaction with friend support with scores to measure Mental Adjustment to Cancer (MAC)

Type of coping attitude	Correlations with satisfaction with support from friend(s)
Fatalism (MAC)	.193, p=.038
All 4 other coping attitudes	Not significant

Kendall's tau-b , 2-tailed n=80

Hypothesis 8c. Satisfaction with overall support given by their health care professional(s) is associated with the use of positive coping mechanisms by patients with advanced cancer.

Kendall's tau-b, 2-tailed, was employed to correlate scores for participants' satisfaction with overall support given by their health care professionals with scores for coping attitudes of anxious preoccupation, fatalism, helplessness/hopelessness, fighting spirit and avoidance as measured by the Mental Adjustment to Cancer scale (MAC).

There were significant and negative associations between participants' satisfaction with overall support given by their health care professionals and scores for coping attitudes of anxious preoccupation (-.287, p= 0.001) and helplessness/hopelessness (-.265, p <0.005) as indicated in Table 60.

Table 60. Associations of scores for overall satisfaction with health care professional support with scores of the Mental Adjustment to Cancer scale (MAC)

Type of coping attitude	Correlations with satisfaction with support from HCPs
Anxious preoccupation	-.287, p=.001
Helplessness/hopelessness (MAC)	-.265, p=.004
All 3 other coping attitudes	Not significant

Kendall's tau-b, 2-tailed, n=80

Hypothesis 9a. Satisfaction with overall support given by their family is negatively associated with (i) psychological distress and (ii) perceived loss in patients with advanced cancer.

Scores for participants' satisfaction with overall support given by their family were correlated, using Kendall's tau-b, 2-tailed, with scores for variables associated with psychological distress (i.e. RSCL items irritability, worrying, depressed mood, nervousness, desperate feelings about the future, tension, anxiety and difficulty in concentrating; and HAD Scale items anxiety and depression), and with scores for variables associated with perceived loss (i.e. physical strength, independence, role, physical restriction, social deficit and overall perceived loss).

As shown in Table 61, psychological distress items which showed a significant negative association with participants' satisfaction with overall support given by their family were RSCL items irritability (-.270, p<0.005), depressed mood (-.217, p<0.025), tension (-.199, p<0.05) and anxiety (-.225, p<0.025) and HAD Scale items anxiety (-.300, p<.001) and depression (-.192, p<0.05). Overall perceived loss was significantly negatively associated with participants' overall satisfaction with family support (-.185, p<0.05).

Table 61. Associations of scores of overall satisfaction with family support with scores to measure psychological distress (RSCL & HAD Scale) and perceived loss

Type of psychological distress/perceived loss	Correlations with satisfaction with overall support from family
Irritability (RSCL)	-.270, p=.004
Depressed mood (RSCL)	-.217, p=.017
Tension (RSCL)	-.199, p=.030
Anxiety (RSCL)	-.225, p=.013
Anxiety (HAD)	-.300, p=.001
Depression (HAD)	-.192, p=.028
Overall perceived loss	-.185, p=.035
All 9 other scores of psychological distress and loss	Not significant

Kendall's tau-b, 2-tailed. n=98

Hypothesis 9b. Satisfaction with overall support given by their friend(s) is negatively associated with (i) psychological distress and (ii) perceived loss in patients with advanced cancer.

Scores for participants' satisfaction with overall support given by their friend(s) were correlated, using Kendall's tau-b, 2-tailed, with scores for variables associated with psychological distress (i.e. RSCL items irritability, worrying, depressed mood, nervousness, desperate feelings about the future, tension, anxiety and difficulty in concentrating; and HAD Scale items anxiety and depression), and with scores for variables associated with perceived loss (i.e. physical strength, independence, role, physical restriction, social deficit and overall perceived loss).

As shown in Table 62, no significant associations emerged between satisfaction with overall support given by their friends and scores of psychological distress and perceived loss experienced by participants in the study.

Table 62. Associations of scores of overall satisfaction with friend(s) support with scores to measure psychological distress (RSCL & HAD Scale) and perceived loss

Type of psychological distress/perceived loss	Correlations with satisfaction with overall support from friend(s)
All 16 psychological distress and loss scores	Not significant

Kendall's tau-b, 2-tailed. n=98

Hypothesis 9c. Satisfaction with overall support given by their health care professional(s) (HCPs) is negatively associated with (i) psychological distress and (ii) perceived loss in patients with advanced cancer.

Scores for participants' satisfaction with overall support given by their health care professionals were correlated, using Kendall's tau-b, 2-tailed, with scores for variables associated with psychological distress (i.e. RSCL items irritability, worrying, depressed mood, nervousness, desperate feelings about the future, tension, anxiety and difficulty in concentrating; and HAD Scale items anxiety and depression), and with scores for variables associated with perceived loss (i.e. physical strength, independence, role, physical restriction, social deficit and overall perceived loss).

Table 63 shows that anxiety, as measured by the HAD Scale, was the single psychological distress variable significantly and negatively associated with participants' overall satisfaction with support given by their health care professionals (-.201, p<0.025).

Table 63. Associations of scores of overall satisfaction with health care professional(s) (HCPs) support with measures of psychological distress (RSCL & HAD Scale) and perceived loss

Type of psychological distress/loss	Correlations with satisfaction with overall support from HCPs
Anxiety (HAD)	-.201, p=.017
All 15 other psychological distress and perceived loss scores	Not significant

Kendall's tau-b, 2-tailed. n=98

The relationships found in testing the hypotheses can be summarised as follows:

Table 64. Significance levels of the hypotheses tested

	Number of items at significance levels						
Hypothesis	.05	.025	.01	.005	.0025	.001	Number of items not significant
1	2	2	1				44
2	5						44
3	1	1		1			46
4	6	4				1	38
5	1	1	1				49
6	2						50
7	2	1	2				47
8	2		1	2		1	9
9	3	3		1		1	40
Total	24	12	5	4		3	367

Of the 415 significance tests carried out, by chance alone one would expect about 20 to be significant at the .05 level, 10 to be significant at the .025 level and 4 at the .01 level. Hence, the only correlations in which one would place much reliance are those significant at the .005 or, better still, the .001 level. A cross-validation study would be desirable to decide which correlations at lower levels of significance than the .001 level are spurious chance effects and which are genuine ones.

Results related to qualitative analysis

As indicated in the methodology section a qualitative question focused upon the effects of cancer on participants' quality of life. The researcher asked participants to describe in their own words what change having cancer had made to their lives. The most salient theme which emerged was one of loss which impacted on many aspects of life, from every-day activity to long-term hopes. Within the theme of loss were the following sub-themes:

(1) The restriction imposed upon activities of daily living by the experience of cancer is reflected in the following comments by participants:

It (cancer) prohibits everything, puts up barriers. I've had to give up cycling.

I used to go for bike rides with my friends.

The main change is the restriction of my social and practical life.

The greatest change is lack of confidence because I can no longer do the things I used to do. It's terrible.

I cannot do simple things like going for a walk. Everything is a major problem.

I can't travel or move about, I am unable. I wouldn't mind if I was able to move.

My social life and every thing has changed. I can't go out the way I used to. It's horrible, absolutely horrible.

I miss getting out and walking. Life is restricted.

The day revolves around treatment rather than work.

I used to cycle. I cannot do that anymore. Life has completely changed in the last year.
It (cancer) has cut down on my activity. Very much loss. Everything.

I gave up work. Can no longer cycle. I could walk miles before this happened.

I used to enjoy manual work and now I'm restricted. I used to play golf and I cannot do that anymore.

(2) Participants' inability to make plans because of restrictions imposed by cancer continues the previous theme of activity restriction:

I can't make plans for the future. I'm slowed down, restricted.

I cannot make plans. It (cancer) has stopped me from working. I make plans but find I cannot carry them through.

My whole world is shattered. I cannot plan for tomorrow or anything.

You don't think long-term, just day to day. Before, I would have been thinking years and years ahead.

(3) The loss of independence (and privacy) was a salient feature in the comments made by participants.

My independence has been compromised.

I have lost independence and freedom of choice.

I'm not going to let it interfere. I'll try to carry on just the same, even though I've lost my independence.

I have lost my independence because I cannot drive and I'm restricted in what I do, even dressing myself, since my arm lost its mobility with lymphoedema.

I find the loss of independence very hard to take. The loss of privacy is dreadful.

(4) A feeling of dissatisfaction with quality of life and the negative effect of having cancer is evident in the following comments made by participants:

I feel crippled, frustrated, confused. You want to get on with your life. You feel crippled, I cannot even carry my handbag. It's 'don't do this'...I am very angry. Work is the only sanity they've left me. I can't go on holiday. Your life is taken out of your control, no control. You take the tablets, do what you're told. They stick you with needles. You submit because it's your only option.

One participant speaking of their metastatic recurrence of cancer stated: *Up to now it hasn't made much change in my life as I've been able to cope. But this last illness has been terrible. My whole attitude to my life and to life, my everyday life, has changed. Everything is negative at the moment. During my previous illness I was never this low.*

You have to stare fear in the face.

Shattering. My whole world is shattered.

I'm off-balance all the time.

The major change is financial.

My standard of living has dropped fifty percent.

I am concerned about the children getting cancer. I am really worried about my children, grandchildren and husband getting cancer.

I was 73 when diagnosed (with cancer). At that age your life is over anyway.

Having cancer has changed everything, the loss of health is the main thing. I cannot communicate easily, I am very slowed down.

(5) Several people commented on the sexual difficulties they were experiencing, as a result of the disease or the treatment. One person stated: *My sex life is severely affected. I'm tired and not sleeping. I have no control. I feel differently about things. Due to having cancer I've seen things in a different perspective. Lots of things that were unimportant became important.*

(6) The impact of pain on daily living and quality of life of participants was clearly expressed:

I had a reduction in confidence until the pain was controlled. I cut back activity because I would tire more easily. I wasn't sure of seeing work through to the end.

It has really spoilt my life. The pain took over me and my whole life.

I'm going through the chemotherapy, the pain, the worry and I don't have the confidence that it will work. It has changed my total attitude to life for the second time. Everything you get you are going to think it's cancer back again. I am terrified of living through it.

I can't do all the things I'd love to do. The pain is very depressing. It seems to be hospital after hospital.

(7) Some participants found that relationships with their families and friends became detrimentally altered:

My friends dropped me like a hot potato.

There is loneliness, less contact with people. I've had to give up sports.

I find the neighbours compare me to a person who has just died rather than seeing me as a person.

My illness has affected the family.

My relationship with my daughters has deteriorated. I have lost friends, relatives and family.

The happiness in the home has gone. Everything was carefree, now everyone is putting on a front.

Overall, the verbal descriptions most people gave of the effects of cancer on their lives were of imposed restriction and loss, strain and reduced quality of life with increased distress, financial burden and unhappiness; so there was a broad spectrum of suffering. Some were able to find a more positive meaning to their altered lives. The experience of cancer as a positive influence on developing new values is reflected in the following comments made by some participants. Nonetheless, the experience of living with the effects of cancer was generally perceived as extremely difficult.:

I value little things more—a walk on the beach.

Another participant stated: *Having cancer has made me look at things completely differently—it has made me value my time more. What I used to think of as major worries are now of no importance. I don't worry about things too much.*

Other comments included:

I *value every day.*

I've learned to be more open with myself.

Makes one more aware of how people suffer with the disease.

It has put things into perspective. I feel calmer, less worried about things.

The improved quality in their emotional life was commented on by one participant who said: *It has changed my outlook. I feel more caring towards other people. I suppose the reason for that is that I am getting so much caring from others.* Another participant commented: *I try to help others more. Now I work for others and do things for other people, whereas I didn't before.*

Table 65: Participants' overall perception of the effects of cancer on quality of life

Participants' overall perception of the effects of cancer on quality of life		
	Male	Female
Negative	83.3%	85.7%
Positive	4.8%	8.9%
No change	11.9%	5.4%
Total	100.0%	100.0%

Results related to regression analysis

Step-wise regression analyses were carried out to see if appropriately weighted combinations of the independent variables would improve notably on their individual power to predict various dependent variables.

Summaries of the main findings follow here:

Dependent variable: average pain

Table 66. Coefficients for dependant variable average pain

Variables entered	Model	Standardised coefficients Beta
Model 1: physical restriction	1 physical restriction	.309
Model 2: MAC avoidance	2 physical restriction	.288
	MAC avoidance	.263
Model 3: perceived overall support from health care professionals	3 physical restriction	.245
	MAC avoidance	.271
	perceived overall support from HCPs	-.229
Model 4: received emotional support from HCPs	4 physical restriction	.166
	MAC avoidance	.196
	perceived overall support from HCPs	-.351
	received emotional support from HCPs	.336
Variable removed		
Model 5: physical restriction	5 MAC avoidance	.198
	perceived overall support from HCPs	-.396
	received emotional support from HCPs	.381
Variables entered		
Model 6: received tangible support from family	6 MAC avoidance	.212
	perceived overall support from HCPs	-.446
	received emotional support from HCPs	.410
	received tangible support from family	.206
Model 7: perceived tangible support from family	7 MAC avoidance	.226
	perceived overall support from HCPs	-.422
	received emotional support from HCPs	.374
	received tangible support from family	.330
	perceived tangible support from family	.244

Table 67. Model summary for dependant variable average pain

Model	R	R Square	Adjusted R Square	Std.error of the estimate
1	.309	.095	.083	1.08
2	.405	.164	.141	1.05
3	.463	.215	.182	1.02
4	.551	.303	.264	0.97
5	.528	.278	.248	0.98
6	.564	.318	.280	0.96
7	.600	.360	.314	0.94

Table 68. Analysis of variance for dependant variable average pain

Model	Sum of Squares	df	Mean Square	F	Sig
1 Regression	9.103	1	9.103	7.785	0.007a
Residual	86.529	74	1.169		
Total	95.632	75			
2 Regression	15.673	2	7.837	7.155	0.001b
Residual	79.958	73	1.095		
Total	95.632	75			
3 Regression	20.514	3	6.838	6.554	0.001c
Residual	75.117	72	1.043		
Total	95.632	75			
4 Regression	28.988	4	7.247	7.721	0.000d
Residual	66.644	71	0.939		
Total	95.632	75			
5 Regression	26.623	3	8.874	9.259	0.000e
Residual	69.008	72	0.958		
Total	95.632	75			
6 Regression	30.426	4	7.606	8.282	0.000f
Residual	65.206	71	0.918		
Total	95.632	75			
7 Regression	34.385	5	6.877	7.860	0.000g
Residual	61.247	70	0.875		
Total	95.632	75			

Predictors (Constant):
a: physical restriction
b: physical restriction, MAC avoidance
c: physical restriction, MAC avoidance; perceived overall support from HCPs
d: physical restriction, MAC avoidance; perceived overall support from HCPs received emotional support from HCPs
e: MAC avoidance; perceived overall support from HCPs; received emotional support from HCPs
f: MAC avoidance; perceived overall support from HCPs; received emotional support from HCPs; received tangible support from family
g: MAC avoidance; perceived overall support from HCPs; received emotional support from HCPs; received tangible support from family; perceived tangible support from family

The main conclusion to be drawn is that in an appropriately weighted combination, the predictors in Model 7, i.e.: MAC avoidance, perceived overall support from health care professionals, received emotional support from health care professionals, received tangible support from family and perceived tangible support from family, account for 31.4% of the variance in the dependent variable (average pain).

NB. Other variables, such as length of time since diagnosis, marital status and education level, were not significantly associated with average pain, so were not included in the regression analysis.

Dependent variable: average pain intensity rated as moderate to high

Table 69. Coefficients for dependent variable average pain intensity rated as moderate to high

Variables entered	Model	Standardised coefficients beta
Model 1: MAC fatalism	1 MAC fatalism	-.349
Model 2: perceived reassurance support from HCPs	2 MAC fatalism	-.369
	perceived reassurance support from HCPs	.309
Model 3: received overall support from HCPs	3 MAC fatalism	-.306
	perceived reassurance support from HCPs	.418
	received overall support from HCPs	.339

Table 70. Model summary for dependent variable average pain intensity rated as moderate to high

Model	R	R Square	Adjusted R Square	Std. Error of the estimate
1	.349	.122	.099	.45
2	.466	.217	.175	.43
3	.562	.316	.259	.41

Table 71. Analysis of variance for dependent variable average pain intensity rated as moderate to high

Model	Sum of squares	df	Mean Square	F	Sig.
1 Regression	1.071	1	1.071	5.282	.027a
Residual	7.704	38	0.203		
2 Regression	1.907	2	0.954	5.138	.011b
Residual	6.868	37	0.186		
3 Regression	2.771	3	0.924	5.538	.003c
Residual	6.004	36	0.167		

Predictors (Constant)

a: MAC fatalism
b: MAC fatalism, perceived reassurance support from HCPs
c: MAC fatalism, perceived reassurance support from HCPs, received overall support from HCPs

The main conclusion to be drawn is that in an appropriately weighted combination, the predictors in Model 3, i.e., MAC fatalism, perceived reassurance support from health care professionals and received overall support from health care professionals, account for 25.9% of the variance in the dependent variable (average pain rated as moderate to high).

Dependent variable: present pain

Table 72. Coefficients for dependent variable present pain

Variables entered	Model	Standardised coefficients beta
Model 1: HAD Anxiety	1 HAD Anxiety	.346
Model 2: MAC anxious preoccupation	2 HAD Anxiety	.523
	MAC anxious preoccupation	-.323
Model 3: received tangible support from friends	3 HAD Anxiety	.553
	MAC anxious preoccupation	-.352
	received tangible support from friends	.266

Table 73. Model summary for dependent variable present pain

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.346	.120	.108	.93
2	.439	.193	.171	.89
3	.513	.263	.232	.86

Table 74. Analysis of variance for dependent variable present pain

Model	Sum of Squares	df	Mean Square	F	Sig
1 Regression	8.603	1	8.603	10.053	0.002a
Residual	63.331	74	0.856		
Total	71.934	75			
2 Regression	13.859	2	6.930	8.710	0.000b
Residual	58.075	73	0.796		
Total	71.934	75			
3 Regression	18.904	3	6.301	8.556	0.000c
Residual	53.030	72	0.737		
Total	71.934	75			

Predictors (constant)

a: HAD anxiety
b: HAD anxiety, MAC anxious preoccupation
c: HAD anxiety, MAC anxious preoccupation, received tangible support from friends

The main conclusion to be drawn is that in an appropriately weighted combination, the predictors in Model 3, i.e.: HAD anxiety, MAC anxious preoccupation and received tangible support from friends, account for 23.2% of the variance in the dependent variable (present pain).

Dependent variable: overall evaluated pain experience

Table 75. Coefficients for dependent variable overall evaluated pain experience

Variables entered	Model	Standardised coefficients beta
Model 1: physical restriction	1 physical restriction	.331
Model 2: irritability	2 physical restriction	.304
	irritability	.270
Model 3: MAC avoidance	3 physical restriction	.286
	irritability	.272
	MAC avoidance	.219

Table 76. Model summary for dependent variable overall evaluated pain experience

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.331	.109	.097	1.52
2	.426	.181	.159	1.46
3	.478	.229	.197	1.43

Table 77. Analysis of Variance for dependent variable overall evaluated pain experience

Model	Sum of Squares	df	Mean Square	F	Sig.
1: Regression	20.851	1	20.851	9.080	0.004a
Residual	169.938	74	2.296		
Total	190.789	75			
2: Regression	34.578	2	17.289	8.079	0.001b
Residual	156.211	73	2.140		
Total	190.789	75			
3: Regression	43.641	3	14.547	7.118	0.000c
Residual	147.148	72	2.044		
Total	190.789	75			

Predictors (Constant)

a: physical restriction
b: physical restriction, irritability
c: physical restriction, irritability, MAC avoidance

The main conclusion to be drawn is that, in an appropriately weighted combination, the predictors in Model 3, i.e. physical restriction, irritability and MAC avoidance, account for 19.7% of the variance in the dependent variable (overall evaluated pain experience).

DISCUSSION

In view of the large number of hypotheses tested and the consequent possibility of spuriously significant results, the first part of the discussion will focus on those where for the most part the findings had $p < 0.01$ or less. Those where $.01 < p < 0.05$ will be considered after that. As most of the statistical tests applied were 2-tailed, it does not necessarily follow that all of the results with $p < 0.01$ ran in the predicted direction, but those that did will be considered at the outset.

Hypotheses supported by study findings

The present study looked at support offered by health care professionals caring for participants. Findings showed that participants' average pain experience was significantly and positively associated with received emotional support from health care professionals (Table 27). As discussed in Chapter 4, health care professionals, including nurses and doctors, are viewed as providers of emotional, informational and appraisal support for patients with cancer (e.g. Galbraith, 1995; Northouse & Peters-Golden, 1993; Grande *et al.*, 1996). Emotional support is viewed as being especially helpful by patients (Dunkel-Schetter, 1984). However, the finding of the present study is that the more pain, the more support. One possible interpretation of this is that the support is ineffective, so the connection with Dunkel-Schetter's finding is by no means clear.

Relevant to the present study is the consideration of whether the coping ability of patients with cancer can be enhanced by social support and if so, what type of support is optimal and what conditions must be met for support to be effective. Emotional, tangible, appraisal or informational forms of social support are considered to have the capacity to buffer major life events (Wills, 1985). Social support may work by assisting an individual either to change the situation through problem-focused coping, or to change how he or she feels about the situation, through emotion-focused coping (Lazarus & Folkman, 1984; Thoits, 1986), thus helping to control his or her feelings of anxiety or depression brought about by the demands of the situation. Research indicates that overall network structure and tangible support are less effective in producing stress-buffering effects than is emotional aid (e.g. Turner, 1981). Effective support is most likely to come from socially similar others who have faced, or are facing the same stressors and who have done so, or are doing so, more calmly than the distressed individual, thereby enhancing the likelihood of the perception and reception of empathic understanding, the condition under which coping assistance should be most effective (Thoits, 1986). It is predicted that for people facing high or low levels of difficult life events, those with higher quality social support will enjoy greater physical and mental health (Cutrona, 1996). A study by Thoits (1984), on the psychological vulnerability of disadvantaged people to undesirable life events, found that emotional support was significantly and negatively associated with anxiety and depression.

Levels of present pain were lower than levels of average pain (Tables 13 & 14). One reason for this is that, as shown in Table 12, 50% of study participants were receiving palliative radiotherapy and 30.2% were receiving palliative chemotherapy as modes of symptom control (e.g. Souhami & Tobias, 1998). Although few investigations have described the nature of coping with pain (Arathuzik, 1991a), the relationship of the two appears to correspond with a transactional theory of stress as discussed in Chapter 3 (e.g. Lazarus & Folkman, 1984). A key feature of this model is that both cognitive and affective appraisal are used to interpret and guide coping responses (Arathuzik, 1991a). Viewed from this perspective, pain is a stressor (Selye, 1979a). The person's response to pain is an interpretation of the significance of pain in terms of the person's well-being (Copp, 1973). A person's pain is not only a direct result of the pain sensation, but is formed by the cognitive and emotional reactions to the noxious pain experience. The emotional responses include anxiety, depression and anger, which, in conjunction with the physiological and psychosocial effects, contribute to the appraisal of the pain experience as future threat, actual harm and/or challenge. The appraisal of challenge places the focus positively on potential growth (Cohen & Lazarus, 1980). Cognitive and emotional factors appear to play a central role in the response to pain and in the coping methods used to deal with it.

In the present study, there was a significant and positive association between participants' perception of their present pain experience and anxiety (Table 36).
As discussed in Chapter 2, cancer pain almost always results in some degree of anxiety or depression (e.g. Daut & Cleeland, 1982; Bonica, 1990; Spiegel, Sands & Koopman, 1994). Psychologically, cancer pain can be devastating. If a person with cancer

believes that pain indicates the worsening of a feared, destructive, fatal disease, he or she may lose hope. The inability to cope or to understand pain treatment options may lead to impaired self-image, anxiety and depression (Breitbart, 1994). The relationship between pain and anxiety or depression is complicated and unclear. Although anxiety or depression is rarely the sole cause of pain, it certainly affects how the patient handles pain. For example, anxiety or depression probably makes pain more difficult to bear and adversely affects the patient's outlook and motivation or ability to be involved in his/her own pain control. Anxiety is usually associated with brief pain, whereas depression tends to accompany prolonged pain; an element of both is usually present with all pain (McCaffrey *et al.*, 1994). Partly unrelieved pain contributes to the overall total pain experience, not only by causing immediate physical suffering, but also by increasing anxiety levels and fear about the future (Strang, 1997).

One interpretation of the finding that there was a significant and positive association between participants' perception of their present pain experience and anxiety (Table 36), is that, in the present study, participants viewed their pain as harmful and/or threatening, in accordance with the conceptual framework of Lazarus (1982) as outlined in Chapter 3 (Arathuzik, 1991a). However, results do not indicate that participants were able to view their present pain as a challenge, sufficient to mobilise their own coping resources (e.g. Watson *et al.*, 1988b; Greer *et al.*, 1979) to deal with the difficulties the pain experience imposed. Analyses of the microrelations between self-efficacy and anxiety arousal reveal that perceived coping inefficacy is accompanied by high levels of subjective distress, autonomic arousal and catecholamine secretion. Environmental events are not always completely under personal control, and most human activities contain some potential risks. The exercise of control over anxiety arousal, therefore, requires not only development of behavioural coping efficacy but also of efficacy in controlling dysfunctional apprehensive cognitions (Bandura, 1988). Perceived self-efficacy in thought control is a key factor in the regulation of cognitively-generated arousal (Bandura, 1992). It is not the sheer frequency of disturbing cognitions, but the perceived inability to stop them, that is the major source of distress (e.g. Churchill, 1990; Kent, 1987). People experience anxiety when they cannot control potentially injurious events. People are saddened and depressed by their perceived inefficacy in gaining highly valued outcomes (Bandura, 1992). Therefore, a focus by health care professionals on optimal pain control becomes central to the care of the person with cancer-induced pain. The aim is to reduce physical discomfort and improve the quality of life of patients with cancer, to help restore their sense of control (D'Zurilla & Sheedy, 1991), and to facilitate positive forms of coping, in order to lessen negative emotions and reduce physiological arousal (Katz & Epstein, 1991).

As discussed in Chapter 2, although recent advances enable pain to be controlled in approximately 90% of patients with cancer, under-treatment of pain constitutes a serious problem (Breitbart, 1994). Doctors and nurses may under-estimate the patient's level of pain because they use inadequate assessment tools, fail to recognise the patient's psychological distress as being due to pain, or because they have insufficient knowledge. Doctors and nurses may label a patient's pain as 'psychological,' without recognising that psychological distress contributes to pain perception (McCaffrey *et al.*, 1994).

A nurse may expect a patient to communicate his or her pain verbally or to show signs of pain through non-verbal behaviour. However, patients may adapt to pain both behaviourally and physiologically, perhaps because they place a high value on self-control and suppress signs of suffering (Sofaer, 1998). Western society tends to separate the experience of pain from the expression of pain. Only patients can indicate what pain they experience and the efficacy of the analgesia given to them. It is not only language which gives clues to a patient's discomfort or pain. A patient's silence must not be taken to mean that he or she is not suffering; for some patients, cultural and spiritual beliefs may require silence. However, many therapies are based on patients' expression of pain. Pointing to an area is the only communication nurses may receive from one patient; while more demonstrative behaviour and articulation may be elicited from another. This does not mean that the pain is greater for the second than for the first, but may simply reflect cultural differences. Both patients may be equally difficult to assess for appropriate administration of analgesia (Waddie, 1996). Nurses must realise that many patients may experience pain which is not expressed and is unrelieved (Foucault, 1989). The aim of pain management should be to ensure that pain never exceeds patients' abilities to cope (Walker, 1992).

Optimal pain control is a prerequisite for patients to gain maximally from the benefits of social support. Pain and distress are known to have a circular effect, one upon the other (cf. Twycross, 1994). Social support has been shown to be associated with reduced anxiety and depression (Cutrona, 1986; Thoits, 1984; Turner, 1981). Therefore, it is important to look at the possible interactions of pain and negative coping attitudes in the context of the present study, before looking at the ways in which coping might be enhanced by social support. Participants' overall evaluated pain was significantly and positively associated with helplessness/hopelessness and significantly and negatively associated with fighting spirit (Table 41). As discussed in Chapter 3, a learned-helplessness theory of depression suggests that, although anxiety is the initial response to a stressful situation, it is replaced by depression if a person comes to believe that control is unattainable. An ongoing experience of pain may reduce a person's sense of mastery (Pearlin *et al.*, 1981). The severe psychological distress associated with advanced cancer may be brought about by a person's experience of pain, together with the consequences of the pain experience, such as reduced social contact, family distress, impaired physical strength and reduced activity level (e.g. Daut & Cleeland, 1982; Breitbart, 1989; Bonica, 1990). Once again, these findings highlight the absolute necessity of adequate pain control. At the time of questionnaire completion, 59.2% of the study participants stated that they were pain-free, while 37.8% of participants described their average pain intensity for the month prior to the study as 'severe' and 51% of study participants rated their overall evaluated pain for the month prior to the study as 'distressing' to 'excruciating' (Tables 13, 14 and 15).

According to the attributional revision of helplessness theory (Abramson, Seligman & Teadale, 1978), the way a person attributes failure will determine its subsequent effects. Global attributions should increase the generality of the effects of failure. Attributions to stable factors will make the effects long-term. Finally, attributing the failure to internal characteristics is more likely to diminish self-esteem, particularly if the personal fault is also global and persistent. People become depressed when they believe either that desired outcomes are unattainable or that negative outcomes are unavoidable. The generality and chronicity of a person's depression and loss of self-esteem depend on the globality and persistence of the factors blamed. The depression-prone individual is thought to show a 'depressive attributional style', a tendency to attribute bad outcomes to personal, global, stable faults of character. When persons with this style have unhappy, adverse experiences, they become depressed and self-esteem shatters (Peterson & Seligman, 1984). Thus, optimal pain control underpins and is the starting point for interventions aimed at reducing distress, restoring control and maximising the quality of life of the person with cancer.

The relevancy of specific coping attitudes to survival outcome is controversial. As discussed in Chapter 3, some studies have shown that a coping attitude of helplessness/hopelessness is associated with less favourable survival rates than is fighting spirit or denial as an initial reaction to a diagnosis of cancer (Greer et al, 1979; Pettingale *et al.*, 1985). Watson (1999) found no effect for an attitude of fighting spirit, but found that a high helpless/hopeless response had a detrimental effect on five-year event-free survival for women with early breast cancer. Derogatis *et al.* (1979) showed that psychological coping mechanisms correlated positively with length of survival in women with metastatic breast cancer. The importance of pain control both in the context of quality of life and in the context of length of survival thus becomes paramount. If coping skills and sense of mastery are eroded by the experience of severe pain, then it is possible that both quality of life and length of survival will be detrimentally affected (e.g. Pearlin *et al.*, 1981; Daut & Cleeland, 1982; Breitbart, 1989; Bonica, 1990). The consequences of severe pain highlight the importance of pre-empting and preventing its experience. Adequate and effective methods of pain assessment by health care professionals, combined with supportive interpersonal relations, may reduce the aversiveness of life events that give rise to stress and depression (e.g. Cassel, 1982; Bonica, 1990; McCaffrey *et al.*, 1994). When pain is optimally controlled and psychological distress has been assessed (e.g. Holland, 1999), consideration can be given to other factors that may enhance the quality of life of the patient with cancer. In the context of the present study, it was important to find out which type of support was considered to be most appropriate, and who the most appropriate support providers were from the point of view of participants. Whether enhanced coping would be a possible outcome, as a consequence of ensuring that such support was provided, was another relevant issue.

As already mentioned, participants' overall evaluated pain experience was significantly and positively associated with helplessness/hopelessness and significantly and negatively associated with fighting spirit (Table 41). In contrast, satisfaction with overall support provided by their family was significantly and negatively associated with participants' anxious preoccupation, helplessness/hopelessness, five measures of psychological distress, and overall perceived loss; and significantly and positively associated with fighting spirit (Tables 58 and 61). Satisfaction with overall support provided by their health care professionals was significantly and negatively associated with participants' anxious preoccupation, helplessness/hopelessness and anxiety (Tables 60 and 63). Average pain intensity was shown to be positively associated with physical restriction but with no other measures of psychological distress or perceived loss (Table 28).

One possible interpretation of these findings is in line with the idea of social support as having a stress-buffering effect, with the potential to reduce anxiety and depression (Turner, 1981; Thoits, 1984). This viewpoint is further enhanced by the finding that satisfaction with overall support by their health care professionals was significantly and negatively associated with participants' experience of anxiety (Table 63). It points to the need for (1) help for spouses and families so that they can provide the necessary support as required by people with cancer, and (2) raising the awareness of health care professionals that the provision of social support is associated with reduced distress, enhanced coping and therefore improved quality of life for patients with cancer.

Emotion-focused coping, including distraction and avoidance, is relied on more when situations are regarded as not changeable (Folkman, Chesney, McKusick, Ironson, Johnson & Coates, 1991). In the present study, participants' average pain experience was significantly and positively associated with avoidance (Table 29). Denial of a diagnosis of cancer has been defined as 'apparent active rejection of any evidence about the diagnosis which might have been offered' (Greer *et al*., 1979). As indicated in Chapter 3, some patients who have been informed of their diagnosis may find that an attitude of avoidance/denial (i.e. 'I don't really believe I have cancer') helps to lessen psychological distress (Watson, Greer, Blake & Shrapnell, 1984). It has been found that people with few social resources tend to use avoidance more than do those with more social resources (Billings & Moos, 1981). There is controversy about whether denial, although the most common response among cancer patients, is the most effective method of stress reduction in the long term, although this coping attitude has been shown to be a good short-term adaptive response for people newly diagnosed with cancer. Research has indicated that people with cancer who denied the seriousness of a cancer diagnosis experienced significantly less mood disturbance during this period than did those who were more accepting of the implications (Watson *et al.*, 1984). The phenomenon of avoidance/denial may also become less common with changes in medical practice (Watson *et al.*, 1988b). However, in the sample of participants recruited for the present study, care was taken to check with their medical team that each participant had definitely been informed of his or her diagnosis, but not necessarily of the prognosis. Therefore, issues are raised about (1) whether participants' avoidant coping attitudes were influenced by their experience of pain and/or their experience of social support; (2) whether participants were informed of their diagnosis in a way that they could fully understand; and (3) if participants did fully understand the implications of the information, whether their coping attitude of avoidance/denial helped to reduce their psychological distress (e.g. Watson *et al.*, 1984) or reflected their perceived loss of self-efficacy (Bandura, 1988).

An attitude of avoidance might be one way for a person with cancer to cope with the anxiety associated with the uncertainty surrounding their illness (Watson *et al.*, 1984; Waitzkin, 1985). During the past two decades, many psycho-oncological studies have focused on communications between oncologists and their patients. Most studies have reported that patients wish to be well informed about both general and specific aspects of their disease and its treatment. Many topics are usually discussed during oncological consultations, and exposure to potentially threatening information may be a source of distress to patients (Fallowfield, 1993). In studies of patients' coping styles in uncontrollable, hypothetical stress situations (Miller, 1987; Krohne, 1989), two basic modes of coping were distinguished. One coping style has been called 'monitoring' or 'cognitive confrontation' and involves the tendency to actively seek information about the aversive event. The other coping style has been termed 'blunting' or 'cognitive avoidance', describing the individual's tendency to seek distraction from the threatening situation. Patients' coping styles have been shown to influence doctors' provision of information (Watkins, Weaver & Odegaard, 1986). A monitoring style appears to encourage patients' question-asking and dominance during the oncological consultation (Ong, Visser, Van Zuuren, Rietbroek, Lammes & de Haes, 1999). Also, prognosis and clinical uncertainty about either diagnosis or prognosis might be major factors influencing how information is being given to patients by doctors (Waitzkin, 1985).

In a study by Weisman & Worden (1977), patients were categorised as using denial if they avoided using the word 'cancer' or blatantly ignored the disease. Also included were patients who were reluctant to talk about illness symptoms and who minimised potential areas of distress (Watson *et al.*, 1984). Doctor-patient communication should be considered not only as information exchange and central to creating a therapeutic relationship, but also as support for the person with cancer (cf. Chapter 4; also Delvaux & Razavi, 1997). With regard to the present study, it is possible that doctors used language that was unclear for some participants. Also, given the lack of back-up facilities at the time, many doctor were working within serious time constraints. Some participants may have been reluctant to 'make a nuisance of themselves' and, if informed that they had a 'tumour,' may genuinely have believed that they did not have cancer. As stated in Chapter 4, doctors often avoid the use of the word 'cancer' when discussing a patient's diagnosis with them, resorting to the use of euphemistic terms such as 'tumour,' 'growth,' 'lump,' 'wart' or 'polyp' which may evoke less strong emotions in both patient and doctor. Health care professionals may communicate nonverbal signals that discourage communication in an effective and empathic manner. Patients can evoke reactions in health professionals that lead to various forms of indirect avoidance, so that their communication and psychological needs are never appreciated or dealt with (Anstey, 1991). These communication deficits, coupled with attitudes of passivity by the patient and paternalism by the doctor, might mitigate against the sharing of information as part of a two-way dialogue (Buckman, 1992). Although there is an increasing proportion of doctors combining the passive withholding of information with the provision of carefully chosen facts (Razavi, Delvaux & Hopwood, 1997), the success of the interaction also requires active participation by the patient. Patients and their spouses and families require access to accurate information that can be repeated, questioned and clarified as necessary, with opportunities to interpret it and gain an accurate understanding (Northouse *et al.*, 1991).

Participants' present pain experience was significantly and positively associated with tangible support received from family and friends (Table 35). However, in those patients with high average pain experience, the pain was significantly and negatively associated with perceived emotional, informational and tangible support from friends (Table 34). As previously pointed out, cancer alters the dynamics of relationships between friends, and most friendships are circumscribed in time, depth, intimacy and commitment (Weisman, 1979). There is no reason to assume friends will give a person more support after, than before, a cancer diagnosis. Furthermore, although help in the form of tangible support may have been provided in the short term to participants as required, participants with moderate and severe average pain may have experienced difficulty in obtaining from friends the ongoing support they perceived as potentially helpful to their situation. People's motivation to help and support others is governed by specific emotions and cognitions, among them outcome and self-efficacy expectancies (Schwarzer, Dunkel-Schetter, Weiner & Woo, 1992). If a person requiring help is seen as not trying to relieve his or her own distress in order to maintain daily function and normal life, giving him or her help and support may be seen as wasted labour, even by close family and friends. If, however, a great deal of effort is made by a person to solve their own difficulties, assistance might be perceived as worthwhile, and thus others might be motivated to help (Schwarzer *et al.*, 1992). The willingness to help depends partly on the provider's emotions at the time, but helping also depends on judgments about the situation and about characteristics of the recipient and of self. The more the provider of help feels that the situation can be changed and that they possess the ability to provide the necessary support, the more likely they are to so do. The ongoing and obvious distress of a close relative or friend might arouse feelings of incompetence in family members and friends, a sense that the situation is unchangeable, i.e. that help could not be provided easily, or that the situation might not change even if help were provided. Thus the task of giving assistance might be perceived as too difficult.

Isolation and reduced social contact may present additional difficulties in obtaining necessary help for the elderly person with cancer (Redmond & Aapro, 1997). As a person ages, social network size is likely to decrease naturally due to the death of contemporaries. In the present study, because of the wide age range of participants, data on participants who were 60 years or older were analysed separately from data on younger participants. Redmond & Aapro (1997) state that age sixty-five is frequently adopted as an arbitrary starting point for defining people as elderly, even though there is no biological reason for so doing and many people in their late sixties are very fit. However, the oncology literature indicates that the incidence of cancer increases with age and currently it is estimated that older persons have a risk of developing cancer ten times greater than that of individuals younger than sixty-five (Yancik & Ries, 1994). In the present study, among the older group, age was significantly and negatively associated with received tangible support from friends (Table 43), whilst in the younger group, age was significantly and negatively associated with received emotional support from health care professionals (Table 48). As discussed in Chapter 4, although there is generally a significant positive relation between network size and perceived social support (Cutrona, 1986) and most people know many other people (McCallister & Fischer, 1978), a recipient's satisfaction with perceived support has been shown to be a better predictor of their psychological adjustment than is the actual availability of support to them (Schaefer, Coyne & Lazarus, 1981). Possibly, younger people have difficulty obtaining certain types of support. It may be that health care professionals are not sufficiently aware of the support requirements of different age groups of patients with cancer. Many doctors and nurses are not trained to recognise psychological and social distress and therefore cannot respond with the appropriate support (Ford *et al.*, 1996).

Gender may also influence support provision. Female participants were recipients of more emotional and overall support from health care professionals than were male participants, whereas female participants were recipients of less informational support from family members than were male participants (Table 53). As described in Chapter 4, type of coping has been found to vary with gender, with men relying more heavily than women on problem-focused coping, even when the context permitted only emotion-focused coping (Folkman and Lazarus, 1980; McCarthy & Newcomb, 1992). This finding suggests that providers of support need to be more aware of the specific support requirement of patients with advanced cancer. It is possible that female participants were more readily listened to or that they communicated their support requirements to health care professionals more effectively than did male participants. Male patients may be more reticent about obtaining any type of support from health care professionals unless specific efforts are made to make such support easily accessible. Gender-role expectations about appropriate behaviour for men and women may influence how and when men and women seek and obtain support under stressful conditions (e.g. Derlega, Barbee & Winstead, 1994).

Cancer patients' perceptions of the severity of pain are usually associated with the perception of the impact that the pain has on daily activities (cf. Arathuzik, 1991a, 1991b; Daut & Cleeland, 1982; Rankin, 1980). In the present study, physical restriction was significantly and positively associated with participants' average pain experience (Table 28). As pointed out in Chapter 2, family members rarely appreciate the intensity of a person's pain, although they do understand the location of the person's pain in approximately 75% of cases. Discrepancies may exist between patients' and family members' perceptions of the pain experience of the person with cancer (Madison & Wilkie, 1995). People with advanced cancer frequently experience severe pain (cf. Bonica, 1990, Twycross, 1994). Reduced energy may affect a person's ability to cope with pain (e.g. Rankin, 1980; Spiegel, Sands & Koopman, 1994). This situation may be made worse by fatigue due to sleep disturbances and various biochemical changes secondary to the disease of cancer and its treatment (Winningham, Nail, Barton-Burke, Brophy *et al.*, 1994). Physical restriction imposed by cancer and the effects of such restriction upon participants, together with lack of recognition by family members of the severity of these difficulties (Madison & Wilkie, 1995), may have resulted in participants being unable to mobilise people in their social network to help them obtain the necessary medical intervention early in their pain experience. In line with the coping theory of Lazarus & Folkman (1984) discussed in Chapter 3, this situation could result in participants being discouraged from seeking a problem-focused solution to their pain (e.g. a medical consultation early in the pain experience), rather than 'putting up with it' or 'not making a fuss.'

It is important to remember that people with cancer may have negative attitudes without an experience of pain. For many people a diagnosis of cancer is a catastrophic event (Mermelstein & Lesko, 1992). In patients aged 59 years or less in the present study, age was significantly and positively associated with fatalism (Table 51) and was significantly and negatively associated with received emotional support from health care professionals (Table 48). As previously discussed, for people facing stressful events, those with higher-quality social support enjoy greater physical and mental health (Cutrona, 1996), and emotional aid is most effective in producing stress-buffering effects (e.g. Turner, 1981). It was pointed out in Chapter 4 that social support serves a positive function in fostering coping competencies that alter the threat value of potential stressors (Bandura, 1986, 1992). However, the relative importance of the various kinds of support may vary with the individual, as well as over time. For example, the 24-year-old patient with Hodgkin's disease who is single may depend especially on the emotional support provided by his or her parents, whereas the 24-year-old patient with Hodgkin's disease who is married with a small child at home may rely more on, and hence value greatly, tangible assistance (Rowland, 1989). The lack of adequate support for the youngest participants may have implications for their coping ability. The stronger the perceived self-efficacy in coping, the more venturesome the behaviour, regardless of whether self-beliefs of efficacy are strengthened by mastery experiences, modeling influences or cognitive simulation (Bandura, 1988). Younger patients with cancer may have less well developed coping skills than their older counterparts, who may already have started to come to terms with their mortality and all the losses imposed by increasing age. For example, Gotay (1985) concluded that elderly patients with cancer suffered less psychosocial disruption from cancer treatment than did younger patients. Elderly patients had less pressing demands from jobs and family responsibilities and had learned ways of coping (Redmond & Aapro, 1997).

The present study found a significant and positive association between participants' overall evaluated pain experience and emotional support received from health care professionals (Table 39). There was a significant and negative association between participants' overall evaluated pain experience and perception of overall support from family, whereas tangible support provided by family was perceived as adequate by participants (Table 42). There was a significant and negative association between participants' moderate to high average pain experience and perceived support from friends (Table 34). It is possible that the lack of support as perceived by some participants may both contribute to, and be a consequence of, ongoing difficulty with pain (Schwarzer *et al.*, 1992; Madison & Wilkie, 1995). Also, as pointed out in Chapter 4, there is an implication that family and friends were, in certain cases, not providing support in accordance with participants' expectations and therefore that the support was perceived as insufficient (Schaefer, Coyne & Lazarus, 1981). Significant others may react with fear or feelings of aversion towards people with cancer.

Consequently, it is possible that significant others avoid open communication with the patient about cancer and its consequences, leading to feelings of rejection and abandonment in the patient (Dunkel-Schetter & Wortman, 1982). Also, cancer frequently results in temporary or permanent loss of functions or roles (Barraclough, 1994). Several tasks can no longer be performed and have to be taken over by other people, increasing the dependency of the person with cancer and leading to possible decrease in social networks and support because the person with cancer is no longer fulfilling his or her previous social role and is less capable of meeting the needs of others (Courtens, Stevens, Crebolder & Philipsen, 1996).

The elements of psychological distress and perceived loss measured in the study, which were positively associated with overall evaluated pain, were fear of the future, anxiety, loss of strength, physical restriction and overall sense of loss (Table 40). These variables may have a circular effect on one another, anxiety reinforcing pain and being reinforced by it, thereby affecting participants' mood, vigour and fatigue levels (Spiegel, Sands & Koopman, 1994). As outlined in Chapter 2, the physical limitations, debility and emotional reactions imposed by cancer are increased by pain, with repercussions on all aspects of family life, social activities and contacts, which further increase the distress of patients (Bonica, 1990).

As discussed in Chapter 4, Shumaker & Brownell (1984) defined social support as an exchange of resources between individuals which is perceived by the provider or the recipient as intended to enhance the well-being of the recipient. Exchange-derived models of social support point to the complexity introduced into interactions which previously were operating with the norm of reciprocity, so that accepting benefits may place recipients in a state of tension which they want to reduce. Options for reciprocation or non-acceptance are not always available, thus people find alternative ways to reduce their discomfort. If people feel they will not be able to return a benefit, they may be less likely to seek help or accept it when offered. In situations where help is needed over an extended period of time (for example, in cases of chronic disease), the recipient's inability to reciprocate fully may become increasingly apparent, and asking for help may become especially difficult. If reciprocity is prevented, then the relationship between providers and recipients may diminish. Recipients, for example, may denigrate providers or the resources received, to reduce feelings of discomfort.

Over time this can cause social ties to disintegrate and make recipients more vulnerable to stress (Shumaker & Brownell, 1984). Situations in which both provider and recipient perceive an exchange as beneficial to themselves represent the optimal form of perceived support. There is a clear match between the recipient's perceived needs and the provider's response to those needs. Over time, such a match has the highest probability of engendering an ongoing, satisfying relationship. If providers and recipients differ in their ideas about how help should be offered, then recipients are unlikely to receive what they feel is needed (Shumaker & Brownell, 1984).

The expression of too much distress strains the social network, evokes negative reactions and turns away those who would have been supportive if the distress level had only been moderate (Schwarzer *et al.*, 1992). It has been shown that, even after failure due to lack of sufficient effort, new expenditure of effort generates positive affect and rewards for a failed student (e.g. Karasawa, 1991). When generalised to the health domain, this finding suggests that positive attempts to cope with a serious health condition could play an important role in determining the affective and behavioural reactions of others (Schwarzer *et al.*, 1992). However, family and friends of participants in the present study may not have been able to assess what other types of support participants needed apart from the tangible support provided. It is also possible that participants were being partly blamed for their distress by family and friends, and were perceived as not motivating themselves to cope (Schwarzer *et al.*, 1992). This could be due to a complexity of causes. Creating frustration and helplessness in the potential provider may reduce his or her motivation to help.

Research suggests that the relationship between emotion and self-efficacy is bi-directional, so that in some instances, self-efficacy influences mood, while in other instances, emotions influence appraisals of self-efficacy. It has been shown that inducing a pleasant mood by having subjects recall a pleasant romantic experience enhances self-efficacy for athletic performance, whereas inducing a sad mood by recalling unhappy romantic moments lowers athletic self-efficacy (Kavanagh & Bower, 1985). Bower (1981) suggests that memory is mood-dependent, and that people in a given mood state can more easily recall past experiences that evoked similar feelings at the time they occurred. This implies that the emotion a person experiences at the moment of self-appraisal will activate memories and judgments that are congruent with that emotion. When subjects were in a happy mood, favourable self-appraisals became more accessible in short-term memory (Kavanagh & Bower, 1985). When sad, patients with cardiac disease were more likely to underestimate their capabilities by recalling their weakest physical moments, whereas when happy, they were more inclined to base their appraisals on memories of how they had performed when at their best (Ewart, 1992). These findings, though still controversial (Schmidtke, 1999), may have implications for understanding how pain in people with cancer might affect mood and sense of self-efficacy. Female participants demonstrated significantly higher scores on levels of irritability and loss of independence compared with male participants (Table 55). More female than male participants rated their present, average and overall evaluated pain as severe (Tables 13-15). This possibly contributed to their perceived greater recall of psychological distress and loss (e.g. Bonica, 1990; Breitbart *et al.*, 1997). If this, rather than the reverse is true, it again highlights the need for adequate pain relief to reduce the psychological distress of people with cancer (Breitbart *et al.*, 1997).

Within the over-59-year-old age group in the present study, the older participants were, the less the emotional and informational support provided by health care professionals was perceived as sufficient (Table 44). A possible interpretation of this finding is that there was inadequate communication between older participants and health care professionals (Ford, Fallowfield & Lewis, 1996). Communication can be a problem for the elderly because of the presence of confusional states, poor cognitive functioning, or impairment of hearing or speech (Redmond & Aapro, 1997). Cassileth, Zupkis, Sutton-Smith & March (1980) reported that elderly patients tend to ask fewer questions of health care professionals than do their younger counterparts. This was attributed to a trend with advanced age towards decreased participation in information gathering and greater dependence on health care professionals for spontaneous advice or guidance. Communication with patients with cancer has support as a third purpose (Delvaux & Razavi, 1997). However, communication with an elderly person may be impaired by his or her cognitive and hearing deficits (Lubinski & Welland, 1997) so that physicians may find it easier to provide comprehensive information to younger patients. There is evidence that elderly patients may be less thoroughly investigated and less aggressively treated than younger individuals (Redmond & Aapro, 1997). Many elderly people were brought up in an age when health education was uncommon or non-existent. The current trend towards an active patient-professional partnership is a foreign concept to many older people (Welch-McCaffrey, 1986; Redmond & Aapro, 1997).

In the present study, 40.8% of the sample were aged 60 years or more and 48% had received only primary education. Seniority in years was significantly and negatively associated with socio-economic grouping (Table 3). Cartwright (1964) found that professional and non-manual workers obtained most of their information about illness by asking their physicians and nurses direct questions. In contrast, the information that unskilled and partly skilled workers received resulted from a passive process in which they were given information without asking; also they tended to receive less information. However, despite their reluctance to request information, lower-class patients did not show any less desire than higher socio-economic class patients for adequate information presented in non-technical language.

Cartwright (1964) attributed the diffidence of lower-class patients to four causes. Firstly, lower-class patients believe that doctors do not expect them to ask question. Doctors' dislike for patient-initiated questions has subsequently been documented (Waitzkin, 1985). Secondly, there is a language problem that results from patients' unfamiliarity with the technical terms doctors use. Thirdly, patients frequently regard doctors with awe. Fourthly, there is a perceived social distance between patients and doctors (Waitzkin, 1985). Although controversial, Bernstein's (1964) research and theory have helped to highlight the social class differences in language use. Bernstein (1964) distinguished between two linguistic codes, elaborated and restricted, and claimed that lower-class and middle-class individuals use these codes to a different degree. In a restricted code, nonverbal rather than verbal signals become the important bearers of meaning; middle-class subjects have been shown to make greater use of an elaborated code, lower-class subjects of a restricted one (e.g. Bernstein, 1964). This sociolinguistic distinction may help clarify the observed diffidence of lower-class patients within the doctor-patient relationship. Although both lower-class and middle-class patients want information about their illnesses, it is possible that lower-class people tend to take a less active role in asking questions due to their often restricted linguistic code rather than to an actual disinterest in information, whereas doctors, using an elaborated code, expect that intent will be expressed verbally and therefore do not provide unasked-for information (e.g. Bernstein, 1964; Waitzkin, 1985). In the present study, 58.5% of participants were in socio-economic classes IV and V of the British Registrar General's classification (Blane, Brunner & Wilkinson, 1996).

Although additional demographic variables such as patients' age, sex and marital status may be associated with the informative process, patients' general attitudes about information transmission, as well as their specific desire for information, could be related to doctors' communicative behaviour. One person's ignorance is often the basis of another's power. The 'competence gap' between doctors and patients is an important source of mis-communication and alienation in medicine. Regardless of patients' educational background in other spheres, their knowledge of pathophysiology and therapy seldom approaches physicians' technical expertise. Although both physician and patient experience uncertainty, the 'competence gap', which derives from a discrepancy in technical knowledge, means that uncertainty is greater for the patient than for the physician (Waitzkin, 1985). One study found that communication problems were more common among patients who were less optimistic about their disease and had less assertive coping styles (Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan & Martin, 1993). These problems were associated with increased anxiety, depression, anger and confusion (Lerman *et al.*, 1993).

As discussed in Chapter 3, patients with cancer may experience symptoms similar to those of post-traumatic-stress disorder, including intrusive thoughts (Tjemsland, Soreide & Malt, 1996a, 1996b; Watson, 1999). Studies of patients with cancer and those with other serious illnesses show that co-morbidity of a depressive disorder and a medical illness leads to greater emotional distress and decreased physical and psychological functioning. Therefore, early recognition, diagnosis and management of a depressive disorder within the context of cancer becomes important in order to help patients with cancer have less distressing thoughts and be better able to cope with their situation (Bandura, 1992; Mermelstein & Lesko, 1992). Social support enhances perceived self-efficacy, which in turn fosters successful adaptation and reduces stress and depression (e.g. Cutrona & Troutman , 1986). The effect is circular, as a strong sense of self-efficacy also facilitates development of socially supportive relationships and social support, thereby facilitating coping and making adverse events less depressogenic (Bandura, 1992).

Hypotheses not supported by study findings

The hypothesis that there was a significant and negative association between average pain intensity and perceived support within the social networks of patients with advanced cancer was not supported. However, there was a significant and positive association between average pain intensity and perceived reassurance support from health care professionals (Table 30). Staff members in the study locations were generally very supportive. It is possible that health care professionals were sensitive to individual patients' support requirements (Galbraith, 1995; Grande *et al.*, 1996). Another explanation is that in the oncology unit and hospice where data were collected, the staff were aware that the study was taking place and the purpose of the study. An effect similar to the Hawthorne effect may have taken place in that health care professionals, under observation, may have increased their levels of support to patients in pain (Homans, 1965).

Katz *et al.* (1970) found psychological disturbance to be greater where the patient's coping response involved fatalism, displacement or projection. With regard to the coping response of fatalism, in the present study a significant and negative association was found between average pain intensity rated as moderate to high and fatalism (Table 33). This does not fit in with (1) the positive correlation found between helplessness/hopelessness and (2) the negative correlation found between fighting spirit and overall evaluated pain experience (Table 41). Watson *et al.* (1988b) examined intercorrelations between the subscales of the MAC Scale. Results indicated that scores on the 'helplessness/hopelessness' category were significantly associated with both 'anxious preoccupation' and 'fatalism' ($p<0.01$), suggesting some overlap between the three items. With regard to the present study, the finding of a significant and negative association between average pain intensity rated as moderate to high and fatalism (Table 33).is possibly anomalous, unlikely to be replicated in other studies. There were no significant associations between average pain intensity rated as moderate to high and psychological distress and perceived loss. One possible explanation for the latter finding is that participants' reception and perception of support may have been sufficient to help to reduce psychological distress and loss, which may also have helped to prevent the development of a fatalistic attitude. As outlined in Chapters 3 and 4, studies have found that, whether people face high or low levels of difficulty, those with higher-quality support will enjoy greater physical and mental health (Cutrona, 1996). Emotional, informational and reassurance support received and perceived by high-average-pain participants from health care professionals may have had a buffering effect (Wills, 1985). It is hypothesised that the occurrence of negative events in the presence of social support should produce less distress than would their occurrence in its absence (Thoits, 1982). The primary benefit to the recipient of social support is protection against the deterioration of health and well-being that would otherwise be caused by the pressures of recent or ongoing stressful events (Pearlin *et al.*, 1981). Similar explanations might be applicable to the findings that there were no significant associations between participants' experience of present pain and coping deficit or perceived support (Tables 37 & 38). Social support may impact on ability to manage stressful situations, increase self-esteem, self-efficacy and coping ability (Bandura, 1992; Thoits, 1991; Greenglass, 1993).

The hypotheses that within the over-59-years old group, the older the patients are, the more likely they will be to experience psychological distress, to perceive loss, to report a coping deficit and to suppress emotions were not supported (Tables 45, 46 & 47). Perhaps this was because the benefits of social support were not as available to this particular subset of participants. An alternative explanation might be that life experience plus adapting to and coping with a changed life-style after retirement can often develop an emotional strength in the older person (Redmond & Aapro, 1997). Although some elderly people are frail emotionally, the majority may cope better with illness than their younger counterparts do (Ganz, Schag & Heinrich, 1985).

In patients under 60 years old there were no significant associations between age and measures of psychological distress, perceived loss or suppression of emotions (Tables 50 & 52). The finding that there was no significant association in this group between age and perceived deficit in support (Table 49) is interesting, given the finding previously discussed of a significant, negative correlation of age with received emotional support from health care professionals. Even though the support experienced may have not been perceived as inadequate, nevertheless, younger participants may not have experienced sufficient support to prevent a fatalistic attitude developing. It may also be that support of a certain type from specific members of a social network is required to promote positive coping attitudes and prevent psychological distress (Watson, 1983; Bandura, 1992). A significant and positive association was found between satisfaction with overall support from friends and a coping attitude of fatalism (Table 59). It is possible that it is specific emotional and informational support from health care professionals which is required to help to prevent a negative coping attitude of fatalism in patients with advanced cancer. As discussed earlier, satisfaction with overall support from their health care professionals was significantly and negatively associated with the negative coping attitudes of anxious preoccupation and helplessness/hopelessness in study participants.

As previously discussed, research indicates that overall network support structure and tangible support are less effective in producing stress-buffering effects than is available emotional aid (e.g. Turner, 1981). No significant associations were found between overall support given by their friends and scores for psychological distress and perceived loss in study participants (Table 62), whereas, as discussed earlier, there were several indices of psychological distress and perceived loss which were significantly and negatively associated with participants' satisfaction with overall support from their family and health care professionals (Tables 60, 61and 63). Finally, gender was not associated with the perception of support, coping attitudes or suppression of emotions (Tables 54, 56 & 57), but there was no strong evidence from previous research that it would be (e.g. Derlega *et al.*, 1994).

Incidental findings

The replies of participants to the question regarding the impact of cancer on their lives was sorted into 10 categories (including 'other' and 'no response'). Classification according to participants' primary responses was done by two raters working independently. Responses were sorted according to the first verbal response made by each participant to the question 'what change has having cancer made to your life?' Where a participant's initial response to the questions was not relevant, the main overall theme of the response made by the participant was classified. The raters spontaneously agreed in 88% of cases, which seems reasonably satisfactory inter-rater reliability. This qualitative analysis revealed a major theme of loss which impacted on many aspects of participants' lives. The subthemes of loss are typified by the following examples of the categories into which responses were sorted.

(1) *The restriction imposed upon activities of daily living by the experience of cancer.* For example, one participant stated: 'The greatest change is lack of confidence because I can no longer do the things I used to do. It's terrible'.

(2) *Inability to make plans because of restrictions imposed by cancer.* One participant stated: 'My whole world is shattered. I cannot plan for tomorrow or anything'.

(3) *Loss of independence.* For example, one participant stated: 'I have lost independence and freedom of choice.'

(4) *A feeling of dissatsfaction with quality of life and the negative effect of having cancer*. For example, one participant stated: 'I feel crippled, frustrated, confused. You want to get on with your life. You feel crippled, I cannot even carry my handbag. It's ''don't do this''....I am very angry. Work is the only sanity they've left me. I can't go on holiday. Your life is taken out of your control, no control. You take the tablets, do what you're told. They stick you with needles. You submit because it's your only option'.

(5) *Sexual difficulties experienced as a consequence of the disease or treatment.* This theme was included because, although neither a primary response nor an overall theme, several participants commented on the sexual difficulties they were experiencing as a result of the disease or treatment. For example, one participant stated: 'My sex life is severely affected. I am tired and not sleeping. I have no control.'

(6) *The impact of pain on daily living and quality of life.* For example, one participant stated: 'I can't do all the things I'd love to do. The pain is very depressing. It seems to be hospital after hospital.'

(7) *Alterations in relationships with family and friends.* For example, one participant commented: 'My relationship with my daughters has deteriorated. I have lost friends, relatives and family.'

(8) *The experience of cancer as a positive influence on developing new values* was commented on by some participants. One participant stated: 'I value every day.'

In summary, participants regretted the restrictions on their daily lives, their inability to make plans, loss of independence, dissatisfaction with quality of life, disease- or treatment-induced sexual difficulties, the impact of pain and adversely altered relationships with family and friends. Less than 10% of female and less than 5% of male participants had found a positive element in their experience of cancer. These findings reflect participants' perceived loss of control over events since their diagnosis and the severe effect of the disease of cancer on quality of life. In the case of male participants, 83.3% found the experience of having cancer to be negative, and only 4.8% found it positive. With regard to female participants, 85.7% found the experience of having cancer to be negative and only 8.9% found it positive. Approximately 10 responses did not fit into the above categories and 6 participants did not complete the question. Further details of participants' responses are set out in Chapter 10.

Type of family support most appreciated varied by gender, with emotional and tangible support being most appreciated by female participants and all types of support most appreciated by male participants (Table 21). In the present study, of the male participants, 40% considered hospital doctors and 16.7% considered nurses to be the most supportive health care professionals, while, of the female participants, 23.3% considered hospital doctors and 34.9% considered nurses to be the most supportive health care professionals (Table 23). A combination of all types of support was most appreciated, while informational support was the next most appreciated type of support from health care professionals by both male and female participants (Table 24). It is possible that male and female patients with cancer may have different health-related support preferences and requirements (e.g. Derlega *et al.*, 1994).

Strengths and limitations of the research

The reliability and validity of the measuring instruments used are examined in Chapter 7. Pain is a multi-dimensional construct. In the study only a sensory and a cognitive component of pain were looked at. Even though the study was constrained by lack of a larger sample, some interesting associations between (a) coping, pain and support and between (b) psychological distress, pain and support were highlighted. The questionnaires and rating scales administered were readily understood by most participants, any difficulty arising mainly from failing eyesight or reduced literacy and being capable of resolution by oral administration. Participants' preference for having the questionnaire administered by the researcher may also have increased the risk of a biased response by participants, through enthusiasm shown by the researcher in voice inflection and non-verbal cues. This disadvantage has to be balanced against the lack of energy that may have prevented many of the participants completing the questionnaire themselves. One selected questionnaire, the Courtauld Emotional Control Scale (Watson & Greer, 1983), did not show any significant associations with age or any significant gender differences. Perhaps the sample sizes of the relevant subsets of participants may have been too small, although, quite regularly in the literature, samples in studies of patients with advanced cancer are shown to be comprised of fifty or fewer participants (cf. Watson & Greer, 1998). The lack of expression of anger is stereotypically linked to type C personality behaviour. Although type C personality has been promulgated as a possible risk factor for cancer, there is little scientific evidence to support this hypothesis and no clear biological link between type C behaviour and cancer has been found (cf. Watson & Greer, 1998). With regard to completing psychological questionnaires, co-operation from patients with advanced cancer might not be easy to obtain, as they may be too distracted with their own situation to be interested in taking part in research studies (Watson & Greer, 1998). It is possible that some people who declined to participate considered that their contribution might not be worth-while. A measure of self-esteem would also have been helpful in this study to look at deficits that might be associated with pain experience and psychological distress.

A cross validation study would be necessary to decide which correlations at the lower levels of statistical significance are spurious chance effects. Findings which should stand up to a cross-validation study are those where $p < 0.005$ or $p < 0.001$. This is because the larger the probability α, the more likely that the null hypothesis will be rejected falsely. The power of a test is defined as the probability of rejecting the null hypothesis when it is in fact false. A researcher's stringency may differ from that of a reader due to different subjective or perceived consequences of the applications of the results by different individuals. Ideally, the α levels should be set prior to a research study being carried out, thus helping to determine the necessary sample size (Siegel & Castellan, 1988). This is seldom possible in research outside the laboratory and particularly difficult in a population in which, as already outlined, so many factors militate against participation in research studies. Siegel & Castellan (1988) pointed out that it is for heuristic reasons that significance levels are emphasised. Hypotheses relating to associations between (a) present pain and psychological distress; (b) overall evaluated pain and coping; (c) satisfaction with overall support by family, coping mechanisms and psychological distress; and (d) between satisfaction with overall support by health care professionals and coping mechanisms showed the highest significance and are likely to stand up to cross validation checks. These findings are central to many of the thirteen research questions outlined in the methodology section, most of which, being mindful that correlation is not causation, can be answered in the affirmative. Practical implications arising from these significant findings are discussed later.

The number of hypotheses tested that showed significant association at the .05, .025 and .01 level was less than anticipated but higher than would be expected by chance. The hypotheses were to some extent based upon research that had taken place outside of Ireland. However, cultural differences alone would hardly explain all cases of low or absent statistical significance, as some measures of association between the selected variables showed high levels of significance. A more likely explanation is that the size of the sub-samples in the present study was too small to adequately determine significant associations between some of the variables selected. Another explanation for the findings may relate to the validity of the data collected, in that responses were not made anonymously by the participants, so some bias may have been introduced, especially due to the researcher having assisted participants to complete the questionnaire. This may have been further compounded by a volunteer bias due to the 60% inclusion level of the possible total research sample. The latter situation may mean that patients who felt either stronger in health or strongly about the need for support service expansion were more likely to agree to take part, and therefore select themselves into the study. This may have introduced bias into the findings, in that people who felt less well may have felt the support they received from all sources was optimal, but were unable to express their views. Ideally, for a research study, participants would be selected at random, provided they fitted the inclusion criteria. The size of the patient population attending the oncology centre and hospice where the study took place was too small to facilitate this methodology and time and funding considerations militated against widening the study to a national sample. Another limitation is that, although the medical information relating to the participants who did not participate was readily accessible, comprehensive sociodemographic information was less so, therefore comparison between participators and refusers on this variable was not possible. These factors are limitations to the validity of the results of the study and need to be taken into account when interpreting the findings and their possible application to the health care setting.

Improvements to the design of the research would include a larger, more homogeneous sample. Ideally, the application of the design of the present study to a large sample of patients with advanced breast cancer might clarify some of the issues related to pain and coping. However, this design would relate more to the pain experience, support needs, psychological distress and coping mechanism of women. Although, in the study sample, more women than men were married, men considered all types of support from family members and tangible support from friends most important, in constrast to emotional support from family and friends being most apreciated by women (Tables 21 & 22). Gender requirements for support may be very different (e.g. Derlega *et al.*, 1994) and if gender issues in the context of oncology are to be further investigated, a comparative study of men and women with advanced lung cancer might be more relevant and informative. The study failed to look at the sexual difficulties experienced by some participants due to cancer and its treatment (e.g. Dennison, 1997). A separate investigation of these problems and the distress associated with them is needed.

The present study probed some of the associations between the experience of pain and psychological distress and between psychological distress, coping and social support. While pain was associated with psychological distress and negative coping mechanisms, satisfaction with perceived social support from family members and health care professionals was associated with reduced psychological distress and negative coping mechanisms. These findings imply that adequate family and health care professional support should be available to patients preferably as early as the stage at which cancer is diagnosed. The data point to the desirability of service expansion in this area in Ireland and to the importance of determining the pain and psychological distress levels of patients every time they visit an oncology centre (Holland, 1999).

Recommendations for future research

Future studies should look at issues related to gender and different age groups. More female than male participants rated their pain as severe. One obvious explanation for this finding is that 30.9% of study participants (96.7% of whom were female & 3.3% of whom were male) were diagnosed with breast cancer. Bone metastases are present in 60-70% of patients with advanced breast cancer and are a major cause of pain (Slevin & Tate, 1998). A particular point that does need clarifying is whether men express their pain in different ways from women and whether men may be socially conditioned to understate their level of physical suffering. It would be interesting to examine the possible different methods utilised by males and females to express their psychological and physical suffering.

In the present study some of the correlations may have been affected by the relatively small sample and sub-sample sizes. Future research should focus on larger samples where possible, to look particularly at issues related to coping mechanisms and pain, as these issues were not clarified as much as was hoped they would be. It would be especially useful to consider the higher range of patients' pain experience and how this is associated with coping. The content of this study was new to the Irish context, so cross-validation studies should be carried out in this country, utilising the same measuring instruments. Assessment of the differences in coping and psychological distress and loss within and between older and younger patients, and between genders might also be more accurately determined by a study involving relevant comparison groups.

Paediatric psycho-oncology is beyond the scope of this study. However, it is essential that topics similar to those researched with adults in the present investigation should be examined with children in an Irish context.

Recommendations for policy and practice

The present study suggests that effective coping attitudes and behaviours, contributing to optimal quality of life, are enhanced by (1) optimal pain control, (2) the early and effective assessment and treatment of distress, and (3) adequate social support. Thus, inter alia, consideration must be given to the provision of adequate pain control at all times. The treatment of psychological distress and depression and the provision of help to enable patients change negative coping attitudes which reduce their sense of self-efficacy and control are desirable. Methods of increasing effective support by health care professionals, and of removing obstacles to effective provider behaviour by family members need to be considered. Underlying all these requirements is the necessity for adequate, effective communication among health care professionals and between health care professionals and their patients (Delvaux & Razavi, 1997).

Adequate nurse and doctor-patient communication. Adequate communication to make the patient feel supported would appear central to helping patients to change negative coping attitudes to more positive ones geared to self-efficacy. Thus, methods of communication by physicians which provide information exchange, create a therapeutic relationship and encourage active patient participation are likely to engender patient satisfaction, and enhance perception of support and the fostering of self-efficacy to render events less depressogenic (Waitzkin, 1984; Peterson & Seligman, 1984; Cutrona & Troutman, 1986; Moorhead & Winefield, 1991; Amack, 1997; Delvaux & Razavi, 1997). Communicating with patients with cancer has also been recognised as one of the most important aspects of nursing care. There is evidence to suggest that the way nurses communicate depends on their work environment and their own communication style (Wilkinson, 1991). Johnston (1976) found that nurses' communication skills with patients prior to training was very limited and that nurses tended to overestimate psychological problems and underestimate physical ones. The importance of communication skills training for health care professionals, especially in the palliative care setting is well documented. Deficits in skills utilised by doctors and nurses can be improved by training (e.g. Maguire, 1982; Faulkner & Maguire, 1984; Faulkner, 1992). Comprehensive programmes of nurse education in communication and support skills are desirable to provide the necessary theory and practice. The use of communication skills by doctors and nurses is especially important in regard to adequate pain assessment and control (Sofaer, 1998).

Optimal pain control. It is clear from the literature and supported by findings in the present study that optimal pain control is the primary prerequisite for quality of life of patients with cancer. The following recommendations will outline the elements central to helping to manage the problem of pain in this context. Pain is now recognised as a psychological event involving nociception, pain perception and pain expression. Psychological variables such as perception of control, the meaning of pain, fear of death, depressed mood and hopelessness contribute to the experience of cancer pain (Breitbart, 1989). An outline of the main reasons for the under-treatment of pain by doctors and nurses is given in Twycross (1994). As previously stated, the under-treatment of pain constitutes a major public health problem (Breitbart, 1994).

Adequate and up-to-date teaching of the pharmacology of pain control applied to oncology and palliative care ought to be more widely available. Doctors and nurses need constant updating of their knowledge and skills in this area if they are to provide adequate patient care. Nurses have a vital role to play in the optimal management of pain, as they have more frequent and direct contact with patients both on the ward and in the context of an outpatient clinic. Instruction and open discussion at ward level would help to change attitudes and improve pain management (Sofaer, 1998). Copp (1974) examined how nurses appear to patients who have requested relief from pain. A patient may see a nurse as acting in a variety of roles: (1) a controller, relieving or denying relief; (2) a communicator, passing on, validating and interpreting the bid for pain reduction; (3) a judge, deciding if pain is reasonable, timely and expected in terms of quality and quantity; (5) an avoider, refusing to report that medication does not bring relief; (4) an empathiser, able to identify with the patient or (6) a barterer, giving relief in return for good patient behaviour. Acceptance of individual patients' differences in pain tolerance and coping patterns is a basic prerequisite for any nurse who wishes to be effective in relieving pain (Sofaer, 1998).

Lack of relevant training could be a primary problem faced by nursing staff when trying to help patients in pain. Sofaer (1984) found that only 14% of nurses felt themselves to be well prepared for this task, 75% would have liked more education, and 11% felt themselves to be badly instructed. Relevantly trained nurses can act as models for less experienced ones. If staff are poorly informed on current research and theory in relation to pain and its relief, then the status quo of knowledge and ill-founded myths will continue (Sofaer, 1998). According to Sofaer (1984), education is more effective when it is ward-based and is directed at all members of the nursing team. Franke, Garssen & Abu-Saad (1996) having examined 12 studies of educational programmes on pain management for nurses, concluded that they had a positive impact on both nurses and patients.

Cancer pain is highly associated with structural pathology and the nature of the underlying etiology of the pain are essential outcomes of pain assessment (Gonzales, Elliott, Portenoy & Foley, 1991; Fields, 1995). The perception of pain is modulated by the patient's mood, morale, individual and cultural differences in the reaction to life threatening and painful illness and response to therapies (Fields, 1995). Anxiety and depression are common among patients with cancer pain. However, somatically oriented interventions designed to alleviate cancer pain have been shown to reduce psychological distress, while psychosocial interventions aimed at relieving emotional distress have a profound impact on nociception (Breitbart *et al*, 1997). Patients with cancer sometimes describe their whole life as painful, so all aspects of discomfort and distress need to be addressed (Twycross, 1994).

Addiction is fundamentally a psychological and behavioural disorder characterised by loss of control over drug use, compulsive drug use and continued drug use despite harm sustained. Iatrogenic addiction during opioid treatment for cancer pain is almost never observed (Fields, 1995). Substance abusing individuals need close monitoring for drug use, as there is an increased likelihood of under-treatment of pain in this population (Fields, 1995). With the advent of improved training in pain management techniques and a heightened awareness of how complex and intense the experience of cancer pain can be, the onus is now on all health-care staff to accept patients' pain experience as real for them (Twycross, 1994). Along with formal teaching of pain assessment and management in nursing practice, the use of pain charts in hospitals and outpatient units is to be recommended as they increase the awareness by the nursing staff of individual patients' pain levels, and thus facilitate pre-emptive pain control. The use of a pain chart can also help the individual patient's perception of pain, in that anxiety about their pain is reduced, rather than just being the focus of intervention for the professional (McCaffrey *et al.* 1994; Bisset, 1996; Sofaer, 1998). The immediate goal of medical and nursing interventions is to maintain comfort at all times, and this can usually be achieved when patients have access to skilled, highly specific interventions (Bisset, 1996). Accurate pain assessment is not adequately emphasised in hospital settings (Sofaer, 1998). 'Initial assessment' tools for measuring patients' pain experience are available for clinical settings, and all information is obtained directly from the patient whenever possible; no one else really knows the location, intensity and other characteristics of the pain. A continuous assessment sheet allows ongoing evaluation of pain. The only safe and effective way to administer an analgesic is to monitor the patient's response to medication and make changes based on these responses (McCaffrey *et al.*, 1994). Useful reviews of instruments commonly used for pain assessment can be found in Chapman, Casey & Dubner (1985); Karoly (1985); McGuire (1984); Syrjala & Chapman (1984) and Meinhart & McCaffrey (1983).

The assessment and treatment of distress. It is estimated that up to 50% of patients with cancer have varying degrees of difficulties coping with anxiety and depression. (Mermelstein & Lesko, 1992). In the present study, as already pointed out, participants' present pain experience and overall evaluated pain experience were shown to be associated with psychological distress and negative coping mechanisms. It is increasingly recognised that all aspects of cancer patients' experience of pain and distress have to be addressed to maximise their quality of life (e.g. Ferrell *et al*, 1989; Fallowfield, 1990; Fields, 1995). In the United States, standards of care and management of distress in patients have been developed by a panel of the National Comprehensive Cancer Network (NCCN) (cf. Appendix i). Their statement of the problem refers to the fact that, despite the increased attention to control of several troublesome symptoms in patients with cancer, particularly pain, fatigue, nausea and vomiting, there has been no similar concerted effort to address the psychosocial dimension, i.e. the distress which patients and their families experience. This omission becomes glaring when it is recognised that the psychosocial domain should be a part of the care of all patients, at all stages, for all disease sites, in all treatments, and as part of each encounter with the oncologist and staff. The NCCN-recommended standards of care and management of distress in patients can be adapted to the requirements of a given institution and attempt a comprehensive and consistent management of the problem of identifying psychological distress at an early stage. It is suggested by NCCN that more information be given to the primary oncology staff about how to recognise significantly high levels of anxiety and depression, how to question patients to elicit information about their feelings and how to identify appropriate resources to which the patients could be referred (Holland, 1999).

The NCCN recommends unified action by professional and patient advocacy organisations to raise the level of awareness of oncology staff, patients and families and the public regarding the under-recognition and under-treatment of distress in patients with cancer. Screening tools such as the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) permit a rapid screening for distress, as does a Distress Thermometer, with the patient indicating his or her level of distress on the 'thermometer' with a range of scores from zero to ten, zero indicating 'no distress' and ten indicating 'extreme distress' (Holland, 1997, 1999) (cf. Appendix i). The NCCN recommends also the exploration of service delivery models in which the primary oncology team has an algorithm which triggers the referral of the significantly distressed patient to proper psychosocial interventions. The expected outcome of this early treatment of patient distress includes improved quality of life for patients, improved doctor-patient communication, lessened staff distress, and fewer calls and visits related to patient distress (Holland 1997, 1999).

There are many negative consequences of the current state of insufficient attention to psychological distress. These include emergency calls and visits because of unrecognised and untreated anxiety; difficulty in making treatment decisions because of anxiety and depression; patients' feelings which lead them to stop or fail to start a treatment programme; dissatisfaction and disillusionment with care which results in people leaving traditional for alternative rather than complementary therapies and undue stress upon caregivers (Holland, 1999). Psychological interventions can have their greatest impact when applied to cancer pain and related suffering (Breitbart, 1989). It is imperative that the patient's mental state be reassessed after pain has been controlled enough to allow determination of whether a psychiatric disorder is indeed present. For the most part, the physician treating patients with cancer works with psychologically healthy individuals who are reacting to the stresses of cancer and its treatment. Nearly 90% of the psychiatric disorders seen are either reactions to, or manifestations of, increased morbidity, and their treatment is essential to maintaining the patient's quality of life.

The provision of adequate social support. For those with cancer pain, cognitive-behavioural interventions that help diminish mood disturbance also help to reduce pain (e.g. Spiegel & Bloom, 1983). Patients with cancer are highly motivated to learn cognitive-behavioural techniques because they are often effective not only in symptom alleviation but in restoring a sense of control, self-efficacy and active participation in their own care (Sloman, 1995). It is important that these techniques be used not as a substitute for appropriate analgesic management but rather as part of a comprehensive multimodal approach to the control of cancer pain. Most cognitive-behavioural techniques, such as progressive muscle relaxation, autogenic training, meditation and guided imagery can be taught by nurses who have acquired the necessary skills (Sloman, 1995; Crowther, 1995; Rankin-Box, 1995).

One of the intended outcomes of psychological/cognitive-behavioural therapies for patients with cancer is that their sense of self-efficacy would be sufficiently enhanced to allow more adaptive coping attitudes and behaviours to develop (Moorey, 1991). Patients who are more confident may be more pro-active in their management of the disease experience (Spiegel, 1993). They may actively seek more involvement and more information. Information can be provided at a level to suit each individual. In this context, the sensitive use of communication skills by health care professionals is necessary to ensure that adequate information to meet patients' needs is provided without giving unwanted information and incurring further distress (Faulkner, 1992). Such a patient-centered orientation to care has implications for better treatment outcome, quality of life, and possible improved survival rates (e.g. Speigel, 1993). Therefore, hospital organisations need to be geared towards a patient-centered, rather than organisational-centered, mode of functioning so that benefits patients may derive from cognitive-behavioural interventions are not negated. Thus, it is necessary to ensure that the emotional and informational support that patients expect from health care professionals is not neglected (Galbraith, 1995; Nichols, 1995).

The present study showed a negative association between adequate perceived support by family and health care professionals and psychological distress and coping attitudes, i.e. more perceived support was associated with less psychological distress. This suggests that optimal support services for both patients and family care-givers are essential in helping to reduce psychological distress and foster positive coping attitudes for patients with cancer. The present study also showed that a combination of emotional, informational and reassurance support as well as informational support alone were greatly appreciated from health care professionals. Thus, it is necessary when providing psychosocial interventions to ensure that back-up services are also in place to provide the informational and emotional support which is part of holistic patient-centered care, and which patients who possess effective coping attitudes and who wish to be more pro-active in their own care are likely to expect. The type of support looked at in the present study can be provided by all health care professionals given adequate training. In order to reduce distress, sufficient emotional, informational and reassurance should be readily available for patients with cancer when required. If appropriately selected and trained, clinical nurse specialists may prove particularly suitable for these interventions (Bullen, 1997; Grande *et al.*, 1996) as they have the necessary oncological knowledge combined with regular contact with patients with cancer (Watson, 1984; Watson, Denton, Baum & Greer, 1988a; Burton & Watson, 1998). The intervention of such clinical nurse specialists and of other appropriately trained health care professionals can be helpful at any time in a patient's and family's experience of cancer, but may be especially desirable at diagnosis, at the start of treatment and when cancer recurs (Watson, 1984; Watson *et al.,* 1988a; Burton & Watson, 1998). Attention can be focused upon those with greatest need for emotional and informational support and for rapid psychological intervention to reduce distress. Specialist support programmes may be of particular value for patients who are poor at coping with stress and who constantly need help over long periods in order to change their psychological responses. However, not every patient will require such intense and protracted help (Watson, 1983).

Spouses and other relatives need help in order to be maximally supportive to their relative with cancer. The family is the primary support system (Rowland, 1989). Relatives may need help in learning how to be effective support providers without feeling that their own stress levels and emotional needs are being neglected. This point is relevant to the present study as satisfaction with family support was negatively associated with psychological distress, perceived loss and negative coping mechanisms. Studies have shown that up to 50% of women who undergo mastectomy alone for treatment of cancer will develop depression, anxiety and sexual difficulties, which may cause emotional distress in their husbands. This level of morbidity can be reduced dramatically by informational support from nurses who have basic training designed to help them discuss the control of patients' symptoms and the resolution of associated family and marital problems (Bond, 1987). Additional psychotherapeutic interventions, such as counselling, educational courses and support groups for families and other caregivers are vital to the quality of life of patients with cancer. However, discussion of such interventions is beyond the scope of the present thesis. The area of psycho-oncology is very broad. All its components need to mesh together to provide a coherent service which should focus on assessment and control of the patient's pain, support with their psychosocial requirements, and prevention and reduction of distress associated with cancer. Along with health care professionals, spouses, partners, close relatives and friends should be provided with help to learn how to be more effective in the provision of support, in order to promote self-efficacy and enhance coping attitudes and behaviours for the person with cancer, thereby improving his or her quality of life (Northouse & Peters-Golden, 1993).

SUMMARY

The research project was devised to examine which elements of support, available through their social network, might impact positively or negatively upon the quality of life of people with advanced cancer. The literature review outlines the major changes to a person's relationships and quality of life wrought by a diagnosis of cancer. Pain is discussed as the aspect of cancer that causes most concern. The aims of palliative care are described as the maximisation of the patients' quality of life, with a major emphasis on the control of pain and other psychological and physical symptoms. In chapter 2, the perception of pain, the different causes of cancer pain, pain theories and physiology, along with pharmacological methods, are reviewed. The effects of cancer pain on all aspects of a person's life are described. The concept of total pain is explained (Saunders, 1967) in terms of the psychological distress and loss, emotional and social consequences permeating all aspects of life of the person with cancer.

In chapter three theories of stress, emotion and coping are outlined, with a discussion of how these theories might be applied to the experience of cancer. The engineering, medicophysiological and psychophysiological models of stress are briefly described and the relevance of the latter approach to contemporary stress theory is explained. A description is given of present day transactional models of stress (Lazarus & Folkman, 1984), concerned with cognitive evaluation, centered on the appraisal of harm, threat or challenge and an expansion of psychological stress theory into a theory of emotion by Lazarus (1991) is outlined. A description is given of how the attributes of the pain experience and their relationship to coping appear to correspond with the postulates of stress theory, with pain viewed as a stressor (Selye, 1979), and to theories of social support (e.g. Cobb, 1976; Thoits, 1982). For the person with cancer, coping well depends on the social context, including supportive others; therefore social support may be considered as coping assistance (Thoits, 1986), the active participation of significant others in an individual's efforts to manage stress, resulting in possible increases in self-efficacy, esteem and sense of control (Bandura, 1992).

The literature review also outlines definitions and issues of measurement of quality of life which is described as having multiple dimensions. Social support enhances quality of life and provides essential information, shared among individuals by the process of communication. It is concluded that the considerations required to maximise quality of life for the person with cancer are numerous and complex, especially as the disease of cancer advances and symptom control assumes major importance. The disease trajectory is marked by loss, grief, uncertainty, anxiety, pain and activity restriction and is therefore a potential devastation of quality of life. The person who is suffering from advanced cancer or who is terminally ill requires detailed frequent assessment on a patient-centered holistic basis in order to maximise quality of life (Saunders, 1967).

The aim of the present study was to assess the implications of perceived pain and social support for coping ability, levels of distress and quality of life in a group of patients with advanced cancer. A total of 98 patients who were undergoing palliative treatment and/or care and who were aware of their cancer diagnosis, but not necessarily of their prognosis, consented verbally to participate. A questionnaire was administered to each participant comprised of scales to measure perceived pain intensity and to evaluate overall pain experience, to measure perceived and actual support given by each patient's family, friends and health care professionals, and to measure the patient's present coping attitudes. Measures of anxiety, depression and quality of life were also included. A qualitative aspect to the study was included which asked patients which type of support they most appreciated, to describe any changes cancer had made to their lives and to describe their perceived loss.

Although perceived pain was significantly and positively associated with received and perceived support from health care professionals and tangible support from the family, results showed significant negative associations between the perception of pain and perceived appropriate social support from family and friends. Results also showed a deficit in perceived support from health care professionals for older participants Overall evaluated pain experience was significantly and positively associated with items measuring psychological distress, loss and helplessness/hopelessness and was significantly and negatively associated with fighting spirit. Perceived satisfactory support given by family and health care professionals was significantly and negatively associated with overall perceived loss as well as with 'negative' coping attitudes. Perceived satisfactory family support was also significantly and positively associated with fighting spirit.

This study suggests that to facilitate effective coping attitudes and behaviours contributing to the maximisation of quality of life of patients with advanced cancer, consideration must be given to the provision of optimal pain control at all times and how this can best be provided. The adequate treatment of psychological distress and depression and the provision of help to patients to change negative coping attitudes which reduce their sense of self-efficacy and control also require looking at. Underlying all these requirements is the necessity for adequate, effective communication (Delvaux & Razavi, 1997).

The present study showed a negative association between adequate perceived support by family and health care professionals and psychological distress and coping attitudes. Therefore, development of good support services for family caregivers and the expansion of services which allow early recognition of distress and provide adequate provision of support by health care professionals would appear to be essential in helping to reduce psychological distress and foster positive coping attitudes for patients with cancer. The present study showed that all types and informational support were most appreciated from health care professionals. Thus it is necessary when providing psychosocial interventions to ensure that back-up services are also in place to provide the informational and emotional support that is part of holistic patient-centered care, and that patients who possess effective coping attitudes and who wish to be more proactive in their own care are likely to require.

REFERENCES

Aaronson, N.K. & Beckmann, J.H. (1987). *The Quality of Life of Cancer Patients*. New York: Raven Press.

Aaronson, N.K. (1986). Methodological issues in psychosocial oncology. In V. Ventafridda, F.S.A.M van Dam & R. Yancik (Eds), *Assessment of Quality of Life and Cancer Treatment.* Amsterdam: Elsevier Science Publishers.

Aaronson, N.K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N.J., Filiberti, A., Flechtner, H., Fleishman, S.B. &de Haes J.C. (1993). The European Organisation for Research and Treatment of Cancer QLQ-C30: A quality of life instrument for use in international clinical trials in oncology. *Journal of The National Cancer Institute,* **85**, 365-376.

Abram, H.S. (1969). The psychology of terminal illness as portrayed in Solzhenitsyn's 'The Cancer Ward'. *Archives of Internal Medicine*, **124**, 758-760.

Abramson, L.Y., Seligman, M.E.P. & Teasdale, J.D. (1978). Learned helplessness in humans. Critique and reformulation. *Journal of Abnormal Psychology*, **87**, 49-74.

Adams, N. (1997). *The Psychophysiology of Low Back Pain.* New York: Churchill Livingstone.

Ader, R. (1981). *Psychoimmunology*. New York: Academic Press.

Ader, R. (1990). Conditional immune responses. Paper presented at First International Congress of Behavioural Medicine, Uppsala, Sweden.

Age Concern (1974). *The Attitudes of The Retired and Elderly*. London: National Old People's Welfare Council.

Ahmed, P I. & Kolker, A. (1979). The role of indigenous medicine in WHO's definition of health. In Ahmed & C.O. Coelho (Eds), *Towards a New Definition of Health*. New York: Plenum Press.

Ahmedzai, S. (1993). The medicalisation of dying: A doctor's view. In D. Clark (Ed.), *The Future for Palliative Care*. Buckingham: Open University Press.

Ajemian, I. & Mount, B. M. (1981). In C. Saunders, D. Summers & N. Teller (Eds), *Hospice: The Living Idea*. London: Arnold.

Albrecht, T.L. & Adelman, M.B. (Eds) (1987). *Communicating Social Support*. California: Sage.

Allen, L. & Zenz, M. (1999). *Chronic Pain: A Review.* The Netherlands: Excerpta Medica.

Allan, N. (1990). Hospital to hospice in the near east: An instance of continuity and change in late antiquity. *Bulletin of The History of Medicine*, **64**, 446-462.

Alonzo, A.A. (1984). An illness behaviour paradigm: A conceptual exploration of a situational-adaptive perspective. *Social Science and Medicine*, **19**, 499-510.

Alter, C.L., Pelcovitz, D., Axelrod, A., Goldenberg, B., Harris, H., Meyers, B., Grobois, B., Mandel, F., Septimus, A. & Kaplan, S. (1996). Identification of PTSD in cancer survivors. *Psychosomatics*, **37**, 137-143.

Amack, L.O. (1997). Enhancing physician-patient rapport http://www.lawinfo.com/

American Cancer Society (1984). Workshop Conference on Methodology in Behavioural and Psychosocial Research. *Cancer*, **53**, (Suppl) 2290-2299.

American Cancer Society (1989). A summary of the American Cancer Society report to the nation: Cancer in the poor. *Cancer*, **39**, 263-265.

American Cancer Society (1992). *Cancer facts and figures.* (vol 2). Atlanta: American Cancer Society.

American Pain Society (1992). *Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain.* Skokie: American Pain Society.

American Psychiatric Association (1980, 1994). *Diagnostic and Statistical Manual of Mental Disorders.* 3rd & 4th eds. Washington: American Psychiatric Association.

Andersson, S. (1987). Neurophysiology and biochemistry of pain. In M. Swerdlow & V. Ventafridda (Eds), *Cancer Pain.* Lancaster: MTP Press Ltd.

Anstey, S. (1991). Communication. In J. Penson & R. Fisher (Eds), *Palliative Care for People with Cancer.* London: Edward Arnold.

Antonovsky, A. (1992). Locus of control theory. *Journal of Advanced Nursing*, **17**, 1014-1015.

Appleton, I. (1997). Non-steroidal anti-inflammatory drugs and pain. In A. Dickenson & J.M Besson (Eds), *The Pharmacology of Pain.* Berlin: Springer.

Arathuzik, D. (1991a). The appraisal of pain and coping in cancer patients. *Western Journal of Nursing Research*, **13**, 714-731.

Arathuzik, D. (1991b). Pain experiences for metastatic breast cancer patients: Unravelling the mystery. *Cancer Nursing*, **14**, 41-48.

Arathuzik, D. (1994). Effects of cognitive-behavioural strategies on pain in cancer patients. *Cancer Nursing*, **17**, 207-214.

ARC Cancer Support Centre, Dublin (1998). *Male attitudes to breast cancer*. Dublin: Behaviour & Attitudes Marketing Research.

Armenian, H.K., Chamieh, M.A. & Barak, A. (1981). Influences of war-time stress and psychosocial factors in Lebanon on analgesic requirements for post-operative pain. *Social Science and Medicine*, **151,** 63-66.

Arner, S. & Meyerson, B.A. (1988). Lack of analgesic effect on neuropathic and idiopathic forms of pain. *Pain*, **33**, 11-23.

Ashton, J. & Seymour, H. (1988). *The New Public Health*. Milton Keynes: Open University.

Asmundson, G., Kuperos, J. & Norton, G. (1997). Do patients with chronic pain selectively attend to pain-related information? Preliminary evidence for the mediating role of fear. *Pain,* **72**, 27-32.

Atkinson, R.A., Atkinson, R.C. & Hilgard, E.R. (1981). *Introduction to Psychology*. 8th ed. New York: Harcourt Brace Jovanovich.

Auvinen, A. (1992). Social class and colon cancer survival in Finland. *Cancer*, **70**, 402-409.

Auvinen, A., Karjalainen, S. & Pukkala, E. (1995). Social class and cancer patient survival in Finland. *American Journal of Epidemiology*, **142,** 1089-1102.

Averill, J.R. (1980). A constructive view of emotion. In R. Plutchik & H. Kellerman (Eds), *Emotion: Theory, Research and Experience*. Vol.1: Theories of Emotion. New York: Academic Press.

Averill, J.R. (1983). Studies on anger and aggression. Implications for theories of emotion. *American Psychologist*, **38**, 1145-1160.

Balfour, J. & Kaplan, G. (1998). Social class and socioeconomic factors. In J.C. Holland (Ed.), *Psycho-Oncology*. New York: Oxford University Press.

Bandura, A (1992). Exercise of personal agency through the self-efficacy mechanism. In R. Schwarzer (Ed.), *Self-Efficacy: Thought Control of Action*. Washington: Hemisphere.

Bandura, A. (1977). Self-efficacy: Towards a unifying theory of behaviour change. *Psychological Review*, **84**, 191-215.

Bandura, A. (1978). The self-system in reciprocal determinism. *American Psychologist*, **33**, 344-358.

Bandura, A. (1986). *Social Foundations of Thought and Action: A Social Cognitive Theory*. Englewood Cliffs, NJ: Prentice-Hall.

Bandura, A. (1988). Perceived self-efficacy: Exercise of control through self-belief. In J.P. Dauwalder, M. Perez & V. Hobbs (Eds), *Annual Series of European Research in Behaviour Therapy,* 2: The Netherlands: Swets & Zeitlinger.

Bandura, A. (1991). Self-efficacy conception of anxiety. In R. Shwarzer & R.A. Wicklund (Eds), *Anxiety and Self-Focused Attention*. London: Harwood Academic Publisher.

Bandura, A. Taylor, C.B., Williams, S.L., Mefford, I.N. & Barchas, J.D. (1985). Catecholamine secretion as a function of perceived coping self-efficacy. *Journal of Consulting and Clinical Psychology*, **53**, 406-414.

Bard, P. (1934). The neurohumoral basis of emotional reactions. In C.A. Murchison (Ed.), *Handbook of General Experimental Psychology*. Massachusetts: Clark University Press.

Bardelli, D. & Saracci, R. (1978). *Measuring the quality of life in cancer clinical trials: Methods and impact of controlled therapeutic trials in cancer*. IUCC Technical Report Series, No 36.

Barr, L., Cowan, R. & Nicolson, M. (1997). *Churchill's Pocketbook of Oncology*. New York: Churchill Livingstone.

Barraclough, J.(1994). *Cancer and Emotion: A Practical Guide to Psycho-Oncology*. Chichester: Wiley.

Barraclough, J., Pinder, P., Cruddas, M., Osmond, C., Taylor, I. & Perry, M. (1992). Life events and breast cancer prognosis. *British Medical Journal*, **304**, 1078-1081.

Barrera, M. & Ainley, S.L. (1983). The structure of social support: A conceptual and empirical analysis. *Journal of Community Psychology*, **11**, 133-143.

Bates, M.S., Edwards, W.T. & Anderson, K.O. (1993). Ethnocultural influences on variation in chronic pain perception. *Pain*, **52**, 101-112.

Beck, A.T. & Clark, D.A. (1988). Anxiety and depression: An information processing perspective. *Anxiety Research*, **1**, 23-36.

Bee, H. (1998). *Lifespan Development*. 2nd ed. New York: Longman.

Beecher, H.K. (1956). Relationship of significance of wound to pain experienced. *Journal of the American Medical Association*, **161**, 1609-1613.

Benedict, S. (1981). A linguistic analysis of the concept of suffering. Unpublished paper. Alabama: University of Alabama at Birmingham School of Nursing.

Benner, P. & Wrubel, J. (1989). *The Primacy of Caring: Stress and Coping in Health and Illness*. Menlo Park, California: Addison-Wesley.

Bennett, A. (1999). Overview of nimesulide. *Rheumatology*, **38**, Suppl.1, 1-3.

Berard, R.M.F., Boermeester, F. & Viljoen, G. (1998). Depressive disorders in an out-patient oncology setting: Prevalence, assessment and management. *Psycho-Oncology*, **7**, 112-120.

Berg, J.W., Ross, R. & Latourette, H.B. (1977). Economic status and survival of cancer patients. *Cancer*, **39**, 467-477.

Bergner, M., Bobbitt, R.A., Carter, W.B. & Gilson, B.S. (1981). The Sickness Impact Profile: Development and final revision of a health status measurement. *Medical Care*, **19**, 787-805.

Berkman, B.J. & Sampson, S. E. (1993). Psychosocial effects of cancer economics on patients and their families. *Cancer,* **72**, 2846-2849.

Berkman, L.F. & Breslow, L. (1983). *Health and Ways of Living: Findings from The Alameda County Study*. New York: Oxford University Press.

Berkman, L.F. & Syme, S.L. (1979). Social networks, host resistance and mortality: A nine year follow-up study of Alamada County residents. *American Journal of Epidemiology,* **109**, 186-204.

Bernstein, B. (1964). Elaborated and restricted codes: Their social origins and some consequences. *American Anthropologist*, **66**, 55-69.

Billings, A. & Moos, R. (1981). The role of coping responses and social resources in attenuating the stress of life events. *Journal of Behavioural Medicine*, **4**, 139-157.

BioMedical Data Package (BMPD) (1988) Statistical Software. California: University of California.

Birch, P.J. (1997). Tachykinins: Central and peripheral effects. In A. Dickenson & J.M. Besson. *The Pharmacology of Pain*. Berlin: Springer.

Bisset, M. (1996). Tumours of the lung. In V. Tschudin (Ed.), *Nursing the Patient with Cancer*. London: Prentice Hall.

Blane, D., Brunner, E. & Wilkinson, R. (1996). *Health and Social organisation: Towards a Health Policy for the Twenty-First Century.* London: Routledge.

Bliss, J.M., Selby, P., Robertson, B. & Powles, T.J.A. (1992). A method for assessing the quality of life of cancer patients: Replication of the factor structure. *British Journal of Cancer*, **65**, 961-966.

Bloom, J.A. & Spiegel, D. (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer. *Social Science and Medicine*, **19**, 831-837.

Bloom, J.R. (1979). Psychosocial measurement and specific hypotheses. A research note. *Journal of Consulting and Clinical Psychology*, **47**, 637-639.

Bonica, J.J. (Ed.) (1990). *The Management of Pain.* 2nd ed. Philadelphia: Lea & Febiger.

Bond, M.R. (1987). Psychological and Behavioural Aspects of Patient and Therapist. In M. Swerdlow & V. Ventafridda (Eds), *Cancer Pain.* Lancaster: MTP Press.

Boring, E.G. (1957). *A History of Experimental Psychology.* 2nd ed. New Jersey: Prentice Hall.

Bott, E. (1972). *Families and Social Networks.* 2nd ed. London: Tavistock.

Bower, G.H. (1981). Mood and memory. *American Psychologist*, **36**, 129-148.

Bowers, K.S. (1973). Situationalism in psychology: An analysis and critique. *Psychological Review*, **80**, 307-335.

Bowling , A. (1995a). What things are important in people's lives?: A survey of the public's judgements to inform scales of health related quality of life. *Social Science and Medicine*, **41**, 1447-1462.

Bowling, A. (1995b). *Measuring Disease.* Buckingham: Open University Press.

Bowling, A., Farquhar, M. & Browne, P. (1991). Life satisfaction and associations with social network and support variables in three samples of elderly people. *International Journal of Geriatric Psychiatry*, **6**, 549.

Box, V. & Anderson, Y. (1993). *Professional Attitudes to Cancer Survey.* Southampton: University of Southampton.

Boyd, C.O. & Munhall, P.L. (1990). A qualitative investigation of reassurance. *Holistic Nursing Practice*, **4**, 61-69.

Bramley, P.N., Easton, A.M., Morley, S. & Snaith, R.P. (1988). The differentiation of anxiety and depression by rating scales. *Acta Psychiatrica Scandinavica*, **77**, 136-139.

Breitbart, W. (1989). Psychiatric management of cancer pain. *Cancer*, **63**, 2336-2342.

Breitbart, W. (1994). Cancer pain management guidelines: Implications for psycho-oncology. *Psycho-Oncology*, **3**, 103-108.

Breitbart, W.S., Payne, D.K. & Passik, S.D. (1997). Psychiatric and psychological aspects of cancer pain. In W.C.V Parris (Ed.), *Cancer Pain Management: Principles and Practice*. Boston: Butterworth-Heinemann.

Brenneis, J.M (1997). Spirituality and suffering. In W.C.V. Parris (Ed.), *Cancer Pain Management: Principles and Practice*. Boston: Butterworth-Heinemann.

Brinkley, D. (1983). Emotional distress during cancer chemotherapy. *British Medical Journal*, **286**, 663-664.

Broadhead, W. & Kaplan, B. (1991). Social support and the cancer patient. *Cancer;* **67**, 794-799.

Brock, D. (1993). Quality of life measures in health care and medical ethics. In M. Nussbaum & A. Sen (Eds), *The Quality of Life*. Oxford: Clarendon Press.

Brockopp, D.Y., Hayko, D., Davenport, W. & Winscott, C. (1989). Personal control and the needs for hope and information among adults diagnosed with cancer. *Cancer Nursing*, **12**, 112-116.

Brunner, L.S. & Suddarth, D.S. (1991). *The Lippincott Manual of Medical-Surgical Nursing* 2nd ed. London: Harper & Row.

Buchsbaum, M.S., Davis, G.C. & Bunney, W.E. (1977). Naloxone alters pain perception and somatosensory evoked potentials in normal subjects. *Nature*, **270**, 620-622.

Buckingham, R.W. (1996). *The Handbook of Hospice Care*. New York: Prometheus Books.

Buckman, R. (1992). *How To Break Bad News*. London: Papermac.

Buckman, R. (1996). *What You Really Need To Know About Cancer*. London: Macmillan.

Bullen, M. (1997). *The role and function of the Macmillan nurse*. Nursing Standard, **11**, 6-15.

Buller, M.K. & Buller, D.B. (1987). Physicians' communication: Style and patient satisfaction. *Journal of Health and Social Behavior*, **28**, 375-388.

Burgess, C. (1987). *Stress and Cancer. Cancer Surveys, 6*. Oxford: Oxford University Press.

Burish, T.G. & Redd, W.H. (1994). Symptom control in psychosocial oncology. *Cancer*, **74**, 1438-1444.

Burleson, B.R., Albrecht, T.L., Goldsmith , D.J. & Sarason, I. (1994). Introduction: :The communication of social support. In B.R. Burleson, T.L. Albrecht & I. Sarason (Eds), *Communication of Social Support*. California: Sage.

Burleson, B.R..(1994). Comforting messages. In B.R. Burleson, T.L. Albrecht & I. Sarason (Eds), *Communication of Social Support*. California: Sage.

Burnett, F.M. (1970). The Concept of immunological surveillance. *Progress in Experimental Tumour Research*, **13**, 1-27.

Burns, N. & Grove, S.K. (1997). *The Practice of Nursing Research: Conduct, Critique and Utilisation*. 3 rd ed. Philadelphia: W.B. Saunders.

Burton, M. & Watson, M. (1998). *Counselling People with Cancer*. Chichester: Wiley.

Burton, M.V. (1991). Counselling in routine care: A client-centered approach. In M. Watson (Ed.), *Cancer Patient Care: Psychosocial Treatment Methods*. Cambridge: The British Psychological Society & Cambridge University Press.

Calman, K. (1984). Quality of life in cancer patients. *Journal of Medical Ethics*, **10**, 124-127.

Campbell, J.N. & Myer, R.A. (1986). Primary afferents and hyperalgesia. In T.L. Yaksh (Ed.), *Spinal Afferent Processing*. New York: Plenum Press.

Campbell, L. (1986). History of the hospice movement. *Cancer Nursing*, **9**, 333-338.

Cannon, W.B. (1927). The James-Lange theory of emotion: A critical examination and an alternative theory. *American Journal of Psychology*, **39**, 106-124.

Cannon, W.B. (1928). Neural organisation for emotional expression. In M.L. Reymert (Ed.), *Feelings and Emotions: The Wittenberg Symposium*. Massachusetts: Clark University Press.

Cannon, W.B. (1929). *Bodily Changes in Pain, Hunger, Fear and Rage*. Boston: Branford.

Cannon, W.B. (1935). Stresses and strains of homeostasis. *American Journal of Medicine*, **189**, 1-14.

Caplan, G. (1974). *Support Systems and Community Health: Lectures on Conceptual Development*. New York: Behavioral Publications.

Caplan, R. (1979). Patient, provider and organisation: Hypothesised determinants of adherence. In S.J. Cohen (Ed.), *New Directions in Patient Compliance*. Lexington: Heath.

Caplan, R.D., Robinson, E.A.R., French, J.P.R., Caldwell, J.R. & Shinn, M. (1976). *Adhering to medical regiments: Pilot experiments in patient education and social support.* Ann Arbor: Institute of Social Research, University of Michigan.

Caraceni, A., Zecca, E., Martini, C. & De Conno, F. (1999). Gabapentin as an adjuvant to opioid analgesia for neuropathic cancer pain. *Journal of Pain and Symptom Management,* **17**, 441-445.

Carr, D.B., Jacox, A. & Payne, R. (1997). Government guidelines. In W.C.V. Parris (Ed.), *Cancer Pain Management: Principles and Practice*. Boston: Butterworth-Heinemann.

Carruthers, M. (1979). Autogenic Training. *Journal of Psychosomatic Research*, **23**, 437-440.

Cartwright, A. (1964). *Human Relations and Hospital Care*. London: Routledge & Kegan Paul.

Carveth, W.B. & Gottlieb, B.H. (1979). The measurement of social support and its relation to stress. *Canadian Journal of Behavioural Science*, **11**, 179-188.

Cassel, E.J. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*, **306**, 639-645.

Cassel, J. (1975). Social science in epidemiology: Psychosocial processes and 'stress' theoretical formulation. In E. Struening & M. Guttentag (Eds), *Handbook of Evaluation Research* (Vol 2). California: Sage.

Cassel, J. (1976). An epidemiological perspective of psychosocial factors in disease etiology. *American Journal of Public Health*, **64**, 1040-1043.

Cassell, E.J. (1991). *The Nature of Suffering and The Goals of Medicine*. New York: Oxford University Press.

Cassileth, B.R (1987). Sociological implications of mind-body cancer research. In J.C. Holland and M.J. Massie (Eds), *Current Concepts in Psycho-*

Oncology and Aids. New York: Memorial Sloan-Kettering Cancer Centre.

Cassileth, B.R. (1991). Sociological implications of mind-body cancer research. In M. Watson (Ed.), *Cancer Patient Care: Psychosocial Treatment Methods*. Cambridge: The British Psychological Society & Cambridge University Press.

Cassileth, B.R., Lusk, E.J., Miller, D.S., Brown, L.L. & Miller, C. (1985a). Psychosocial correlates of survival in advanced malignant disease. *New England Journal of Medicine*, **312**, 1551-1555.

Cassileth, B.R., Lusk, E.J., Strouse, T.B., Miller, D.S., Brown, LL.& Cross, P.A. (1985b). A psychological analysis of cancer patients vs. their next of kin. *Cancer*, **55**, 72-76

Cassileth, B.R., Lusk, E.J. & Strouse, T.B. (1998). Psychosocial status in chronic illness; A comparative analysis of six diagnostic groups. *New England Journal of Medicine,* 311, 506-511.

Cassileth, B.R., Zupkis, R.V., Sutton-Smith, R. & March, V. (1980). Information and participation preferences among cancer patients. *Annals of Internal Medicine*, **92**, 832-836.

Cella D.F. & Cherin E.A. (1988). Quality of life during and after cancer treatment. *Comprehensive Therapy*. **14**, 69-75.

Cella, D.F. & Tulsky, D.S. (1990). Measuring quality of life today: Methodological aspects. *Oncology*, **4**, 29-38.

Cella, D.F. (1995). Measuring quality of life in palliative care. *Seminars in Oncology*, **22**, 73-81.

Cella, D.F., Mahon, S.M. & Donovan, M.L. (1990). Cancer recurrence as a traumatic event. *Behavioural Medicine*, **16**, 15-22

Chambers, F.A. & MacSullivan, R. (1994). Intrathecal morphine in the treatment of chronic intractable pain. *Irish Journal of Medical Science*, **163**, 318-321.

Chapman, C. R. (1979). Psychological and behavioural aspects of cancer pain. In J.J. Bonica & V. Ventafridda (Eds), *Advances in Pain Research and Therapy* (Vol. 2). New York: Raven.

Chapman, D.D., Casey, K.I. & Dubner, R. (1985). Pain measures: An overview. *Pain*, **22**, 1-31.

Chapman, R., Syrjala, K. S. & Sargur, M. (1985). Pain as a manifestation of cancer treatment. *Seminars in Oncology Nursing*, **1**, 100-108.

Chapman, R., Syrjala, K.S. (1990). Measurement of pain. In J.J. Bonica (Ed.), *The Management of Pain*. 2nd ed. Philadelphia: Lea & Febiger.

Christ, G.H. (1991). A model for the development of psychosocial interventions. *Recent Results in Cancer Research*, **121**, 301-311.

Churchill, A.C. (1990). Metacognitive self-efficacy and intrusive thought. Unpublished Doctoral Dissertation. University of Melbourne, Australia.

Clark, D. & Seymour, J. (1999). *Reflections on Palliative Care*. Buckingham: Open University Press.

Clark, W.C., Yang, J.C. & Janai, M.N. (1986). Altered pain and visual sensitivity in humans: The effect of acute and chronic stress. *Annals of The New York Academy of Science*, **467**, 116-129.

Clarke, P. & Spear, F. (1964). Reliability and sensitivity in the self-assessment of well-being. *Bulletin of the British Psychological Society*, **17**, 55.

Cleeland, C.S. (1984a). Assessing pain in cancer: The patient's role. In *Management of Cancer Pain*. New York: HP Publishing.

Cleeland, C.S. (1984b). The impact of pain on the patient with cancer. *Cancer*, **54**, 2635-2641.

Cleeland, C.S. (1985). Measurement and prevalence of pain in cancer. *Seminars in Oncology Nursing* **1**, 87-92.

Cleeland, C.S., Gonin, R. & Hatfield, A.K. (1994). Pain and its treatment in outpatients with metastatic cancer. *New England Journal of Medicine*, **330**, 592-596.

Cleeland, C.S. & Tearnan, B.H. (1986). Behavioural control of cancer pain. In A.D. Holzman & D.C. Turk (Eds), *Pain Management: A Handbook of Psychological Treatment Approaches*. Oxford: Pergamon Press.

Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, **38**, 300-314.

Coe, C.L. & Levine, S. (1991). Psycho-immunology: An old idea whose time has come. In P.R. Barchas, (Ed.), *Social Physiology of Social Relations*. Oxford: Oxford University Press.

Cohen, F. & Lazarus, R.A. (1980). Coping with the stresses of life. In G. Stone, F. Cohen & N.E. Adler (Eds), *Health Psychology: A Handbook*. San Francisco: Jossey-Bass.

Cohen, S. & Wills, T. (1985). Stress, social support and the buffering hypothesis. *Psychological Bulletin*, **98**, 310-357.

Cohen, S.R., Mount, B.M., Tomas, J.J.N. & Mount, L.F. (1996). Existential well-being is an important determinant of quality of life. *Cancer*, **77**, 576-586.

Cohen. S & Syme, L. (Eds) (1985). *Social Support and Health*. New York: Academic Press.

Coles, C. (1990). Diabetes education: Letting the patient into the picture. *Practical Diabetes*, **7**, 110-112.

Conrad, N.L. (1985). Spiritual support for the dying. *Nursing Clinics of North America*. **20**, 415-427.

Cook Gotay, C. (1984). The experience of cancer during early and advanced stages: The views of patients and their mates. *Social Science and Medicine*, **18**, 605-613.

Cooper, C.L. & Watson, M. (1991*). Cancer and Stress: Psychological, Biological and Coping Studies.* Chichester: Wiley.

Cooper, C.L., Davies Cooper, R.F. & Faragher, E.B. (1986). A prospective study of the relationship between breast cancer and life events, type A behaviour, social support and coping skills. *Stress Medicine*, **2**, 271-277.

Copp, L.A. (1973). The psychology and philosophy of suffering. Paper presented at the 18th Annual Conference of Veterans Administration Studies in Mental Health and Behavioral Sciences, New Orleans.

Copp, L.A. (1974). The spectrum of suffering. *American Journal of Nursing*, **74**, 491-495.

Cordova, M.J., Andrykowski, M.A., Kenady, D.E., McGrath, P.C., Sloan, D.A. and Redd, W. H. (1995). Frequency and correlates of posttraumatic-stress-disorder-like symptoms after treatment for breast cancer. *Journal of Consulting and Clinical Psychology,* **63**, 981-986.

Cortis, J.D. & Lacey, A.E. (1996). Measuring the quality and quantity of information-giving to inpatients. *Journal of Advanced Nursing*, **24**, 674-681.

Courtens, A.M., Stevens, F.C.J., Crebolder, H.F.J.M. & Philipsen, H. (1996). Longitudinal study on quality of life and social support in cancer patients. *Cancer Nursing*, **19**, 162-169.

Cox, T. & Mackey, C. (1981). A transactional approach to occupational stress. In E.N. Corlett & J. Richardson (Eds), *Stress, Work Design and Productivity*. Chichester: Wiley.

Cox , T. & Mackey, C. (1982). Psychosocial factors and psychophysiological mechanisms in the aetiology and development of cancers. *Social Science and Medicine*, **16**, 381-396.

Cox, S., Cox, T., Thirlaway, M., & Mackay, C.J. (1982). Effects of simulated repetitive work on urinary catecholamine excretion. *Ergonomics*, **25**, 1129-1141.

Cox, T. & Cox, S. (1985). The role of the adrenals in the psychophysiology of stress. In E. Karas (Ed.), *Current Issues in Clinical Psychology*. Vol. 2, Plenum: New York.

Cox, T., Cox, S. & Thirlaway, M. (1983). The psychological and physiological response to stress. In A. Gale & J.A. Edwards (Eds), *Physiological Correlates of Human Behaviour*. London: Academic Press.

Cox. T. (1995). Stress, coping and physical health. In A. Broome & S. Llewelyn (Eds), *Health Psychology: Processes and Applications*. London: Chapman & Hall.

Coyne, J.C., Ellard, J.H. & Smith, D.A. F. (1990). Social support, interdependence and the dilemma of helping. In B.R Sarason, I.G. Sarason & G.R. Pierce (Eds), *Social Support: An Interactional View*. New York: Wiley.

Craig, K.D. (1983). Emotional aspects of pain. In P.D. Wall & R. Melzack (Eds), *Textbook of Pain*. Edinburgh: Churchill Livingstone.

Craven, J. & Wald, F.S. (1975). Hospice care for dying patients. *American Journal of Nursing*, **75**, 1816-1822.

Cronqvist, A., Klang, B. & Bjorvell, H. (1997). The use and efficacy of coping strategies and coping styles in a Swedish sample. *Quality of Life Research*, **6**, 87-96.

Crowther, D. (1995). Autogenic Training. In D. Rankin-Box, (Ed.), *The Nurses' Handbook of Complementary Therapies*. Edinburgh: Churchill Livingstone.

Cuello, C., Correa, P. & Haenszel, W. (1982). Socio-economic class differences in cancer incidence in Cali, Colombia. *International Journal of Cancer*, **29**, 637-643.

Cull, A., Hay, C., Love, S.B., Mackie, M., Smets, E. & Stewart, M. (1996). What do cancer patients mean when they complain of concentration and memory problems? *British Journal of Cancer*, **74**, 1674-1679.

Cunningham, A.J. & Edmonds, C.V.I. (1996). Adjuvant group psychological therapy for cancer patients: A point of view and discussion of the hierarchy of options. *International Journal of Psychiatry in Medicine*, **25**, 171-187.

Cutrona, C.E. & Russell, D.W. (1990). Types of social support and specific stress. Toward a theory of optimal matching. In B.R. Sarason, I.G. Sarason & G.R. Pierce (Eds), *Social support: An Interactional View*. New York: John Wiley.

Cutrona, C.E. & Suhr, J.A. (1992). Controllability of stressful events and satisfaction with spouse support behaviours. *Communication Research*, **19**, 154-174.

Cutrona, C.E. & Troutman, B.R. (1986). Social support, infant temperament and parenting self-efficacy: A mediational model of postpartum depression. *Child Development*, **57**, 1507-1518.

Cutrona, C.E. (1986). Objective determinants of perceived social support. *Journal of Personality and Social Psychology*, **50**, 349-355.

Cutrona, C.E. (1996). *Social Support in Couples*. London: Sage.

Cutrona, C.E., Cohen, B.B. & Igram, S. (1990). Contextual determinants of the perceived helpfulness of helping behaviours. *Journal of Social and Personal Relationships,* **7**, 553-562.

Dalton, J.A. & Feuerstein, M. (1989). Fear, alexithymia and cancer pain. *Pain*, **38**, 159-170.

Dantzer, R. (1993). Coping with stress. In S. Clare Stanford. & P. Salmon (Eds), *Stress: From Synapse to Syndrome*. London: Academic Press.

Darwin, C.R. (1872). *The Expression of Emotion in Man and Animals*. London: Albemarle.

Daut, R.L. & Cleeland, C.S. (1982). The prevalence and severity of pain in cancer. *Cancer*, **50**, 1903-1918.

Daut, R.L., Cleeland, C.S. & Flanery, R.C. (1983). Development of the Wisconsin Brief Pain Questionnaire to assess pain in cancer and other diseases. *Pain*, **17**, 197-210.

Davidson, M. & Cooper, C. (1983). *Stress and The Woman Manager*. Oxford: Martin Robertson.

Davis, H. & Fallowfield, L. (Eds) (1991). *Counselling and Communication in Health Care*. Chichester: Wiley.

Dawson, N.J. (1991). Need satisfaction in terminal care settings. *Social Science and Medicine*, **1**, 83-87.

de Haes, J.C.J.M. & Van Knippenberg, F.C.E. (1985). The quality of life of cancer patients: A review of the literature. *Social Science and Medicine*, **20**, 809-817.

Ehrenreich, B. & Ehrenreich, J. (1978). Medicine and social control. In J. Ehrenreich (Ed.), *The Cultural Crisis of Modern Medicine*. New York: Monthly Review Press.

Ekehammer, B. (1974). Interactionalism in personality from an historical perspective. *Psychological Bulletin*, **81**, 1026-1048.

Ell, K., Nishimoto, R., Mediansky, L, Mantell, J. & Hamovitch, M. (1992). Social relations, social support and survival among patients with cancer. *Journal of Psychosomatic Research*, **36**, 531-541.

Engel, G.L. (1980). The clinical application of the biopsychosocial model. *American Journal of Psychiatry*, **137**, 535-544.

Engler, C.M., Saltzman, G.A., Walker, M.L. & Wolf, F.M. (1981). Medical student acquisition and retention of communication and interviewing skills. *Journal of Medical Education*, **56**, 572-579.

Epstein, S. (1982). Conflict and stress. In L. Goldberger & S. Breznitz (Eds), *Handbook of Stress: Theoretical and Clinical Aspects*. New York: Free Press.

Epstein, S. (1983). A research paradigm for the study of personality and emotions. In M. Page (Ed.), *Personality: Current Theory and Research. Nebraska Symposium on Motivation*. Lincoln: University of Nebraska.

Ewart, C.K. (1992). Role of physical self-efficacy in recovery from heart attack. In R. Schwarzer (Ed.), *Self-Efficacy: Thought Control of Action*. Washington: Hemisphere Publishing Corporation.

Faggioni, F., Zanetti, R. & Costa, G. (1994). Cancer risk and social inequalities in Italy. *Journal of Epidemiology and Community Health*, **48**, 447-452.

Fallowfield, L. (1990). *The quality of life: The missing measurement in health care*. London: Souvenir Press.

Fallowfield, L. (1991). Counselling patients with cancer. In H. Davis & L. Fallowfield (Eds), *Counselling and Communication in Health Care*. Chichester: Wiley.

Fallowfield, L. (1993). Giving sad and bad news. *The Lancet*, **341**, 476-478.

Fallowfield, L. (1995). Psychosocial interventions in cancer should be part of every patient's management plan. *British Medical Journal*, **311**, 1316-1317.

Faris, R.E.L. & Dunham, H. (1939). *Mental Disorders in Urban Areas*. Chicago: University of Chicago Press.

In H.S. Friedman (Ed.), *Interpersonal Issues in Health Care*. New York: Academic.

Dunkel-Schetter, C. (1984). Social support and cancer. Findings based on patient interviews and their implications. *Journal of Social Issues*, **40**, 77-98.

Dunkel-Schetter, C., Feinstein, L.G., Taylor, S.E. & Falke, R.L. (1992). Patterns of coping with cancer. *Health Psychology*, **11**, 79-87.

Dworkin, S.F., Von Korff, M. & LeResche, L. (1992). Epidemiologic Studies of Chronic Pain: A Dynamic-Ecologic Perspective. *Annals of Behavioural Medicine*, **14**, 3-11.

D'Zurilla, T.J. & Nezu, A. (1982). Social problem-solving in adults. In Kendall, P.C. (Eds), *Advances in Cognitive-Behavioural Research and Therapy*. Vol.1 New York: Academic Press.

D'Zurilla, T.J. & Sheedy, C.F. (1991). Relation between problem-solving ability and subsequent level of psychological stress in college students. *Journal of Personality and Social Psychology*, **61**, 841-846.

D'Zurilla, T.J. (1986). *Problem-Solving Therapy. A Social Competence Approach to Clinical Intervention*. New York: Springer.

D'Zurilla, T.J. & Goldfried, M.R. (1971). Problem-solving and behaviour modification. *Journal of Abnormal Psychology*, **78**, 107-126.

Ebbs, S.R., Fallowfield, L.J. & Fraser, S. (1989). The treatment outcomes and the quality of life. In J. Bunker & M. Baum. (Eds), *Technology Assessment and Surgical Policy*. Cambridge: Cambridge University Press.

Echternach, J. (1987). *Pain. Clinics in Physical Therapy*. Vol. 12. New York: Churchill Livingstone.

Eckenrode, J. (1984). Impact of chronic and acute stressors on daily reports of mood. *Journal of Personality and Social Psychology*, **46**, 907-918.

Eckenrode, J. (Ed.) (1991). *The Social Context of Coping*. New York: Plenum Press.

Edgar, L, Rosberger, Z. & Nowlis, D. (1992). Coping with cancer during the first year after diagnosis: Assessment & intervention. *Cancer*; **69**, 817-828.

Edmonds, C.V.I., Lockwood, G.A. & Cunningham, A.J. (1999). Psychological response to long term group therapy: A randomised trial with metastatic breast cancer patients. *Psycho-Oncology*, **8**, 74-91.

Derogatis, L.R., Abeloff, M.D. & Melisaratos, N. (1979). Psychological coping mechanisms and survival time in metastic breast cancer. *Journal of the American Medical Association,* **242**, 1504-1508.

Derogatis, L.R., Morrow, G.R., Fetting, J., Penman, D., Piasetsky S., Schmale, A.M., Henrichs, M. & Carnickee, C.L. (1983). The prevalence of psychiatric disorders among cancer patients. *Journal of The American Medical Association*, **249**, 751-757.

Dessloch, A., Maiworm, M., Florin, I. & Schulze, C. (1992). Hospital care versus home-bound hospice care: Quality of life in patients with terminal cancer. *Psychotherapeutic & Psychosomatic Medical Psychology*, **42**, 424-429.

Dewey, J. (1971). The theory of emotion. In John Dewey: *The Early Works, 1882-1898 (vol. 4: Early essays and the study of ethics 1893-1894).* Carbondale: Southern Illinois University Press.

Di Clemente, R.J. & Temoshok, L. (1985). Psychological adjustment to having cutaneous malignant melanoma as a predictor of follow-up clinical status. *Psychosomatic Medicine*, **47**, 81.

Diamont, J. & Byers, S.O. (1975). A precise catecholamine assay for small samples. *Journal of Laboratory and Clinical Medicine*, **85**, 679-693.

Dickenson, A.H. & Sullivan, A.F. (1986). Electrophysiological studies on the effects of intrathecal morphine on nociceptive neurones in the rat dorsal horn. *Pain*, **24**, 211-222.

Dobratz, M., Burns, K. & Oden, R. (1989). Pain in home hospice patients: An exploratory descriptive study. *Hospice Journal*, **5**, 117-133.

Dobratz, M., Wade, R., Herbst, L. & Ryndes, T. (1991). Pain efficacy in home hospice patients: A longitudinal study. *Cancer Nursing*, **14**, 20-26.

Doll, F.R.S. & Peto, R. (1981). *The Causes of cancer: Quantitative estimates of available risks of cancer today.* New York: Oxford University Press.

Donovan, K., Sanson-Fisher, R.W. & Redman, S. (1989). Measuring quality of life in cancer patients. *Journal of Clinical Oncology*, **7**, 959-968.

Duffy, E. (1962). *Activation and Behaviour*. New York: Wiley.

Duldt, B. (1991). I-Thou in nursing: Research supporting Duldt's theory. *Perspectives in Psychiatric Care,* **27**, 5-12.

Duncan, G., Gregg, J. & Ghia, J. (1978). The pain profile: A computerised system for assessment of chronic pain. *Pain,* **5**, 275-284.

Dunkel-Schetter, C. & Wortman, C.B. (1982). The interpersonal dynamics of cancer: Problems in social relationships and their impact on the patient.

de Haes, J.C.J.M. (1988). Quality of life: Conceptual and theoretical considerations. In Watson, M., Greer, S. & Thomas, C. (Eds), *Psychosocial Oncology*. Oxford: Pergamon Press.

de Haes, J.C.J.M., de Ruiter, J.H., Tempelaar, R. & Pennink, B.J.W. (1992). The distinction between affect and cognition in the quality of life of cancer patients: Sensitivity and stability. *Quality of Life Research*, **1**, 315-322.

de Haes, J.C.J.M., Van Knippenberg, F.C.E. & Neijt, J.P. (1990). Measuring psychological and physical distress in cancer patients: Structure and application of the Rotterdam Symptom Checklist. *British Journal of Cancer*, **62**, 1034-1038.

de Hennezel, M. (1997). *Intimate Death: How the Dying Teach us how to Live*. Boston: Little, Brown & Co.

de Leval, N. (1995). Scales of depression, ill-being and the quality of life-is there any difference? An essay in taxonomy. *Quality of Life Research*, **4**, 259-269.

Dean, C. & Surtees, P.G. (1989). Do psychological factors predict survival in breast cancer? *Journal of Psychosomatic Research*, **33**, 561-569.

Delongis, A., Coyne, J.C., Dakof, G., Folkman, S. & Lazarus, R.S. (1982). Relation of daily hassles, uplifts and major life events to health status. *Health Psychology*, **1**, 119-136.

Delvaux, N. & Razavi, R. (1997). Psychological training for health-care professionals in oncology: A way to improve communication skills. In A. Surbone & M, Zwitter (Eds), *Communication with The Cancer Patient: Information and Truth*. New York: Annals of The New York Academy of Sciences.

Dennison, S. (1997). Psycho-sexual care for patients with cancer and their partners: A service development. *Journal of Cancer Nursing*, **1**, 141-144.

Depner, C.E., Wethington, E. & Ingersoll-Dayton, B. (1984). Social support: Methodological issues in design and measurement. *Journal of Social Issues*, **40**, 37-54.

Derdiarian, A. (1987). Informational needs of recently diagnosed cancer patients. Part 1: A theoretical framework. *Cancer Nursing*, **10**, 107-115.

Derlega, V., Barbee, A.P. & Winstead, B.A. (1994). Friendship, Gender and Social Support: Laboratory Studies of Supportive Interaction. In B.R. Burleson, T.L. Albrecht & I.G. Satason (Eds), *Communication of Social Support: Messages, Interaction, Relationships and Community*. California: Sage.

Farquhar, M. (1995). Elderly people's definitions of quality of life. *Social Science and Medicine*, **41**, 1439-1446.

Faulkner, A. & Maguire, P. (1984). Teaching assessment skills. In Faulkner, A. (Ed.), *Recent Advances In Nursing.-7. Communication.* Edinburgh: Churchill Livingstone.

Faulkner, A. (1992). *Effective Interaction with Patients.* Edinburgh: Churchill Livingstone.

Faulkner, A. (1998). *When the news is bad: A guide for health professionals on breaking bad news.* Cheltenham: Stanley Thornes.

Fawzy, F., Cousins, N., Fawzy, N., Kemeny, M., Elashoff, R., & Morton, D. (1990a). A structured psychiatric intervention for cancer patients. (1). Changes over time and methods of coping in affect disturbance. *Archives of General Psychiatry*, **47**, 720-725.

Fawzy, F., Cousins, N., Fawzy, N., Kemeny, M., Elashoff, R., & Morton, D. (1990b). A structured psychiatric intervention for cancer patients. (2). Changes over time in immunological measures. *Archives of General Psychiatry*, **47**, 729-735.

Fayers, P.M., Hand, D.J., Bjordal, K. & Groenvold, M. (1997). Causal indicators in quality of life research. *Quality of Life Research*, **6**, 393-406.

Feist, J. & Bannon, L. (1988). *Health Psychology: An Introduction to Behaviour and Health.* Belmont, CA: Wadsworth.

Fennelly, J. (1997). Being honest with the patient and ourselves. Do we give our patients accurate insight into anticipated results of treatment ? An Irish perspective. In A. Surbone & M. Zwitter (Eds), *Communication with the Cancer Patient: Information and Truth.* New York: Annals of the New York Academy of Sciences.

Ferrell, B.A. (1991). Pain management in elderly people. *Journal of The American Geriatric Society,* **39**, 64-73.

Ferrell, B.R. (1995). The impact of pain on quality of life. *Nursing Clinics of North America*, **30**, 609-624.

Ferrell, B.A., Ferrell, B.R. & Osterweil, D. (1990). Pain in the nursing home. *Journal of The American Geriatric Society*, **38**, 409-414.

Ferrell, B.R., Hassey Dow, K., Leigh, S., Ly, J. & Gulasekaram, P. (1995). Quality of life in long-term cancer survivors. *Oncology Nursing Forum*, **22**, 915-922.

Ferrell, B.R., Wisdom, C., & Wenzl, C. (1989). Quality of life as an outcome variable in the management of cancer pain. *Cancer*, **63**, (Suppl. 11) 2321-2327.

Ferrell. B.R. & Dean, G. (1995). The meaning of cancer pain. *Seminars in Oncology Nursing*, **11**, 17-22.

Ferring, D. & Filipp, S. (1998). Still stable after all this ...?: Temporal comparison in coping with severe and chronic disease. *International Journal of Behavioural Development*, **22**, 339-355.

Field, D. (1989). *Nursing the Dying*. London: Tavistock and Routledge.

Fielding, R.G. & Llewelyn, S.P. (1987). Communication training in nursing may damage your health and enthusiasm: some warnings. *Journal of Advanced Nursing*, **12**, 281-290.

Fields, H.L. (1995). *Core Curriculum for Professional Education in Pain.* Seattle: IASP Press.

Fields, H.L., Emson, P.C., Leigh, B.K., Gilbert, R.F.T. & Iverson, L.L. (1980). Multiple opiate receptor sites on primary afferent fibres. *Nature*, **284**, 351-353.

Fisher, R. (1991). Introduction: Palliative care; a rediscovery. In J. Penson & R. Fisher (Eds), *Palliative Care for People with Cancer*. London: Edward Arnold.

Fishman B.& Loscalzo, M. (1987). Cognitive-behavioural interventions in management of cancer pain. *Medical Clinics of North America*, **71**, 271-287.

Fitzpatrick, R., Fletcher, A., Gore, S., Jones, D., Spielgelhalter, D. & Cox, D. (1992). Quality of life measures in health care.1: Applications and issues in assessment. *British Medical Journal*, **305**, 1074-1077.

Fletcher, A., Gore, S., Jones, D., Fitzpatrick, R., Spiegelhalter, D. & Cox, D. (1992). Quality of life measures in health care.2: Design, analysis and interpretation. *British Medical Journal*, **305**, 1145-1148.

Fletcher, B.C. (1988). The epidemiology of occupational stress. In C.L. Cooper & R. Payne (Eds), *Causes, Coping and Consequences of Stress at Work*. Chichester: Wiley.

Flor, H., Knost, B. & Birbaumer, N. (1997). Processing of pain and body-related verbal material in chronic pain patients: Central and peripheral correlates. *Pain*, **73**, 413-421.

Foley, K.M. (1994) Pain management in the elderly. In W.R. Hazzard, E.L. Bierman, J.P. Glass, W.H. Ettinger & J.B. Halter (Eds), *Principles of Geriatric Medicine*, 3rd ed. New York: McGraw-Hill.

Foley, K.M. (1985). The treatment of cancer pain. *New England Journal of Medicine*, **313**, 84-95.

Foley, K.M. (1987). Pain syndromes in patients with cancer. In M. Swerdlow & V. Ventafridda, (Eds), *Cancer Pain*. London: MTP Press.

Folkman, S. & Lazarus, R.S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behaviour*, **21**, 219-239.

Folkman, S. & Lazarus, R.S. (1988). The relationship between coping and emotion: Implications for theory and research. *Social Science and Medicine*, **26**, 309-317.

Folkman, S., Chesney, M., McKusick, L., Ironson, G., Johnson, D.S. & Coates, T.J. (1991). Translating coping theory into an intervention. In J. Eckenrode (Ed.), *The Social Context of Coping*. New York: Plenum Press.

Folkman, S., Lazarus, R.S., Dunkel-Schetter, C., Delongis, A. & Gruen, R.J. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping and encounter outcomes. *Journal of Personality and Social Psychology*, **50**, 571-579.

Ford, S., Fallowfield, L. & Lewis, S. (1996). Doctor-patient interactions in oncology. *Social Science and Medicine*, **42**, 1511-1519.

Fordyce, W.E. (Ed.) (1995). *Back Pain in the Workplace*. Seattle: IASP Press.

Foreman. R.O. (1986). Spinal substrates in visceral pain. In T.L. Yaksh (Ed.), *Spinal Afferent Processing*. New York: Plenum Press.

Forsen, A. (1991). Psychosocial stress as a risk for breast cancer. *Psychotherapy and Psychosomatics.* **55**, 176-185

Foster, G.M. & Anderson, B.G. (1978). *Medical Anthropology*. New York: Wiley.

Foucault, M. (1989). *The Birth of The Clinic: An Archaeology of Medical Perception*. London: Routledge.

Franke, A.L., Garssen, B. & Abu-Saad, H.H. (1996). Continuing pain education in nursing: A literature review. *International Journal of Nursing Studies*, **33**, 567-578.

Frankenhauser, M. (1972). *Biochemical events, stress and adjustments.* Reports from the Psychological Laboratories, University of Stockholm, No. 368.

Freidman , H.L. (1992). Changing patterns of adolescent sexual behaviour: Consequences for health and development. *Journal of Adolescent Health*, **13**, 345-350.

French, H.P. (1979). Reassurance: A nursing skill. *Journal of Advanced Nursing*, **4**, 627-634.

French, J.R.P., Caplan, R.D. & van Harrison, R. (1982). *The Mechanisms of Job Stress and Strain*. New York: Wiley.

French, J.R.P., Rogers, W. & Cobb, S. (1974). A model of person-environment fit. In G.W. Coehlo, D.A. Hamburg & J.E. Adams. *Coping and Adaptation*. New York: Basic Books.

Friederichs-Fitzwater, M.M., Callahan, E.J., Flynn, N. & Williams, J. (1991). Relational control in physician-patient encounters. *Health Communication*, **3**, 17-36.

Gagne, R.M. (1966). Human problem-solving: Internal and external events. In B. Kleinmuntz (Ed.), *Problem Solving: Research, Method and Theory*. New York: Wiley.

Galbraith, M.E. (1995). What kind of social support do cancer patients get from nurses? *Cancer Nursing*, **18**, 362-367.

Galen. De Tumoribus. Cited in P.J. Rosch. (1984). Stress and cancer. In C.L. Cooper, (Ed.), *Psychosocial Stress and Cancer*. Chichester: Wiley.

Ganong, W.F. (1991). *Review of Medical Physiology*. London: Prentice-Hall.

Ganster, D.C. & Victor, B. (1988). The impact of social support on mental and physical health. *British Journal of Medical Psychology*, **61**, 17-36.

Ganz, P. (1994). Quality of life and the patient with cancer: Individual and policy implications. *Cancer*, **74**, 1445-1452.

Ganz, P.A., Schag, C.C. & Heinrich, R.I. (1985). The psychosocial impact of cancer on the elderly: A comparison with younger patients. *Journal of the American Geriatric Society*, **33**, 429-435.

Gatchel, R.J. (1995). Stress and coping. In B. Parkinson & A.M. Colman. (Eds), *Emotion and Motivation*. London: Longman.

Gendron (1701). Cited in P.J. Rosch (1984). Stress and cancer. In C.L. Cooper, (Ed.), *Psychosocial Stress and Cancer*. Chichester: Wiley.

Gilhooly, M., Berkeley, J. & McCann, J. (1988). Truth telling with dying cancer patients. *Palliative Medicine*, **1**, 64-71.

Goethals, G.R. & Darley, J.M. (1977). Social comparison theory: An attributional approach. In J.M. Suls & R.L. Miller (Eds), *Social* *comparison processes: Theoretical and empirical perspectives.* Washington: Hemisphere.

Golden, W.L., Gersh, W.D. & Robbins, D.M. (1992). *Psychological Treatment of Cancer Patients: A Cognitive-Behavioral Approach.* Boston: Allyn & Bacon.

Goldberg, D.P., Cooper, B., Eastwood, M.R., Kedward, H.B. & Shepherd, M. (1970). A standardised psychiatric interview for use in community surveys. *British Journal of Preventive and Social Medicine*, **24**, 18-23

Goldfried, M.R. & D'Zurilla, T.J. (1969). A behaviour-analytic model for assessing competence. In C.D. Spielberger (Ed.), *Current Topics in Clinical and Community Psychology.* Vol.1. New York: Academic Press.

Goldsheider, A. (1894). *Uber den Schmerz in Physiologischer und Klinischer Hinisich.* Berlin: Hirshwald.

Goldthorpe, J.H. (1987). *Social Mobility and Class Structure in Modern Britain.* Oxford: Clarendon Press.

Gonzales, G.R., Elliott, K.J., Portenoy, R.K. & Foley, K.M. (1991). The impact of a comprehensive evaluation in the management of cancer pain. *Pain*, **47**, 141-144.

Gotay, C. (1985). Why me? Attributions and adjustment by cancer patients and their mates at two stages in the disease process. *Social Science and Medicine*, **90**, 825-831.

Gottlieb, B.H. (1981). *Social Networks and Social Support.* London: Sage.

Gottlieb, B.H. (1985). Theory into practice: Issues that surface in planning interventions which mobilise support. In I.G. Sarason & B.R. Sarason (Eds), *Social support: Theory, research and application.* The Netherlands: Martinus Nijhof.

Gottschalk, L.A. & Hoigaard-Martin, J. (1986). The Emotional Impact of Mastectomy. *Psychiatry Research*, **17**, 153-167.

Graham, C., Bond, S., Gerkovich, M. & Cook, M. (1980). Use of the McGill Pain Questionnaire in the assessment of cancer pain: Replicability and consistency. *Pain*, **8**, 377-387.

Grande, G.E., Todd, C.J., Barcley, S. & Doyle, J. (1996). What terminally ill patients value in the support provided by GPs, District and Macmillan Nurses. *International Journal of Palliative Nursing,* **2**, 138-143.

Granstrom, S.L. (1985). Spiritual nursing care for oncology patients. *Topics in Clinical Nursing,* **7**, 39-45.

Greenberg, D.B. (1998). Fatigue. In J.C. Holland (Ed.), *Psycho-Oncology*. New York: Oxford University Press.

Greene, W.A. & Swisher, S.N. (1969). Psychological and somatic variables associated with the development and course of monozygotic twins discordant for leukemia. *Annals of The New York Academy of Science*, **164**, 394-408.

Greene, W.A. (1962). The psychosocial setting of the development of leukemia and lymphoma. *Annals of The New York Academy of Science*, **125**, 794-802.

Greenglass, E.R. (1993). The contribution of social support to coping strategies. *Applied Psychology: An International Review*, **42**, 323-340.

Greenwald, H.P. & Nevitt, M.C. (1982). Physician attitudes toward communication with cancer patients. *Social Science and Medicine*, **16**, 591-594.

Greenwald, H.P., Bonica, J.J. & Bergner, M. (1987). The prevalence of pain in four cancers. *Cancer*, **60**, 2563-2569.

Greer, S. & Morris, T. (1975). Psychological attributes of women who develop breast cancer: A controlled study. *Journal of Psychosomatic Research*, **19**, 147-153.

Greer, S. & Watson, M. (1985). Towards a biological model of cancer. Psychological considerations. *Social Science*, **20**, 773-777.

Greer, S. (1983). Cancer and the mind. *British Journal of Psychiatry*, **143**, 535-543.

Greer, S. (1984). The psychological dimension in cancer treatment. *Social Science and Medicine,* **18,** 345-349.

Greer, S. (1991). Foreword. In M. Watson (Ed.), *Cancer Patient Care: Psychosocial Treatment Methods.* Cambridge: The British Psychological Society & Cambridge University Press.

Greer, S., Morris, T. & Pettingale, K.W. (1979). Psychological response to breast cancer: Effect on outcome. *Lancet* ii,785-787.

Gregson, O. & Looker, T. (1996). The biological basis of stress management . In S. Palmer & W. Dryden (Eds), *Stress Management and Counselling. Theory, Practice, Research and Methodology*. London: Cassell.

Grond, S., Zech, D., Diefenbach, C., Radbruch, L. & Lehmann, K.A. (1996). Assessment of cancer pain: A prospective evaluation in 2266 cancer patients referred to a pain service. *Pain*, **64**, 107-114.

Guyatt, G.H., Berman, L.B., Townsend, M., Pugsley, S.O. & Chambers, L.W.A. (1987). A measure of quality of life for clinical trials in chronic lung disease. *Thorax,* **42**, 773-778.

Guyatt, G.H., Jaeschke, R. (1990). Measurements in clinical trials: Choosing the appropriate approach. In B. Spiker (Ed.), *Quality of Life Assessments in Clinical Trials*. New York: Raven.

Haan, M.N., Kaplan, G.A. & Syme, S.L. (1989). Socioeconomic status and health: Old observations and new thoughts. In J.P. Bunker, D.S. Gomby & B.H. Kehrer (Eds), *Pathways To Health: The Role of Social Factors*. Menlo Park.CA.: Henry J Kaiser Foundation.

Haan, N. (1977). *Coping and Defending: Processes of Self-Environment Organisation*. Academic Press: New York.

Hall, J. (1976). Subjective measures of quality of life in Britain 1971-1975: Some developments and trends. *Social Trends*, **7**, 47-60.

Hamberger, L.K. & Lohr, J.M. (1984). *Stress and Stress Management*. New York: Springer.

Hanratty, J.F. (1989). *Palliative Care of the Terminally Ill*. Oxford: Radcliffe Medical Press

Hanson, J.D., Larson, M.E. & Snowdon, C.T. (1976). The effect of control over high intensity noise on plasma cortisol levels in rhesus monkeys. *Behavioural Biology*, **16**, 1265-1270.

Havlik, R.J., Yancik, R., Long, S., Ries, L. & Edwards, B. (1994). The National Institute on Ageing and The National Cancer Institute SEER Collaborative Study on Comorbidity and Early Diagnosis of Cancer in The Elderly. *Cancer Supplement*, 74, 2101-2106.

Hays, R.D., Anderson, R. & Revicki, D. (1993). Psychometric considerations in evaluating health-related quality of life measures. *Quality of Life Research*, **2**, 441-449.

Headey, B., Holmstrom, E. & Wearing, A. (1984). The impact of life events and changes in domain satisfactions on well-being. *Social Indicators Research*, **15**, 203-227.

Healey, J.F. (1999). *Statistics: A Tool For Social Research*. 5th ed. Belmont: Wadsworth.

Herity, B., Hilliard, N., Moriarty, M., Fennelly, J., Conroy, R. & Casey, M. (1987). A study of the needs of cancer patients and their relatives. *Irish Journal of Medical Science*, **156**, 172-181.

Herth, K. (1989). The relationship between level of hope and level of coping response and other variables in patients with cancer. *Oncology Nursing Forum*, **16**, 67-72.

Herth, K. (1990). Fostering hope in terminally ill people. *Journal of Advanced Nursing*, **15**, 1250-1259.

Hinkle, L.E. (1973). The concept of stress in the biological and social sciences. *Science, Medicine & Man*, **1**, 31-48.

Hinton, J. (1981). The adult patient: Reactions to hospice care. In C. Saunders, D. Summers & N. Teller (Eds), *Hospice: The Living Idea*. London: Arnold.

Hirsch, B.J. (1979). Psychological dimensions of social networks: A multimethod analysis. *American Journal of Community Psychology*, **7**, 263-277.

Hirsch, B.J. (1980). Natural support systems and coping with major life changes. *American Journal of Community Psychology*, **8**, 159-171.

Hochschild, A.R. (1979). Emotion work, feeling rules and social structure. *American Journal of Sociology*, **85**, 551-575.

Hogbin, B. & Fallowfield, L. (1989). Getting it taped: The bad news consultation with cancer patients. *British Journal of Hospital Medicine*, **41**, 330-333.

Holahan, C.J. & Moos, R.H. (1987). Personal and contextual determinants of coping strategies. *Journal of Personality and Social Psychology*, **52**, 946-955.

Holden, R.J. (1990). Empathy: The art of emotional knowing in holistic nursing care. *Holistic Nursing Practice*, **5**, 70-79.

Holland, J.C. (1999). Standards of care for management of distress in patients with cancer. New York: National Comprehensive Cancer Network. *Oncology*, **13**, 113-147.

Holland, J.C. & Rowland, J.H. (1989). *Handbook of Psycho-Oncology*. New York: Oxford University Press.

Holland, J.C. (1997). Preliminary guidelines for the treatment of distress. *Oncology*, 11, 109-117.

Holland, J.C. (1998). *Psycho-Oncology*. New York: Oxford University Press.

Hollen, P.J., Gralla, R.J., Kris, M.G., & Potanovich, L.M. (1993). Quality of life assessment in individuals with lung cancer: Testing the lung cancer symptom scale (LCSS). *European Journal of Cancer*, 29a (Suppl.1): S51.

Hollingshead, A.B. & Redlich. F.C. (1958). *Social Class and Mental Illness.* New York: Harper.

Holman, H.R. & Lorig, K. (1992). Perceived self-efficacy in self-management of chronic disease. In R. Schwarzer (Ed.), *Self-Efficacy: Thought Control of Action.* Washington: Hemisphere.

Homans, G. (1965). Group factors in worker productivity. In H. Proshansky & B. Seidenberg (Eds), *Basic Studies in Social Psychology.* New York: Holt, Rinehart & Winston.

Hopwood, P., Howell, A., & Maguire, P. (1991). Screening for psychiatric morbidity in patients with advanced breast cancer: Validation of two self-report questionnaires. *British Journal of Cancer*, **64**, 353-556.

Hord, A.H. (1997). The sympathetic nervous system. In W.C.V. Parris (Ed.), (1997). *Cancer Pain Management: Principles and Practice.* Boston: Butterworth-Heinemann.

Hoskin, P.J. (1989). Scientific and clinical aspects of radiotherapy in the relief of bone pain. *Cancer Surveys*, **7**, 69-86.

Hoskin, P.J., Ford., H.T. & Harmer, C.L. (1989). Hemibody irradiation for metastatic bone pain in two histologically distinct groups of patients. *Clinical Oncology*, **1**, 67-69.

Hoskins Michel, T. (Ed.), (1985). *Pain.* New York: Churchill Livingstone.

House, J.S. & Kahn, R.L. (1985). Measures and concepts of social support. In S. Cohen & R. L .Syme (Eds), *Social Support and Health.* New York: Academic Press.

House, J.S. (1981). *Work, Stress and Social Support.* Massachusetts: Addison-Wesley.

House, J.S., Landis, K.R. & Umberson, D. (1988). Social relationships and health. *Science*, **241**, 540-545

Howard, J. (1975). Humanising and dehumanisation of health care. A conceptual view. In J. Howard & A. Strauss (Eds), *Humanising Health Care.* New York: Wiley.

Hughes, J.J. (1994). Information at the Bedside: The Experience of The Medical Division of Labour by University Hospitals' Inpatients. Dissertation University of Chicago, Sociology Department.

Hull, R., Ellis, M. & Sargent, V. (1989). *Teamwork in Palliative Care.* Oxford: Radcliffe Medical Press.

Hunt, R. (1997). Place of death of cancer patients: Choice versus constraint. *Progress in Palliative Care*, **5**, 238-241.

Hunt, S.M., McEwen, J. & McKenna, S.P. (1986). *Measuring health status.* Beckenham: Croom Helm.

Hunter, C.P, Redmond, C.K., Chen, V.W., Austen, D.F., Greenberg, R.S., Correa, P, Muss, H.B., Forman, M.R., Wesley, M.N., Blacklow, F.S. (1993). Breast cancer: Factors associated with stage at diagnosis in black and white women. *Journal of The National Cancer Institute,* **85**, 1129-1137.

Huskisson, E. (1974). Measurement of pain. *Lancet* i, 1127-1131.

Jacobs, I.J. & Charles (1980). Life events and occurrence of cancer in children. *Psychosomatic Medicine*, **42**, 11-25.

Jacox, A., Carr, D. & Payne, R. (1994). *Clinical Practice Guideline Number 9: Management of Cancer Pain.* U.S. Department of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research. AHCPR Publication No. 94-0592:139-41.

Jadad, A.R., Carroll, D., Glynn, C.J., Moore, R.A. & McQuay, H.J. (1992). Morphine responsiveness of chronic pain: Double blind randomised cross-over study with patient-controlled analgesia. *Lancet*, **339**, 1367-1371.

James, W. (1884). What is an emotion? *Mind*, **9**, 188-205.

Janis I.L. (1982). Decision-making under stress. In L. Goldberger & S. Breznitz (Eds), *Handbook of Stress: Theoretical and Clinical Aspects.* New York: Free Press.

Janis, I.L. & Mann, L (1977). *Decision Making: A Psychological Analysis of Conflict, Choice and Commitment.* New York: Free Press.

Jarrett, S.R, Ramirez, A.J., Richards, M.A. & Weinman, J. (1992). Measuring Coping in Breast Cancer. *Journal of Psychosomatic Research*, **36**, 593-602.

Jenkins, R.A. & Pargament, K.I. (1988). Cognitive appraisals in cancer patients. *Social Science and Medicine,* **26**, 625-633.

Jensen, M. (1987). Psychological factors predicting the course of breast cancer. *Journal of Personality*, **53**, 317-342.

Jerusalem, M. & Schwarzer, R. (1992). Self-efficacy as a resource factor in stress appraisal processes. In R. Schwarzer (Ed.), *Self-Efficacy: Thought Control of Action.* Washington: Hemisphere.

Jerusalem, M. (1990). Temporal patterns of stress appraisals for high and low anxious individuals. *Anxiety Research*, **3**, 113-129.

Johnson, B.W. & Parris, W.C.V. (1997). Mechanisms of cancer pain. In W.C.V. Parris (Ed.), *Cancer Pain Management: Principles and Practice*. Boston: Butterworth-Heinemann.

Johnston, M. (1976). Communication of patients' feelings in hospital. In A.E. Bennett, (Ed.), *Communication between Doctors*. Oxford: Oxford University Press.

Johnston, M. (1982). Recognition of patients' worries by nurses and by other patients. *British Journal of Clinical Psychology*, **21**, 255-261.

Johnston, M., Wright, S.C. & Weinman, J. (1995). *Measures in Health Psychology: A User's Portfolio*. Windsor: NFER-NELSON.

Kaasa, S., Malt, U.F., Hagen, S., Wist, E., Moum, T. & Kvidstad, A. (1993). Psychological distress in cancer patients with advanced disease. *Radiotherapy and Oncology*, **27**, 193-197.

Kagan, A. & Levi, L. (1971). Adaptation of the psychosocial environment to man's abilities and needs. In Levi, L. (Ed.), *Society, Stress and Disease*. Vol. 1. London: Oxford University Press.

Kahn, D. & Steeves, R. (1993). Spiritual well-being: A review of the research literature. In M. Weldon (Ed.), *Quality of life: A nursing challenge*. Philadelphia: Meniscus.

Kane, R.L., Wales, J., Bernstein. L., Leibowitz, A. & Kaplan, S. (1984). A randomised controlled trial of hospice care. *Lancet* i, 890-894.

Kanner, A.D., Coyne, J.C., Schaefer, C. & Lazarus, R.S. (1981). Comparison of two modes of stress measurement: Daily hassles and uplifts versus major life events. *Journal of Behavioural Medicine*, **4**, 1-39.

Karoly, P. (1985). The Assessment of pain: Concepts and procedures. In Karoly, P. (Ed.), *Measurement Strategies in Health Psychology*. New York: Wiley.

Kaplan, B.H., Cassel, J.C. & Gore, S. (1977). Social Support and Health. *Medical Care*, **15**, 47-58.

Kaplan, H. (1970). Self-derogation and adjustment to recent life experiences. *Archives of General Psychiatry*, **22**, 324-331.

Karasawa, K. (1991). The effects of onset and offset responsibility on affects and helping judgments. *Journal of Applied Social Psychology*, **21**, 482-499.

Karasek, R. & Theorell, T. (1990). *Healthy Work: Stress, Productivity and The Reconstruction of Working Life*. New York: Basic Books.

Karasek, R.A. (1979). Job demands, job decision latitude and mental strain: Implications for job redesign. *Administrative Science Quarterly*, **24**, 285-308.

Karnofsky, D.A. & Burchenal, J.H. (1949). The clinical evaluation of chemotherapeutic agents in cancer. In C.M. McLeod (Eds), *Evaluation of Chemotherapeutic Agents*. New York: Columbia University Press.

Katz, J.L., Weiner, H., Gallagher, T.F. & Hellman, L. (1970). Stress, distress and ego defences: Psychoendocrine responses to impending breast tumour biopsy. *Archives of General Psychiatry*, **23**, 131-142.

Katz, L. & Epstein, S. (1991). Constructive thinking and coping with laboratory induced stress. *Journal of Personality and Social Psychology*, **61**, **789-800**.

Kavanagh, D.J. & Bower, G.H (1985). Mood and self-efficacy: Impact of joy and sadness on perceived capabilities. *Cognitive Therapy and Research*, **9**, 507-525.

Keefe, F.J., Block, A.R. & Williams, R.B. (1980). Behavioural treatments of the pre-chronic versus chronic pain patient. In F.J. Keefe & J.A. Blumenthal (Eds), *Assessment Strategies in Behavioural Medicine*. New York: Grune & Stratton.

Keele, K.D. (1967). Pain sensitivity and the pain pattern of cardiac infarction. *Proceedings of The Royal Society of Medicine*, **60**, 417-419.

Keeling, D.I., Price, P.E., Jones, E. & Harding, K.G. (1996). Social support: Some pragmatic implications for health care professionals. *Journal of Advanced Nursing*, **23**, 76-81.

Kent, G. (1987). Self-efficacious control over reported physiological, cognitive and behavioural symptoms of dental anxiety. *Behaviour Research and Therapy*, **25**, 341-347.

Kesley, J.L. & Horn-Ross, P.L. (1993). Breast cancer; magnitude of the problem and descriptive epidemiology. *Epidemiology Review*, **15**, 345-350.

Kiritz, S. & Moos, R.H. (1974). Physiological effects of social environments. *Psychosomatic Medicine*, **36**, 96-114.

Klein, D.F. (1974). Endogenomorphic depression. *Archives of General Psychiatry*, **31**, 447-454.

Kremer, E., Hampton Atkinson, J. & Ignelszi, R. J. (1981). Measurement of pain: Patient preference does not confound pain measurement. *Pain*, **10**, 241-248.

Kripke, M.L. (1988). Immunoregulation of carcinogenesis: Past, present and future. *Journal of The National Cancer Institute*, **80**, 722-727.

Krippendorff, K. (1989). The power of communication and the communication of power: Toward an emancipatory theory of communication. *Communication*, **12**, 175-196.

Krishnasamy, M. (1996). Social support and the patient with cancer: A consideration of the literature. *Journal of Advanced Nursing*, **23**, 757-762.

Krohne, H.W. (1989). The concept of coping modes: Relating cognitive person variables to actual coping behaviour. *Advances in Behavioural Research and Therapy*, **11**, 235-248.

Kuhar, M.J. & Unnerstall, J.R. (1982). In vitro labeling receptor autoradiography: Loss of label during ethanol dehydration and preparative procedures. *Brain Research*, **244**, 178-181.

Kuhar, M.J. & Unnerstall, J.R. (1985). Quantitative receptor mapping by autoradiography: Some current technical problems. *Trends in Neuroscience*, **8**, 49-53.

Kyle, T. (1995). The concept of caring: A review of the literature. *Journal of Advanced Nursing*, **21**, 506-514.

Laffey, J., Murphy, D. Regan, J. & O'Keeffe, D. (1998). Cost-benefit analysis of spinal cord stimulation for intractable angina pectoris: A win-win scenario? *Hospital Medicine*, **59**, 820-821.

Lamont, D.W., Symonds, R.P., Brodie, M.N., Nwabineli, N.J. & Gillis, C.R. (1993). Age, socioeconomic status and survival from cancer of cervix in the west of Scotland, 1980-1987. *British Journal of Cancer*, **67**, 351-357.

Lampl, Y. (1994). Pain. In Ramachandran, V.S. (Ed.), *Encyclopaedia of Human Behaviour*. Vol. 3. New York: Academic Press.

Lange, C.G. (1885). *The Emotions*. (English Translation, 1922) Baltimore: Williams & Wilkins.

Lazarus, R.S. (1966). *Psychological Stress and The Coping Process*. New York: McGraw-Hill.

Lazarus, R.S. (1991a). *Emotion and Adaptation*. Oxford: Oxford University Press.

Lazarus, R.S. (1991b). Progress on a cognitive-motivational-relational theory of emotion. *American Psychologist*, **46**, 819-834.

Lazarus, R.S. (1981). The stress and coping paradigm. In C. Eisdorfer, D. Cohen, A. Kleinman & P. Maxim (Eds), *Theoretical Bases For Psychopathology*. New York: Spectrum.

Lazarus , R.S. & Cohen, J.B. (1977). Environmental stress. In I. Attman & J.F. Wohlwill (Eds), *Human Behaviour and The Environment: Current Theory and Research* (Vol.2). New York: Plenum.

Lazarus, R.S. & Delongis, A. (1983). Psychological stress and coping in ageing. *American Psychologist*, **38**, 245-254.

Lazarus, R.S. & Folkman, S. (1984). *Stress, Appraisal and Coping*. New York: Springer.

Lazarus, R.S. (1982). Stress and coping as factors in health and illness. In J. Cohen, J.W. Cullen & L.R. Martin (Eds), *Psychosocial Aspects of Cancer*. New York: Raven.

Le Shan, L. (1964). The world of the patient in severe pain of long duration. *Journal of Chronic Disease*, **17**, 119-126.

Le Shan, L.L. (1977). *You Can Fight for Your Life*. New York: Evans.

LeConte, J. (1846). Statistical researches on cancer. *Southern Medical and Surgical Journal,* (May 1846), 273-274.

Lee, R. & Spencer, P.S.J. (1977). Antidepressants and pain: A review of the pharmacological data supporting the use of certain tricyclics in chronic pain. *Journal of International Medical Research.* **5**, 146-156.

Lerman, G., Daly, M., Walsh, W.P., Resch, N., Seay, J., Barsevick, A., Birenbaum, L. Heggan, T. & Martin, G. (1993). Communication between patients with breast cancer and health care providers. *Cancer*, **72**, 2612-2620.

Lewandowski, W. & Jones, S.L. (1984). The family with cancer. *Cancer Nursing*, **11**, 313-321.

Lewis, F., Haberman, M. & Wallhagen, M. (1986). How adults with late stage cancer experience personal control. *Journal of Psychosocial Oncology.* **4**, 27-42.

Ley, P. & Llewelyn, S. (1995). Improving patients' understanding, recall, satisfaction and compliance. In A. Broome & S. Llewelyn (Eds), *Health Psychology: Processes and Applications.* 2nd ed. London: Chapman Hall.

Lin, N. (1986). Conceptualising social support. In L. Lin, A. Dean & W. Ensel (Eds), *Social Support, Life Events and Depression.* Orlando: Academic Press.

Linden, W. (1990). *Autogenic Training: A Clinical Guide*. New York: The Guilford Press.

Lindsley, D.B. (1951). Emotion. In S.S. Stevens (Ed.), *Handbook of Experimental Psychology*. New York: Wiley.

Lipowski, Z.J. (1970). Physical illness, the individual and the coping process. *Psychiatry and Medicine*, **1**, 91-102.

Livingston, W.K. (1943). *Pain Mechanisms*. New York: Macmillan.

Loewy, J.W., Kapadia, A.S., Hsi, B., Davis, B.R. (1992). Statistical methods that distinguish between attributes of assessment: Prolongation of life versus quality of life. *Medical Decision Making*, **12**, 83-92.

Lubinski, R. & Welland, R.J. (1997). Normal aging and environmental effects on communication. *Seminars in Speech & Language*, **18**, 107-126.

Luckenotte, D. (1996). *Gerontologic Nursing*. St. Louis: Mosby.

Lunn, L. (1993). Spiritual concerns in palliative care. In C. Saunders & N. Sykes. (Eds), *The Management of Terminal Malignant Disease*. London: Edward Arnold.

Lunt, B.J. (1984). The assessment of symptoms and mood in terminally ill cancer patients (Abstract). In M. Watson. & S. Greer (Eds), *Psychosocial Issues in Malignant Disease*. Oxford: Pergamon.

Luthe, W. & Schultz, J.H. (1969). *Autogenic Therapy; Vol. 1: Autogenic Methods*. New York: Grune Stratton.

Mackworth, N., Fobair, P., & Prados, M.D. (1992). Quality of life self-reports from 200 brain tumour patients: Comparisons with Karnofsky performance scores. *Journal of Neuro-oncology*, **14**, 243-253.

Madison, J.L. & Wilkie, D.J. (1995). Family members' perceptions of cancer pain: Comparisons with patient sensory report and by patient psychological status. *Nursing Clinics of North America*, **30**, 625-645.

Mages, N. & Mendelsohn, G. (1979). Effects of cancer on patients' lives: a personological approach. In G. Stone, I. Cohen & N. Hellen (Eds), *Health Psychology*. San Francisco: Jossey-Bass.

Maguire, G.P., Lee E.G. & Bevington, D.J. (1978). Psychiatric problems in the first year after mastectomy. *British Journal of Medicine*, 1, 963-965.

Maguire, G.P., Tait, A., Brooke, M., Thomas, C., Howat, J.M., Sellwood, R.A. & Bush, H. (1980). Psychiatric morbidity and physical toxicity associated with adjuvant chemotherapy after mastectomy. *British Medical Journal*, **281**, 1179-1180.

Maguire, P. (1982). *Doctor-Patient Skills in Social Skills and Health.* London: Methuen.

Maguire, P. & Selby, P. (1989). Assessing the quality of life in cancer patients. *British Journal of Cancer,* **60**, 437-440.

Mandler, G. (1984). *Mind and Body: Psychology of Emotion and Stress.* New York: Norton.

Manfredi, P.L., Weinstein, S.M., Chandler, S.W. & Payne, R. (1997). Comprehensive medical management: Opioid analgesia. In W.C.V. Parris (Ed.), (1997). *Cancer Pain Management: Principles and Practice.* Boston: Butterworth-Heinemann.

Marcus, A.C., Garret, K.M., Cella, D., Wenzel, L.B., Brady, M.J., Crane, L.C., McClatchey, M.W., Kluhman, B.C. & Pate-Willig, M. (1998). Telephone counselling of breast cancer patients after treatment: A description of a randomised clinical trial. *Psycho-Oncology*, **7**, 470-482.

Marshall, H.R. (1894). *Pain, Pleasure and Aesthetics.* London: Macmillan.

Mason, J.W. (1968). A review of psycho-endocrine research on the pituitary-adrenal cortical system. *Psychosomatic Medicine*, **30**, 576-607.

Mason, J.W. (1975). A Historical view of the stress field. *Journal of Human Stress*, **1**, 22-36.

Massie, M.J. & Holland, J.C. (1987). The cancer patient with pain: Psychiatric complications and their management. *Medical Clinics of North America*, **71**, 243-258.

Mather, M.D., (1970). Obsessions and compulsions. In C.G. Costello (Ed.), *Symptoms of Psychopathology.* New York: Wiley.

Mattlin, J., Wethington, E. & Kessler, R. (1990). Situational determinants of coping and coping effectiveness. *Journal of Health and Social Behaviour*, **31**, 103-122.

Mayberry, R.M., Coates, R.J., Hill, H.A., Click, L.A., Chen, V.W., Austen, D.F., Redmond, C.K., Fenoglio-Preiser, C.M., Hunter, C.P. & Haynes, M.A. (1995). Determinants of black/white differences in colon survival. *Journal of The National Cancer Institute*, **87**, 1686-1693.

Mayer, D.J. & Price, D.D. (1976). Central nervous system mechanisms of analgesia. *Pain*, **2**, 379-404.

McCaffrey, M., Beebe, A., Latham, J. & Ball, D. (Eds) (1994). *Pain: Clinical Manual For Nursing Practice.* London: Mosby.

McCallister, L. & Fischer, C.S. (1978). A procedure for surveying personal networks. *Sociological Methods & Research*, **7**, 131-148.

McCarthy, G. (1990). Coping. *Irish Nursing Forum and Health Services*, July/August, 22-25.

McCarthy, W. & Newcomb, M. (1992). Two dimensions of perceived self-efficacy: Cognitive control and behavioural coping ability. In R. Schwarzer (Ed.), *Self-Efficacy: Thought Control of Action.* Washington: Hemisphere.

McClelland, D.C. & Clark, R.A. (1966). Discrepancy hypothesis. In R.N. Haber (Ed.), *Current Research in Motivation.* New York: Holt, Rinehart &Winston.

McDonnell, F. (1999). Palliative medicine: An opportunity for anaesthesia in the new millenium. Paper presented at the autumn college meeting of the College of Anaesthetists, Royal College of Surgeons in Ireland, Dublin, September.

McDougall. W. (1928). Emotion and feeling distinguished. In M.L. Reymert (Ed.), *Feelings and Emotions.* Worcester: Clark University Press.

McFall, R.M. (1982). A review and reformulation of the concept of social skills. *Behavioural Assessment*, **4**, 1-33.

McGuire, D.B. (1984). The measurement of clinical pain. *Nursing Research*, **33**, 152-156.

McGuire, D.B. (1992). Comprehensive and multidimensional assessment and measurement of pain. *Journal of Pain and Symptom Management*, **7**, 312-319.

McKenzie, A.M. & Parris, W.C.V. (1997). Historical perspectives. In W.C.V. Parris (Ed.), *Cancer Pain Management: Principles and Practice.* Boston: Butterworth-Heinemann.

McMillan, S. & Mahon, M. (1994). Measuring quality of life in hospice patients using a newly developed hospice quality of life index. *Quality of Life Research*, **3**, 437-447.

McMillan, S.C., Williams, F.A. Chatfield, R. & Camp, L.D. (1988). A validity and reliability study of two tools for assessing and managing cancer pain. *Oncology Nursing Forum*, **15**, 735-741.

McQuay, H.J. (1997). Antidepressants and chronic pain. *British Medical Journal*, **314**, 763-765.

Mechanic, D. (1986). Illness Behaviour: An Overview. In S. McHugh & T.M. Vallis (Eds.), *Illness Behaviour: A Multidisciplinary Model.* New York: Plenum Press.

Meinhart, N.T. & McCaffrey, M. (1983). *Pain: A Nursing Approach to Assessment and Analysis.* Norwalk, Conn.: Appleton-Century Crofts.

Mellette, S.J. (1993). Cancer Rehabilitation. *Journal of The National Cancer Institute.* **15**, 781-784.

Melzack, R. (1973). *The Puzzle of Pain.* Harmondsworth: Penguin Books.

Melzack, R. (1975). The McGill Pain Questionnaire: Major properties and scoring methods. *Pain,* **1**, 277-299.

Melzack, R. & Torgerson, W.S. (1971). On the language of pain. *Anaesthesiology*, **34**, 50-59.

Melzack, R. & Wall, P.D. (1965). Pain mechanisms: A new theory. *Science,* **150**, 971-979.

Melzack, R. & Wall, P.D. (1982). *The Challenge of Pain.* London: Penguin.

Melzack, R. & Wall, P.D. (1988). *The Challenge of Pain.* 2nd ed. London: Penguin.

Menninger, K. (1963). *The Vital Balance: The Life Process in Mental Health and Illness.* New York: Viking.

Mermelstein, H.T. & Lesko, L. (1992). Depression in patients with cancer. *Psycho-Oncology,* **1**, 199-215.

Merskey, H. & Bogduk, N. (1994). *Classification of Chronic Pain.* 2nd ed. Seattle: IASP Press.

Miller, D.G. (1980). On the nature and susceptibility to cancer. *Cancer*, **46**, 1307-1318.

Miller, S.M. (1987). Monitoring and blunting: Validation of a questionnaire to assess styles of information seeking under threat. *Journal of Personality and Social Psychology,* **52**, 345-353.

Milne, D. (1997). Seeking social support: An observational instrumental and illustrative analysis. *Behavioural and Cognitive Psychotherapy*, **25**, 173-185.

Montazeri, A., Gillis, C.R. & McEwen, J. (1996). Measuring quality of life in oncology: Is it worthwhile? 1. Meaning, purposes and controversies. *European Journal of Cancer Care,* **5**, 159-167.

Moon, M.H. (1985). Psychological approaches to the treatment of chronic pain. In Hoskins Michel, T. (Ed.), *Pain.* New York: Churchill Livingstone.

Moorey, S. (1991). Adjuvant psychological therapy for anxiety and depression. In M. Watson (Ed.), *Cancer Patient Care: Psychosocial Treatment Methods.* Cambridge: The British Psychological Society & Cambridge University Press.

Moorey, S., Greer, S., Watson, M., Gorman, C., Rowden, L., Tunmore, R., Robertson, B. & Bliss, J. (1991). The factor structure and factor stability of the Hospital Anxiety and Depression Scale in patients with cancer. *British Journal of Psychiatry,* **158**, 255-259.

Moorhead, R. & Winefield, H. (1991). Teaching counselling skills to fourth-year medical students: A dilemma concerning goals. *Family Practitioner*, **8**, 343-346.

Moos, R. H. & Schaefer, J. A. (1984). The crisis of physical illness. An over-view and conceptual approach. In R. H. Moos (Ed.), *Coping with Physical Illness: New Perspectives*, Vol. 2, New York: Plenum Press.

Moos, R.H. & Schaefer, J.A. (1986). Life transitions and crises. A conceptual overview. In R.H. Moos (Ed.), *Coping With Life Crisis*. New York: Plenum Press.

Mor, V. (1987). Cancer patient's quality of life over the disease course: Lessons from the real world. *Journal of Chronic Disease*, **40**, 535-544.

Morris, J., Suissa, S., Sherwood, S., Wright, S. & Greer, D. (1986). Last days: A study of the quality of life of terminally ill cancer patients. *Journal of Chronic Disease*, **34**, 47-62.

Morris, J.N. & Sherwood, S. (1987). Quality of life of cancer patients at different stages in the disease trajectory. *Journal of Chronic Diseases,* **6**, 545-553.

Morris, T., Greer, S., Pettingale, K.W. & Watson, M. (1981). Patterns of expression of anger and their psychological correlates in women with breast cancer. *Journal of Psychosomatic Research,* **25**, 111-117.

Morse, J.M., Bottorff, J., Anderson, G., O'Brien, B. & Solberg, S. (1992). Beyond empathy: Expanding expressions of caring. *Journal of Advanced Nursing.* **17**, 809-821.

Mowrer, O.H. (1960). *Learning Theory and Behaviour*. New York: Wiley.

Mowrer, O.H. (1963). *Learning Theory and The Symbolic Process*. New York: Wiley.

Mullen, F. (1985). Seasons of survival: reflections of a physician with cancer. *New England Journal of Medicine*, **313**, 270-273.

Muller, J. (1842). *Elements of Physiology*. London: Taylor.

Munkres, A., Oberst, M.T. & Hughes, S.H. (1992). Appraisal of illness, symptom distress, self-care burden and mood states in patients receiving chemotherapy for initial and recurrent cancer. *Oncology Nursing Forum*, **19**, 1201-1209.

Murray, J.B. (1971). Psychology of the pain experience. *Journal of Psychology*, **78**, 193-206.

Musci, E. (1985). Family concerns during chemotherapy treatment. *Oncology Nursing Forum*, **12**, 67-72.

National Cancer Registry (1998). *Cancer in Ireland: Incidence and mortality: Report of the National Cancer Registry/National Cancer Registry Ireland.* Cork: National Cancer Registry Board.

National Council for Hospice and Specialist Palliative Care Services (1995). *Specialist Palliative Care: A statement of definitions.* Occasional Paper No. 8. London: NCHSPCS.

Nerenz, D.R., Leventhal, H., Love, R.R. (1982). Factors contributing to emotional distress during cancer chemotherapy. *Cancer*, **50**, 1020-1027.

Neuling, S. & Winefield, H. (1988). Social support and recovery after surgery for breast cancer: frequency and correlates of supportive behaviours by family, friends and surgeon. *Social Science & Medicine*, **27**, 385-392.

Newberry, B.H., Jaikins-Madden, J.E. & Gerstenberger, T.J. (1991). *A Holistic Conceptualisation of Stress and Disease.* AMS: New York.

Newell, G.R., Spitz, M.R. & Sider, J.G. (1989). Cancer and age. *Seminars in Oncology*, **16**, 3-9.

Nichols, K. (1995). Institutional versus client-centered care in general hospitals. In A. Broome & S. Llewelyn (Eds), *Health Psychology: Process and Applications*. 2nd ed. London: Chapman Hall.

Norbeck, J.S., Lindsey, A.M. & Carrieri, V.L. (1981). The development of an instrument to measure social support. *Nursing Research*, **30**, 264-269.

Northouse, L. (1981). Mastectomy patients and the fear of recurrence. *Cancer Nursing,* **4,** 213-320.

Northouse, L.L. & Peters-Golden, H. (1993). Cancer and the family: Strategies to assist spouses. *Seminars in Oncology Nursing*, **9**, 74-82.

Northouse, L.L., Cracchiolo-Caraway, A. & Pappas Appel, C. (1991). Psychologic consequences of breast cancer on partner and family. *Seminars in Oncology Nursing*, **7**, 216-223.

Noyes, R., Holt, C.S. & Massie, M.J. (1998). Anxiety disorders. In J.C. Holland (Ed). *Psycho-oncology*. New York: Oxford University Press.

O'Boyle, C., McGee, H., Hickey, A., O'Malley, K. & Joyce, C.R.B. (1992). Individual quality of life in patients undergoing hip replacement. *Lancet*, **339**, 1088-1091.

O'Connor, A.P., Wicker, C.A., & Germino, B.B. (1990). Understanding the cancer patient's search for meaning. *Cancer Nursing*, **3**, 167-175.

Oberst, M.T., Hughes, S.H., Chang, A.S. & McCubbin, M.A. (1991). Self-care burden, stress appraisal and mood among persons receiving radiotherapy. *Cancer Nursing*, **14**, 71-78.

Ohnhaus, E., & Adler, R. (1975). Methodological problems in the measurement of pain: A comparison between the verbal rating scale and the visual analogue scale. *Pain*, **1**, 379-384.

Okun, B.F. (1992). *Effective helping: Interviewing and Counselling Skills*. London: Brooks Cole.

Olioff, M. & Aboud, F.E.(1991). Predicting postpartum dysphoria in primiparous mothers. Roles of perceived parenting self-efficacy and self-esteem. *Journal of Cognitive Psychotherapy*, **5**, 3-14

Ong, L.M.L., Visser, M.R.M., Van Zuuren, F.J., Rietbroek, R.C., Lammes, F.B. & de Haes, J.C.J.M. (1999). Cancer patients' coping styles and doctor-patient communication. *Psycho-Oncology*, **8**, 155-166.

Orem, D.E (1985). *Nursing Concepts of Practice*. New York: McGraw-Hill.

Orford, J. (1992). *Community psychology: Theory and practice*. Chichester: Wiley.

Osaba, D. (1994). Lessons learned from measuring health -related quality of life in oncology. *Journal of Clinical Oncology*, **12**, 608-616.

Ossipov, M.H., Malan, T.P., Lai, J. & Porreca, F. (1997). Opioid pharmacology of acute and chronic pain. In W.C.V Parris (Ed.), *Cancer Pain Management. Principles and Practice*. Boston: Butterworth-Heinemann.

Pace, J.C. & Meffert, E.L.A. (1997). The hospice movement: a practical approach. In W.C.V. Parris (Ed.), *Cancer Pain Management: Principles and Practice*. Boston: Butterworth-Heinemann.

Palekar, I.S. (1995). Effect of autogenic relaxation with imagery on chemotherapy side effects, as predicted by personality characteristics. Dissertations Abstracts International. 56, 96.

Palmer, S. & Dryden, W. (Eds) (1996). *Stress Management and Counselling. Theory, Practice, Research and Methodology*. London: Cassell.

Parris, W.C.V. (1997). Assessment of the cancer pain patient. In W.C.V Parris (Ed.), *Cancer Pain Management: Principles and Practice*. Boston: Butterworth-Heinemann.

Parris, W.C.V. (Ed.) (1997). *Cancer Pain Management: Principles and Practice*. Boston: Butterworth-Heinemann.

Passik, S.D., McDonald, M.V., Dugan, W.M., Edgerton, S. & Roth, A.J. (1997). Depression in cancer patients: Recognition and treatment. *Medscape Mental Health*, **2**, 1-11.

Patkai, P. (1971). Catecholamine excretion in pleasant and unpleasant situations. *Acta Psychologica*, **35**, 352-363.

Patrick, D.L. & Erickson, P. (1993). *Health status and health policy: Quality of life in health care evaluation and resource allocation.* Oxford: Oxford University Press.

Payne, R. (1986). Neuropathic pain syndromes with special reference to causalgia and reflex sympathetic dystrophy. *Clinical Journal of Pain*, **2**, 59-73.

Payne, R. (1989). Cancer pain: Anatomy, physiology and pharmacology. *Cancer*, **63**, 2266-2274.

Payne, S.A. (1992). A study of quality of life in cancer patients receiving palliative chemotherapy. *Social Science and Medicine*, **35**, 1505-1509.

Pearlin, L. & Schooler, C. (1978). The Structure of Coping. *Journal of Health and Social Behaviour,* **19**, 2-21.

Pearlin, L.I. (1983). Role strains and personal stress. In H.B. Kaplan (Ed.), *Psychosocial Stress: Trends in Theory and Research.* New York: Academic Press.

Pearlin, L.I., Lieberman, M.A., Menaghan, E.G. & Mullan, J.T. (1981). The stress process. *Journal of Health and Social Behaviour*, **22**, 337-356.

Peteet, J., Tay, V., Choen, G. & MacIntyre, J. (1986). Pain characteristics and treatment in an outpatient cancer population. *Cancer*, **57**, 1259-1265.

Peters-Golden, H. (1982). Breast cancer: Varied perceptions of social support in the illness experience. *Social Science and Medicine*, **16**, 483-491.

Peterson, C. & Seligman, M.E.P. (1984). Causal explanation as a risk factor for depression: Theory and evidence. *Psychological Review*, **91**, 347-374.

Pettingale, K.W. (1985). Towards a psychobiological model of cancer: Biological considerations. *Social science and Medicine*, **20**, 779-787.

Pettingale, K.W., Morris, T., Greer, S. & Haybittle, J.L. (1985). Mental attitudes to cancer: An additional prognostic factor (letter). *Lancet,* i, 750.

Phillips, D.C. & Orten, R (1983). The new causal principles of cognitive learning theory: Perspectives on Bandura's reciprocal determinism. *Psychological Review,* **90**, 158-165.

Plumb, M.M. & Holland, J. (1977). Comparative studies of psychological function in patients with advanced cancer.1: Self-reported depressive symptoms. *Psychosomatic Medicine,* **39,** 264-276.

Plumb, M. & Holland, J. (1981). Comparative studies of psychological function in patients with advanced cancer. 11: interviewer-rated current and past psychological symptoms. *Psychosomatic Medicine*, **43**, 243-254.

Portenoy, R.K., Foley, K.M. & Inturrisi, C.E. (1990). The nature of opioid responsiveness and its implications for neuropathic pain: New hypotheses derived from studies of opioid infusions. *Pain*, **43**, 273-286.

Post-White, J. (1996). The immune system. *Seminars in Oncology Nursing*, **12**, 89-96.

Powell, M.E.B. & Hoskin, P.J. (1998). Non-curative radiotherapy for bone metastases. In M.L. Slevin & T. Tate (Eds), *Cancer: How Worthwhile is Non-Curative Treatment*? London: Springer-Verlag.

Procidano, M.E. & Heller, K. (1983). Measures of perceived support from friends and from family: Three validation studies. *American Journal of Community Psychology*, **11**, 1-24.

Proudfit, H. K. & Anderson, E.G. (1975). Morphine analgesia: Blockade by raphe nucleus. *Brain Research*, **98**, 612-618.

Quint, J.C. (1963). The impact of mastectomy. *American Journal of Nursing*, **63**, 88-92.

Rabkin, J.G. & Streuning, E.L. (1976). Life events, stress and illness. *Science*, **194**, 1013-1020.

Ramirez, A.J., Craig, T.K.J., Watson, J.P., Fentiman, I.S., North, W.R.S. & Rubens, R.D. (1989). Stress and relapse of breast cancer. *British Medical Journal*, **298**, 291-293.

Rankin, M.A. (1980). The progressive pain of cancer. *Topics in Clinical Nursing*, **2**, 57-73.

Rankin-Box, D. (Ed.) (1995). *The Nurses' Handbook of Complementary Therapies*. Edinburgh: Churchill Livingstone.

Rathbone, G., Horsley, S. & Goacher, J. (1994). A self-evaluated assessment for seriously ill hospice patients. *Palliative Medicine*, **8**, 29-34.

Razavi, D., Delvaux, N. & Hopwood, P. (1997). Improving communications with cancer patients: A challenge for physicians. In A. Surbone & M.

Zwitter (Eds), *Communication with the Cancer Patient: Information and Truth.* New York: Annals of the New York Academy of Sciences.

Razavi, D., Delvaux, N., Farvacques, C. & Robaye, E. (1990). Screening for adjustment disorders and major depressive disorders in cancer in-patients. *British Journal of Psychiatry,* **156**, 79-83.

Reading, A.E., Everitt, B.S. & Sledmore, C.M. (1982). The McGill Pain Questionnaire: A replication of its construction. *British Journal of Clinical Psychology*, **21**, 339-349.

Redmond, K. & Aapro, M.S. (Eds), (1997). *Cancer in The Elderly: A Nursing and Medical Perspective*. Amsterdam: Elsevier Science.

Reid-Ponte, P. (1992). Distress in cancer patients & primary nurses' empathy skills. *Cancer Nursing*, **15**, 283-292.

Renetsky, L. (1979). The fourth dimension: Applications to the social services. In D.O. Moberg (Ed.), *Spiritual Well-Being: Sociological Perspectives*. Washington: University Press of America.

Revicki, D.A. & Kaplan, R. M. (1993). Relationship between psychometric and utility-based approaches to the measurement of health-related quality of life. *Quality of Life Research*, **2**, 477-487.

Revill, S., Robinson, J., Rosen, M. & Hogg, M. (1976). The reliability of a linear analogue for evaluating pain. *Anaesthesia*, **31**, 1191-1198.

Reynolds, M. (1978). No news is bad news: Patients' views about communication in hospital. *British Medical Journal*, **1**, 1673-1676.

Reynolds, P. & Kaplan, G.A. (1990). Social connections and risk for cancer: Prospective evidence from the Alameda County study. *Behavioural Medicine*, **16**, 101-110.

Richards, D. (1996). Traumatic Stress at Work: A Public Health Model. In Palmer, S. & Dryden, W. (Eds), *Stress Management and Counselling: Theory, Practice, Research and Methodology.* London: Cassell.

Richardson, J.L., Shelton, D.R., Krailo, M. & Levine, A.M (1990). The effect of compliance with treatment on survival among patients with haematologic malignancies. *Journal of Clinical Oncology*, **8**, 356-364.

Riley, V. & Spackman, S. (1976). Modifying effects of a benign virus on the malignant process and the role of physiological stress on tumour incidence. In *Fogarty International Centre Proceedings* (Vol. 28). Washington D.C.: US Government Printing Office

Riley, V. (1981). Psychoneuroendocrine influences on immunocompetence and neoplasia. *Science*, **212**, 110-1109.

Roberts, M.M., Alexander, F.E., Elton, R.A. & Rodger, A. (1990). Breast cancer state, social class and the impact of screening. *European Journal of Surgical Oncology*, **16**, 18-21.

Roberts, M.M., French, K. & Duffy, J. (1984). Breast cancer and breast self-examination: What do Scottish women know? *Social Science and Medicine*, **18**, 791-797.

Rodin, J. & Salovey, P. (1989). Health psychology. *Annual Review of Psychology*, **40**, 533-579.

Rokeach, M. (1973). *The Nature of Human Values*. New York: Free Press & Macmillan.

Rosch, P.J. (1984). Stress and cancer. In C.L. Cooper, (Ed.), *Psychosocial Stress and Cancer*. Chichester: Wiley.

Rosenbaum, M. (1993). The three functions of self-control behaviour: redressive, reformative and experiential. *Work & Stress*, **7**, 33-46.

Rosenberg, R. (1992). Quality of life, ethics and philosophy of science. *Nordic Journal of Psychiatry*, **46**, 75-77.

Roth, A.J. & Breitbart, W. (1996). Psychiatric emergencies in terminally ill cancer patients. *Haematology-Oncology Clinics of North America*, **10**, 235-259.

Rowland, J.H. (1989). Interpersonal resources: social support; coping. In J.C. Holland & J.H. Rowland (Eds), *Handbook of Psycho-Oncology: Psychological Care of The Patient with Cancer*. New York: Oxford University Press.

Roy, D.J. cited In McLennan, M. (1995). Palliative Care: An Ethical Approach., In F. Huser (Ed.), *Palliative Care and Euthanasia*. Edinburgh: Campion Press.

Ruckdeschel, J.C., Blanchard, C.G. & Albrecht, T. (1994). Psychosocial oncology research. Where we have been, where we are going and why we will not get there. *Cancer Supplement*, **74**, 1458-1463.

Ryan-Merritt, M., Mitchell, C.A. & Pagel, I.(1988). Clinical nurse specialist role definition and operationalisation. *Clinical Nurse Specialist*, **2**, 132-137.

Sabbioni, M.E.E. (1991). Cancer and stress: a possible role for psychoneuroimmunology in cancer research? In C.L. Cooper & M. Watson (Eds), *Cancer and Stress: Psychological, Biological and Coping Studies*. Chichester: Wiley.

Samter, W. (1992). Communication characteristics of the lonely person's friendship circle. *Communication Research*, **19**, 212-239.

Sarafino, E.P. (1990). *Health Psychology*. New York: Wiley.

Sarason, I.G., Pierce, G.R. & Sarason, B.R. (1990). Social support and interactional processes: A triadic hypothesis. *Journal of Social and Personal Relationships*, **7**, 495-506.

Sardell, A.N. (1993). Disclosing the cancer diagnosis: Procedures that influence patient hopefulness. *Cancer*, **72**, 3355-3365.

Satariano, W.A. & Ragland, D.R. (1994). The effect of comorbidity on 3-year survival of women with primary breast cancer. *Annals of Internal Medicine*, **120**, 104-110.

Saunders, C. (1958). Dying of Cancer. *St. Thomas's Hospital Gazette*, **56**, 37-47.

Saunders, C. (1967). *The Management of Terminal Illness*. London: Hospital Medicine Publications.

Saunders, C., Summers, D. & Teller, N. (Eds) (1981). *Hospice: The Living Idea*. London: Arnold.

Schaefer, C., Coyne, J. & Lazarus, R. (1981). The health-related functions of social support. *Journal of Behavioural Medicine*, **4**, 381-406.

Schmale, A., Morrow, G. & Schmitt, M. (1983). Well-being of cancer survivors. *Psychosomatic Medicine*, **45**, 163-169.

Schmoll, H.J. (1992). Quality of life measurements in anti-emetic trials: A discussion of Professor Selby's paper. *British Journal of Cancer*, **66**, Supplement XIX, S24-S25.

Schmidtke, W. (1999). *Mood and Memory: An Empirical Study of Mood-Congruent Learning In Relation to Affect Intensity*. MA Thesis, The National University of Ireland, Galway.

Schonpflug, W (1983). Coping efficiency and situational demands. In R. Hockey (Ed.), *Stress and Fatigue in Human Performance*. New York: Wiley.

Schwarzer, R. (Ed.) (1992). *Self-Efficacy: Thought Control of Action*. Washington: Hemisphere Publishing Corporation.

Schwarzer, R., Dunkel-Schetter, C., Weiner, B. & Woo, G. (1992). Expectancies as mediators between recipient characteristics and social support intentions. In R. Schwarzer (Ed.), *Self-Efficacy: Thought Control of Action*. Washington: Hemisphere Publishing Corporation.

Schwarzer, R., Jerusalem, M. & Stiksrud, A. (1984). The developmental relationship between test anxiety and helplessness. In H.M. van der

Ploeg, R. Schwarzer & C.D. Spielberger (Eds), *Advances in Test Anxiety Research* (Vol. 3). Lisse, The Netherlands: Hillsdale.

Selby, P. (1985). Measurement of the quality of life after cancer treatment. *British Journal of Hospital Medicine*, **33**, 267-271.

Selby, P. (1993). Measuring the quality of life of patients with cancer. In S.R. Walker & R. M. Rosser (Eds), *Quality of Life Assessment: Key issues in the 1990s*. Lancaster: Kluwer Academic Publishers.

Seligman, M.E.P. (1974). Depression and learned helplessness. In R.J. Friedman & M.M. Katz (Eds), *The Psychology of Depression: Contemporary Theory and Research*. Washington, D.C.: Winston-Wiley.

Seligman, M.E.P. (1975). *Helplessness: On Depression, Development and Death*. San Francisco: Freeman.

Selye, H. (1950). *Stress*. Montreal: Acta Incorporated.

Selye, H. (1956). *The Stress of Life*. New York: McGraw-Hill.

Selye, H. (1979a). Stress without disease. In C.A. Garfield (Ed.), *Stress and Survival*. St. Louis: The C.V. Mosby Company.

Selye, H. (1979b). Foreword. In N.H. Hendler & J.A. Fenton (Eds), *Coping with Chronic Pain*. New York: Potter.

Selye, H. (1983). The stress concept; past, present and future. In C.L. Cooper (Ed.), *Stress Research: Issues for The Eighties*. New York: Wiley.

Shealy, C.N., Mortimer, J.T. & Reswick, J. (1967). Electrical inhibition of pain by stimulation of the dorsal column: Preliminary clinical reports. *Anaesthesia and Analgesia*, **46**, 489-491.

Sheehan, J., McKay, J., Ryan, M., Walsh, N. & O'Keeffe, D. (1996). What cost chronic pain? *Irish Medical Journal*, **89**, 218-219.

Sheldon, F. (1997). *Psychosocial Palliative Care: Good practice in the care of the dying and bereaved.* Cheltenham: Stanley Thornes.

Sherrington, C.S. (1900). Cutaneous sensations. In E.S. Schafer (Ed.), *Textbook of Physiology*. London: Pentland.

Sherrington, C.S. (1906). *Integrative Action of The Nervous System*. New York: Scribner.

Shipton, E.A. (1999). *Pain: Acute and Chronic*. London: Arnold.

Shumaker, S.A. & Brownell, A. (1984). Toward a theory of social support. *Journal of Social Issues*, **40**, 11-36.

Siegel, S. & Castellan, N.J. (1988). *Nonparametric Statistics for the Behavioural Sciences*. 2nd ed. New York: McGraw-Hill.

Silberfarb, P.M. (1984). Psychiatric problems in breast cancer. *Cancer*, 53, 820-824.

Silberfarb,. P.M., Holland, J.C., Anbar, D., Bahna, G., Maurer, L.H. Chahinian, A.P. & Comis, R. (1983). Psychological response of patients receiving two drug regimens for lung carcinoma. *American Journal of Psychiatry*, **140**, 110-111.

Sinclair, D.C. (1955). Cutaneous sensation and the doctrine of specific nerve energies. *Brain,* **78**, 584-614.

Singer, J.E. (1983). Some issues in the study of coping. *Cancer*, **53**, 2303-2315.

Skeel, R.T. & Lachant, N.A. (1995). *Handbook of Cancer Chemotherapy*. 4th ed. London: Little, Brown & Co.

Skevington, S. (1995). *Psychology of Pain*. Chichester: Wiley.

Sklar, L.S. & Anisman, H. (1979). Stress and coping influence tumour growth. *Science*, **205**, 513-515.

Slevin, M., Stubbs, L., Plant, H., Gregory, W & Massey, L. (1991). 'Cost-benefit' calculations in cytotoxic chemotherapy treatments. In M. Watson (Ed.), *Cancer Patient Care: Psychosocial Treatment Methods*. Cambridge: The British Psychological Society & Cambridge University Press.

Slevin, M.L. & Tate, T. (Eds) (1998). *Cancer: How Worthwhile is Non-Curative Treatment?* London: Springer-Verlag.

Slevin, M.L., Plant, H., Lynch, D., Drinkwater, J. & Gregory, W.M. (1988). Who should measure quality of life, the doctor or the patient? *British Journal of Cancer*, **57**, 109-112.

Sloman, R. (1995). Relaxation and the relief of cancer pain. *Nursing Clinics of North America*, **30**, 697-709.

Smith, .J. (1972). *The Behaviour of Communicating*. Harvard: Harvard University Press.

Smith, C.A. & Lazarus, R.S. (1990). Emotion and adaptation. In L.A. Pervin (Ed.), *Handbook of Personality: Theory and Research*. New York: Guilford.

Smith, E.M. (1979). Epidemiology of oral and pharyngeal cancers in the United States: review of recent literature. *Journal of The National Cancer Institute*, **63**, 1189-1198.

Smith, G.D., Leon, D., Shipley, M.J. & Rose, G. (1991). Socioeconomic differentials in cancer among men. *International Journal of Epidemiology*, **20**, 339-345.

Snaith, R.P., Baugh, S.J., Clayden, A.D., Hussain, A. & Sipple M. (1982). The Clinical Anxiety Scale: a modification of the Hamilton Anxiety Scale. *British Journal of Psychiatry*, **141**, 518-523.

Snyder, S.H. (1977). Opiate receptors and internal opiates. *Scientific American*, **236**, 44-56.

Sobin, L.H. & Wittekind, C.H. (Eds) (1997). *TNM Atlas: Classification of Malignant Tumours* 5th ed. New York: Wiley-Liss.

Sofaer, B. (1984). The effect of focused education for nursing teams on post-operative pain of patients. Unpublished Ph.D. Thesis. University of Edinburgh.

Sofaer, B. (1998). *Pain: Principles, Practice and Patients*. 3rd ed. Cheltenham: Stanley Thornes.

Sokolovsky, Cohen, Berger & Geiger (1978). Personal networks of ex-mental patients in a Manhatten SRO hotel. *Human Organisation*, **37**, 5-15.

Somerfield, M. & Curbow, B. (1992). Methodological issues and research strategies in the study of coping with cancer. *Social Science and Medicine*, **34**, 1203-1216.

Soreq, H. & Friedman, A. (1996). Pyridostigmine brain penetration under stress enhances neuronal excitability and induces early immediate transcriptional response. *Nature Medicine*, **2**, 1382-1385.

Souhami, R. & Tobias, J. (1998). *Cancer and Its Management*. 3 rd ed. Oxford: Blackwell Science.

Spiegel, D. & Bloom, J.R. (1983). Group therapy and hypnosis reduce metastatic breast carcinoma pain. *Psychosomatic Medicine*, **4**, 333-339.

Spiegel, D. (1990). Facilitating emotional coping during treatment. *Cancer*, **66** (Suppl.6), 1422-1426.

Spiegel, D. (1993). Psychosocial intervention in cancer. *Journal of The National Cancer Institute*, **85**, 1198-1205.

Spiegel, D. (1996). Cancer and depression. *British Journal of Psychiatry*, **168** (Suppl.30), 109-116.

Spiegel, D., Bloom, J. Kraemer, H.C. & Gottheil, E. (1989). Effects of psychosocial treatment on survival of patients with metastatic breast cancer. *Lancet*, ii, 888-891.

Spiegel, D., Sands, S. & Koopman, C. (1994). Pain and depression in patients with cancer. *Cancer*, **74**, 2570-2578.

Statistical Package for the Social Sciences (SPSS) (1997) Version 8.0 for Windows. SPSS Inc.

Stein, W.M. (1996). Cancer pain in the elderly. In B.R. Ferrell & B.A. Ferrell (Eds), *Pain in the Elderly: A Report of the Task Force on Pain in the Elderly of the International Association for the Study of Pain.* Seattle: IASP Press.

Sternbach, R.A. (1974). *Pain Patients: Traits and Treatments.* New York: Academic Press.

Sternbach, R.A., Ignelzi, R.J., Deems, L.M. & Timmermanns, G. (1976). Transcutaneous electrical analgesia: A follow-up analysis. *Pain*, **2**, 35-41.

Stjernsward, J. & Teoh, N. (1990). The scope of the cancer pain problem. In K.M. Foley, J.J. Bonica & V. Ventafridda (Eds), *Advances in Pain Research and Therapy.* Vol. 16. New York: Raven.

Stoll, B.A. (Ed.) (1988). *Cost Versus Benefit in Cancer Care.* London: Macmillan.

Stone, D.G., Cohen, F. & Adler, N.E. (1979). *Health Psychology.* London: Jossey-Bass.

Stouman, K. & Falk, I. (1936). Health indices: A study of objective indices of health in relation to environment and sanitation. *Bulletin of Health League of Nations*, **8**, 63-69.

Strain, J.J. (1998). Adjustment disorders. In Holland, J.C. (Ed.), *Psycho-Oncology.* New York: Oxford University Press.

Strang, P. (1992). Emotional and social aspects of cancer pain. *Acta Oncological*, **31**, 323-326.

Strang, P. (1997). Existential consequences of unrelieved cancer pain. *Palliative Medicine*, **11**, 299-305.

Strickland, B.R. (1978). Internal-external expectancies and health related behaviours. *Journal of Consulting and Clinical Psychology*, **46**, 1192-1211.

Stroebe, W. & Stroebe, M. (1987). *Bereavement and Health.* Cambridge: Cambridge University Press.

Strongman, K.T. (1996). *The Psychology of Emotion.* 4th ed. Chichester: Wiley.

Stuber, M.L., Meeske, K., Gonsales, S., Houskamp, B. M & Pynoos, R (1994). Post-traumatic stress after childhood cancer 1: The role of appraisal. *Psycho-Oncology*, **3**, 305-312.

Surbone, A. & Zwitter, M. (Eds) (1997). *Communication with the Cancer Patient: Information and Truth.* New York: Annals of the New York Academy of Sciences.

Sutherland, V.J. & Cooper, C.I (1990). *Understanding stress: Psychological perspective for health professionals. Psychology and Health. 5.* London: Chapman & Hall.

Swerdlow, M. & Ventafridda, V. (Eds) (1987). *Cancer Pain.* Lancaster: MTP Press

Syme, S.L. & Berkman, L.F. (1976). Social class, susceptibility and sickness. *American Journal of Epidemiology*, **104**, 1-8.

Symonds, Sir C.P. (1947). Use and abuse of the term 'flying stress'. In *Air Ministry, Psychological Disorders in Flying Personnel of The Royal Air Force, Investigated During the War, 1939-1945.* HMSO, London.

Syrjala, K.L. & Chapman, C.R. (1984). Measurement of clinical pain: A review and integration of research findings. In C. Benedetti, C.R. Chapman & G. Moricca (Eds), *Advances in Pain Research and Therapy.* Vol. 7. New York: Raven Press.

Syrjala, K.L, Donaldson, G.W., Davis, M.W. Kippes, M.E. & Carr, J.E. (1995). Relaxation and imagery and cognitive-behavioural training reduce pain during cancer treatment: a controlled clinical trial. *Pain*, **63**, 189-198.

Szasz, T.S. & Hollender, M.H.A. (1956). Contribution to the philosophy of medicine: The basic models of the doctor-patient relationship. *Archives of Internal Medicine*, **97**, 585-592.

Szasz, T.S. (1957). *Pain and Pleasure*. London: Tavistock.

Szasz, T.S. (1974). Illness and Indignity. In G.P. Turner & J. Mapa (Eds), *Humanising Hospital Care,* USA: McGraw-Hill.

Taylor, S.E., Bunk, B.P., Collins, R.L. & Reed G.M. (1992). Social comparison and affiliation under threat. In L. Montada, S.H. Filipp & M.J. Lerner (Eds), *Life Crisis and Experiences of Loss in Adulthood.* Hillsdale, N.J: Erlbaum.

Teasdale, K. (1989). The concept of reassurance in nursing. *Journal of Advanced Nursing*, **14**, 444-450.

Temoshok, L. (1985). Biopsychosocial studies on cutaneous malignant melanoma: Psychophysiological factors associated with prognostic indicators, progression, psychophysiology and tumour-host response. *Social Science and Medicine*, **20**, 833-840.

Temoshok, L. (1987). Personality, coping style, emotion and cancer: Towards an integrative model. *Cancer Surveys*, **6**, 545-567.

Temoshok, L., Heller, B.W., Sagebiel, R.W., Blois, M.S., Sweet, D.M., DiClemente, R.J. & Gold, M.L. (1985). The relationship of psychosocial factors to prognostic indicators in cutaneous malignant melanoma. *Journal of Psychosomatic Research*, **29**, 139-154.

Thoits, P.A. (1982). Conceptual, methodological and theoretical problems in studying social support as a buffer against life stress. *Journal of Health and Social Behaviour,* **23**, 145-159.

Thoits, P.A. (1984). Explaining distributions of psychological vulnerability: Lack of social support in the face of life stress. *Social Forces*, **63**, 452-481.

Thoits, P.A. (1985). Self-labelling processes in mental illness: The role of emotional deviance. *American Journal of Sociology*, **92**, 221-249.

Thoits, P.A. (1986). Social support as coping assistance. *Journal of Consulting and Clinical Psychology*, **54**, 416-423.

Thoits, P.A. (1991). Gender differences in coping with emotional distress. In J. Eckenrode (Ed.), *The Social Context of Coping*. New York: Plenum.

Thompson, J. (1984). Communicating with patients. In R. Fitzpatrick, J. Hinton, S. Newman, G. Scambler & J. Thompson (Eds), *The Experience of Illness*. London: Tavistock.

Thorpe, G. (1993). Enabling more dying people to remain at home. *British Medical Journal,* **307**, 915-918.

Tjemsland, L., Soreide, J.A. & Malt, U.F. (1996a). Traumatic distress symptoms in early breast cancer. 1: Acute response to diagnosis. *Psycho-Oncology*, **5**, 1-8.

Tjemsland, L., Soreide, J.A. & Malt, U.F. (1996b). Traumatic distress symptoms in early breast cancer. 11: Outcome six weeks post surgery. *Psycho-Oncology*, **5**, 295-303.

Tolsdorf, C.C. (1976). Social networks, support and coping: An exploratory study. *Family Process*, **15**, 407-417.

Trew, M. & Maguire, P. (1982). Further comparisons of two instruments for measuring quality of life in cancer patients. In J. Beckman (Ed.), *Quality of Life, Third Workshop of The EORTC Study Group on Quality of Life*. Paris: EORTC.

Tully, A. (1998). Spirituality and Nursing Practice. Paper given at the 17th Annual Nursing and Research Conference, Royal College of Surgeons in Ireland, Dublin, February.

Turk, D.C. (1996). Biopsychosocial perspectives on chronic pain. In R.J. Gatchel & D.C.Turk (1996). *Psychological Approaches to Pain Management: A Practitioner's Handbook.* New York: The Guildford Press.

Turner, R.J. (1981). Social support as a contingency in psychological well-being. *Journal of Health and Social Behaviour*, **22**, 357-367.

Turner, R.J. (1983). Direct, indirect and moderating effects of social support on psychological distress and associated conditions. In H.B. Kaplan (Ed.), *Psychosocial stress: Trends in theory and research.* New York: Academic.

Turner, R.J. Frankel, B.G. & Levin, D.M. (1983). Social Support: Conceptualisation, measurement and implications for mental health In J.R. Greenley (Ed.), *Research in Community and Mental Health.* Greenwich, CT: JAI.

Twigg, J. & Atkin, K. (1994). *Carers Perceived.* Buckingham: Open University Press.

Twycross, R. (1994). *Pain Relief in Advanced Cancer.* Edinburgh: Churchill Livingstone.

Twycross, R. (1997). *Introducing Palliative Care* 2nd ed. Oxford: Radcliffe Medical Press.

Unger, D.G. & Powell, D.R. (1980). Supporting families under stress: The role of social networks. *Family Relationships*, **29**, 566-574.

Vailant, G.E. & Vailant, C.O. (1990). Natural history of male psychological health: X11. A 45 year study of predictors of successful ageing at age 65. *American Journal of Psychiatry*, **147**, 31-37.

von Frey, M. (1895). Beitage zur Sinnesphysiologie der Haut. In R. Melzack. & P.D. Wall (1988). *The Challenge of Pain.* London: Penguin.

van Loon, A.J.M., van den Brandt, P.A. & Golbohm, R.A. (1995). Socioeconomic status and colon cancer incidence: A prospective cohort study. *British Journal of Cancer,* **71**, 882-887.

Vecchio, T.J. (1966). Predictive value of a single diagnostic test in unselected populations. *New England Journal of Medicine*, **274**, 1171-1173.

Veenhoven, R. (1984). *Conditions of Happiness.* Dordrecht: Reidel.

Velikova, G., Selby, P.J. Snaith, P.R. & Kirby, P.G. (1995). The relationship of cancer pain to anxiety. *Psychotherapy & Psychosomatics*, **63**, 181-184.

Waddell, G. (1992). Biopsychosocial analysis of low back pain. *Baillieres Clinical Rheumatology*, **6**, 523-557.

Waddie, N.A. (1996). Language and pain expression. *Journal of Advanced Nursing*, **23**, 868-872.

Waitzkin, H. (1984). Doctor-patient communication: Clinical implications of social science research. *Journal of the American Medical Association*, **252**, 2441-2446.

Waitzkin, H. (1985). Information giving in medical care. *Journal of Health and Social Behaviour*, **26**, 81-101.

Wakefield, A. (1995). Pain: An account of nurses' talk. *Journal of Advanced Nursing*, **21**, 905-910.

Waldron, D., O'Boyle, C., Kearney, M., Moriarty, M. & Carney, D. (1999). Quality of Life Measurement in Advanced Cancers: Assessing The Individual. *Journal of Clinical Oncology*, **17**, 3603-3611.

Walker, J. (1992). Taking pains. *Nursing Times*, **88**, 38-40.

Walker, S.R. & Rosser, R.M. (1993). *Quality of Life Assessment: Key issues in the 1990s*. Lancaster: Kluwer Academic Publishers.

Wall, P.D. (1960). Cord cells responding to touch, damage and temperature of skin. *Journal of Neurophysiology*, **23**, 197-210.

Wall, P.D. (1964). Presynaptic control of impulses at the first central synapse in the cutaneous pathway. *Progress in Brain Research*, **12**, 92-118.

Walsh, T.D. (1986). Controlled study of imipramine and morphine in advanced cancer. *Proceedings of The American Society of Clinical Oncology*, **5**, 237.

Walshe (1800). The nature and treatment of cancer. Cited in P.J. Rosch (1984). Stress and cancer. In C.L. Cooper, (Ed.), *Psychosocial Stress and Cancer*. Chichester: Wiley.

Watkins, L.O., Weaver, L. & Odegaard, V. (1986). Preparation for cardiac catheterisation: Tailoring the content of instruction to coping style. *Heart and Lung*, **15**, 382-389.

Watson, M. (1983). Psychosocial interventions with cancer patients: A review. *Psychological Medicine*, **13**, 839-846.

Watson, M. (1984). The Effectiveness of Specialist Nurses as Oncology Counsellors. In M. Watson & S. Greer (Eds), *Psychosocial Issues in Malignant Disease*. Oxford: Pergamon.

Watson, M. (Ed.) (1991). Cancer Patient Care: Psychosocial Treatment Methods. *Cambridge: The British Psychological Society & Cambridge University Press.*

Watson, M. (1999). The effects of psychological response on survival and implications for treatment. Paper presented at the First Symposium on Psycho-Oncology in Dublin, April.

Watson, M., Denton, S., Baum, M. & Greer, S. (1988a). Counselling breast cancer patients: A specialist nurse service. *Counselling Psychology Quarterly*, **1**, 25-34.

Watson, M. & Greer, S. (1983). Development of a questionnaire measure of emotional control. *Journal of Psychosomatic Research*, **27**, 299-305.

Watson, M. & Greer, S. (1998). Personality and Coping. In J.C. Holland (Ed.) Psycho-oncology. New York: Oxford University Press.

Watson, M., Greer, S., Blake, S. & Shrapnell, K. (1984). Reaction to a diagnosis of breast cancer: Relationship between denial, delay and rates of psychological morbidity. *Cancer*, **53**, 2008-2012.

Watson, M., Greer, S., Pruyn, J. & van den Borne, B. (1990). Locus of control and adjustment to cancer. *Psychological Reports*, **66**, 39-48.

Watson, M., Greer, S., Young, J., Inayat, Q., Burgess, C. & Robertson, B. (1988b). Development of a questionnaire measure of adjustment to cancer: The MAC scale. *Psychological Medicine*, **18**, 203-209.

Watson, M., Law, M., Maguire, G.P., Greer, S., Bliss, J.M. & Ibbotson, T. (1992). Further development of a quality of life measure for cancer patients: The Rotterdam Symptom Checklist (Revised). *Psycho-Oncology*, **1**, 35-44.

Weddell, G. (1955). Somesthesis and The Chemical Senses. *Annual Review of Psychology*, **6**, 119-36.

Weiner, B. (1985). *An Attributional Theory of Motivation and Emotion.* Berlin: Springer.

Weiner, B., Perry, R.P. & Magnusson, J. (1988). An attributional analysis of reactions to stigmas. *Journal of Personality and Social Psychology*, **55**, 738-748.

Weinman, J. (1987). *An Outline of Psychology as Applied to Medicine*, Bristol: Wright.

Weisman, A.D. (1979). *Coping with Cancer*, New York: McGraw Hill.

Weisman, A.D. & Worden, J.W. (1976). The existential plight in cancer: significance of the first 100 days. *International Journal of Psychiatry & Medicine*, **7**, 1-15.

Weisman, A.D. & Worden, J.W. (1977). Coping and vulnerability in cancer patients. Unpublished Report, Project Omega, Department of Psychiatry, Harvard Medical School.

Weiss, R. (1974). The Provision of Social Relations. In Z. Rubin (Ed.), *Doing unto Others*. Englewood Cliffs, NJ: Prentice Hall.

Welch-McCaffrey, D. (1986). To teach or not to teach? Overcoming barriers to patient education in geriatric oncology. *Oncology Nursing Forum*, **13**, 25-31.

Welford, A.T. (1974). *Man under Stress. Proceedings of The Ninth Annual Conference of The Ergonomics Society of Australia and New Zealand, 1972*. London: Taylor & Francis.

Wells, P., Frampton, V. & Bowsher, D. (1988). *Pain Management and Control in Physiotherapy*. London: Heinemann Physiotherapy.

Wells, K.B., Golding, J.M. & Burnam, A. (1988). Psychiatric disorders in a sample of the general population with and without chronic medical conditions. *American Journal of Psychiatry*. 145, 976-981.

Wells, N. (1997). Assessment of quality of life. In W.C.V. Parris (Ed.), *Cancer Pain Management: Principles and Practice.* Boston: Heinemann.

Wessman, A. E. & Ricks, D. F. (1966). *Mood and Personality*. New York: Rinehart and Winston.

Wethington, E. & Kessler, R. (1991). Situations and processes of coping. In J. Eckenrode (Ed.), *The Social Context of Coping*. New York: Plenum Press.

Wethington, E. & Kessler, R.C. (1986). Perceived support, received support and adjustment to stressful life events. *Journal of Health and Social Behaviour*, **27**, 78-89.

Wiedenfeld, S., O'Leary, A., Bandura, A., Brown, S., Levine, S. & Raska, K., (1990). Impact of perceived self-efficacy in coping with stressors on components of the immune system. *Journal of Personality and Social Psychology*, **59**, 1082-1094.

Wiggers, J.H., O'Donovan, K., Redman, S & Sanson-Fisher, R.W. (1990). Cancer patient satisfaction with care. *Cancer*; **66**, 610-616.

Wilcox, G.L. (1991). Excitatory neurotransmitters and pain. In M.R. Bond, J.E. Charlton & C.J. Woolf (Eds), *Proceedings of the VIth World Congress on Pain*. Amsterdam: Elsevier.

Wilkie, D.J & Keefe, F.J. (1991). Coping strategies of patients with lung cancer: Related pain. *Clinical Journal of Pain,* **7**, 292-299.

Wilkinson, S. (1991). Factors which influence how nurses communicate with cancer patients. *Journal of Advanced Nursing*, **16**, 677-688.

Williamson, G.M. & Schulz, R. (1995). Activity restriction mediates the association between pain and depressed affect: A study of younger & older adult cancer patients. *Psychology of Aging*, **10**, 369-378.

Willis, W.D. (1985). The pain system: The neural basis of nociceptive transmission in the mammalian nervous system. *Pain and Headache* (Vol. 8). Basel: Karger.

Wills, T.A. (1985). Supportive functions of interpersonal relationships. In S. Cohen & L. Syme (Eds), *Social Support and Health*. New York: Academic Press.

Winefield, H.R. & Neuling, S.J. (1987). Social support, counselling and cancer. *British Journal of Guidance Counselling*, **15**, 6-16.

Wing, J.K., Cooper, J.E. Sartorius, N. (1974). *The Measurement and Classification of Psychiatric Symptoms.* London: Cambridge University Press.

Winningham, M.L., Nail, L.M., Barton-Burke, M., Brophy, L., Cimprich, B., Jones, L.S., Pickard-Holley, S., Rhodes, V., St. Pierre, B., Beck, S., Glass, E.C., Mock, V.L., Mooney, K.H. & Piper, B. (1994). Fatigue and the cancer experience: The state of the knowledge. *Oncology Nursing Forum*, **21**, 23-36.

Woolf, C.J., Shortland, P. & Coggeshall, R.E. (1992). Peripheral nerve injury triggers central sprouting of myelinated afferents. *Nature*, **355**, 75-78.

World Health Organisation (1958). *The First Ten Years of The World Health Organisation.* Geneva: WHO.

World Health Organisation Cancer Control Programme (1992). *Policies for cancer pain control.* Geneva: WHO.

World Health Organisation Constitution (1947). *Chronicles,* **1**, 29. Geneva: WHO.

World Health Organisation. (1990). *Cancer pain relief and palliative care. Report of a WHO expert committee (World Health Organisation Technical Report Series, 804)* Geneva: WHO.

World Health Organisation (1986). *Cancer Pain Relief.* Geneva: WHO.

Wortman, C. (1984). Social support and the cancer patient: Conceptual and methodological issues. *Cancer*, **53**, (suppl.) 2339-2362.

Wortman, C.B. & Dunkel-Schetter, C. (1979). Interpersonal relationships and cancer: A theoretical analysis. *Journal of Social Issues*, **35**, 120-155.

Wortman, C.B. & Lehman, D.R. (1985). Reactions to victims of life crisis: Support attempts that fail. In I.G. Sarason & B.R. Sarason (Eds), *Social support: Theory, Research and Application.* The Netherlands: Martinus Nijhof.

Wright, J. & Mischel, W. (1982). Influence of affect on cognitive social learning person variables. *Journal of Personality and Social Psychology*, **43**, 901-914.

Wruble, J., Benner, P. & Lazarus, R.S. (1981). Social competence from the perspective of stress and coping. In J.D. Wine & M.D. Smye (Eds), *Social Competence*. New York: Guilford.

Wyatt, G.K.H. & Friedman, L.L. (1996). Development and testing of a quality of life model for long-term female cancer patients. *Quality of Life Research*, **5**, 387-394.

Yancik, R. & Ries, L. (1994). Cancer in older persons: Magnitude of the problem; how do we apply what we know? *Cancer Supplement*, **74**, 1995-2003.

Yellens, S., Cella, D. & Bonomi, A. (1993). Quality of life in people with Hodgkin's disease. *Oncology,* **7**, 41-45.

Young, G. (1981). Preface. In C. Saunders, D. Summers & N. Teller (Eds), *Hospice: The Living Idea*. London: Arnold.

Zamble, E. & Gekoski, W.L. (1994). Coping. In Ramachandron, V.S. (Ed.), *Encyclopedia of Human Behaviour* (Vol.3). New York: Academic Press.

Zech, D., Grond, S., Lynch, J., Hertel, D. & Lehmann, K. (1995). Validation of World Health Organisation guidelines for cancer pain relief: 10 year prospective study. *Pain*, **63**, 65-76.

Zigmond, A.S. & Snaith, R.P. (1983). The Hospital Anxiety & Depression Scale. *Acta Psychiatrica Scandinavica*, **67**, 361-370.

Zimmerman, L., Story, K.T., Gaston-Johansson, F. & Rowles, J.R. (1996). Psychological variables and cancer pain. *Cancer Nursing*, **19**, 44-53.

APPENDIX i

Selected information from the NCCN Practice Guidelines for the Management of Psychosocial Distress: NCCN Guidelines for Distress Management (Holland, J.C., 1999)

These guidelines are a work in progress that will be refined as often as new significant data become available.

The NCCN guidelines are a statement of consensus of its authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult any NCCN guideline is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way.

Distress Management

“DISTRESS”

- Term “distress” chosen because it is more acceptable
- Less stigmatizing than “psychiatric,” “psychosocial,” “emotional”
- Sounds “normal” and less embarrassing
- Can be defined and measured by self-report

DEFINITION OF DISTRESS IN CANCER

Distress is an unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that interferes with the ability to cope effectively with cancer and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and spiritual crisis.

Distress Management

NCCN® PRACTICE
GUIDELINES
VERSION 1.0

STANDARDS OF CARE
FOR DISTRESS MANAGEMENT

- Distress should be recognized, monitored, documented, and treated promptly at all stages of disease.
- All patients should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated.
- Screening should identify the level and the nature of the distress.
- Distress should be assessed and managed according to clinical practice guidelines.

STANDARDS OF CARE
FOR DISTRESS MANAGEMENT

- Multidisciplinary institutional committees should be formed to implement standards for distress management.

- Educational and training programs should be developed to ensure that health-care professionals and clergy have knowledge and skills in the management of distress.

- Mental health professionals and clergy experienced in psychosocial issues in cancer should be available as staff members or by referral in a timely manner.

- Medical care contracts must include reimbursement for management of distress.

STANDARDS OF CARE FOR DISTRESS MANAGEMENT

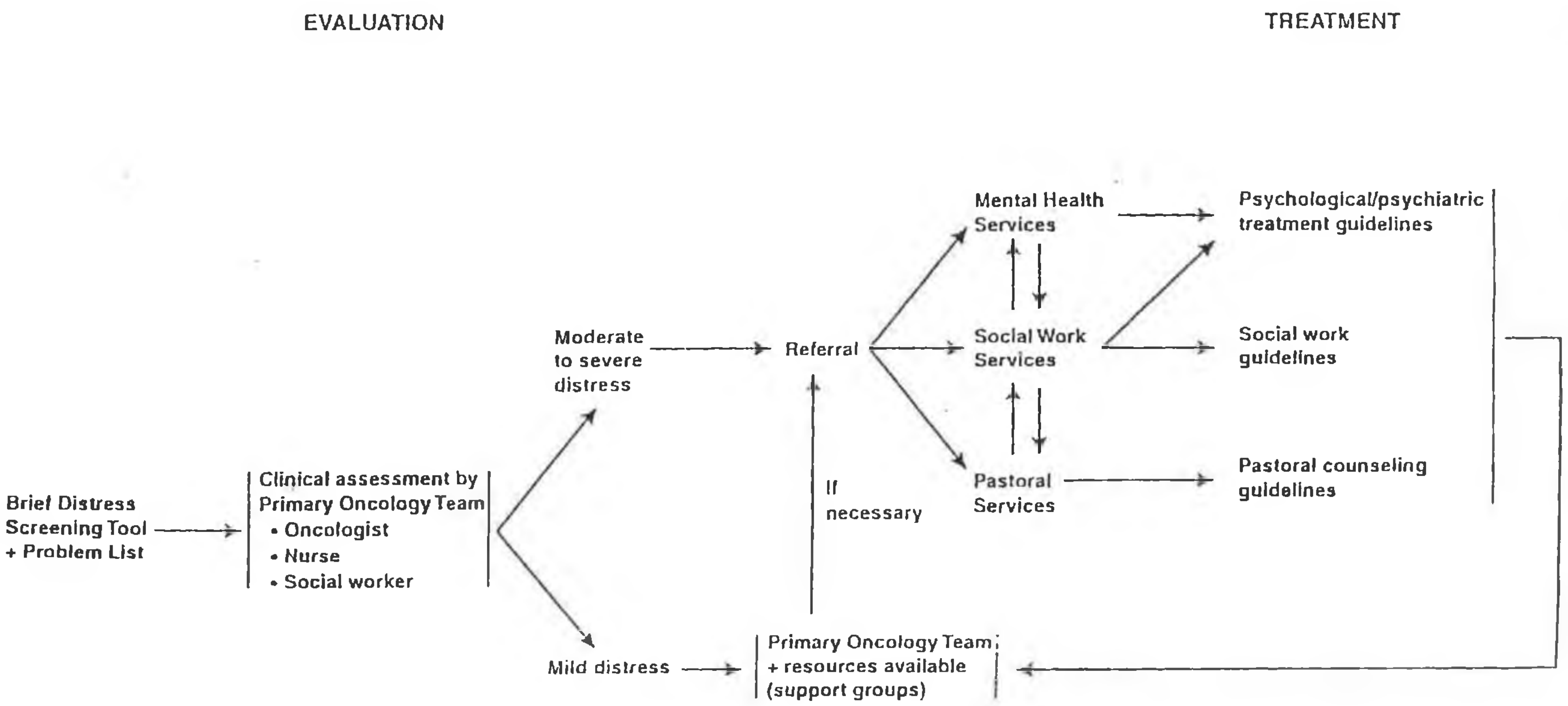
- Clinical health outcomes measurement must include assessment of the psychosocial domain, eg, cost-effectiveness, quality of life, and patient satisfaction.

- Patients and families should be informed that management of distress is an integral part of total medical care.

- Quality of the management of distress should be included in institutional CQI projects.

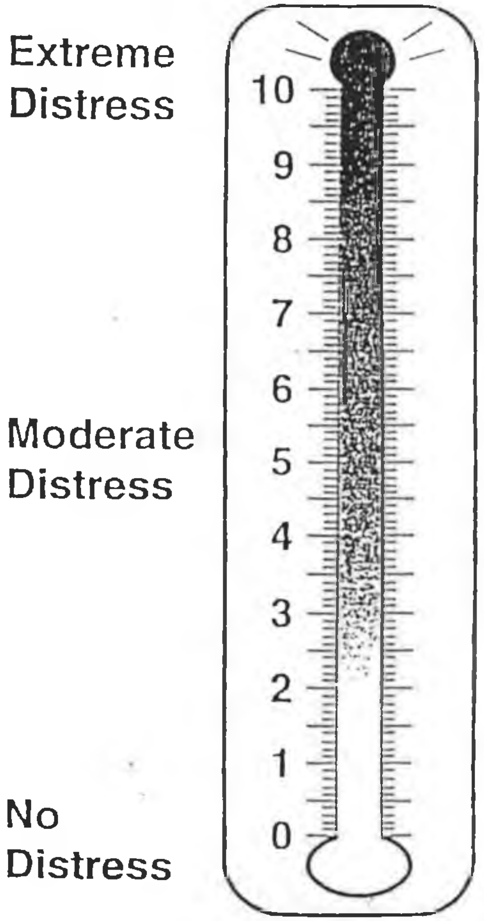
Distress Management

NCCN® PRACTICE GUIDELINES VERSION 1.0



Distress Management

NCCN® PRACTICE GUIDELINES VERSION 1.0



REASONS FOR DISTRESS

Practical problems
- Housing
- Insurance
- Work/school
- Transportation
- Child care

Physical problems
- Pain
- Nausea
- Fatigue
- Sleep problems
- Getting around
- Bathing/dressing

Family problems
- Dealing with partner
- Dealing with children

Emotional problems
- Worry
- Sadness
- Depression
- Nervousness

Spiritual/religious concerns
- Relating to God
- Loss of faith

APPENDIX ii

Questionnaire utilised for research data collection

Research Study

Name:____ Age:_______________

Address:____ Sex:_______________

Education: _____Primary level _____Second level ______Third level______

Marital Status: Single Married Divorced Widowed Separated

Occupation of self:_________________________________

Occupation of spouse:______________________________

Religious Preference:_______________________________

How long has it been since you learned your diagnosis?_________________

Specific diagnosis_________________________________

Dated______________________________1995

(Selected items from BPI, MPQ)

Please rate your pain by circling the one number that best describes your pain on average in the past month (A rating of 10 would indicate pain so severe as to prohibit all activity; the worst pain you can imagine).

No Pain										Pain as bad as you can imagine
0	1	2	3	4	5	6	7	8	9	10

Please rate your pain by circling the one number that best describes how much pain you have right now

No Pain										Pain as bad as you can imagine
0	1	2	3	4	5	6	7	8	9	10

Please circle whichever of the following comes closest to describing your total pain experience in the past month:

no pain   mild pain   discomfort   distressing pain   horrible pain   excruciating pain

What treatment or medication are you receiving for pain ?

____

Please circle the one percentage that indicates how much pain relief your treatments or medication provide for you.

No Relief										Complete Relief
0	10	20	30	40	50	60	70	80	90	100

What do you think is the cause of your pain ?

____

(MDSS)

Please name the one family member who you consider most supportive to you

Please state the relationship of this person to you; e.g. spouse, son, daughter, sister, brother, _

In the past month did this person

Encourage you to talk about your feelings about your illness ?	never	sometimes	often
Encourage you to talk about your illness experience ?	never	sometimes	often
Listen carefully to what you said and try to understand ?	never	sometimes	often
Tell you they loved you or make you feel loved ?	never	sometimes	often
Offer advice about how you could help yourself ?	never	sometimes	often
Suggest new ways of looking at your illness ?	never	sometimes	often
Offer advice about treatments available ?	never	sometimes	often
Tell you what to expect?	never	sometimes	often
Help with chores, transport or childcare?	never	sometimes	often
Take over all your duties and do everything for you?	never	sometimes	often
Help with arrangements that are required as a consequence of your illness?	never	sometimes	often
Try to reassure you that everything would be all right ?	never	sometimes	often
Try to take your mind off your illness ?	never	sometimes	often

(MDSS)

Were you satisfied with how often you got these expressions of concern from this supportive family member or would you have preferred them more often or less often ?

Encourage you to talk about your feelings about your illness ?	satisfied	more often	less often
Encourage you to talk about your illness experience ?	satisfied	more often	less often
Listen carefully to what you said and tried to understand ?	satisfied	more often	less often
Told you they loved you or made you feel loved ?	satisfied	more often	less often
Offer advice about how you could help yourself ?	satisfied	more often	less often
Suggest new ways of looking at your illness ?	satisfied	more often	less often
Offer advice about treatments available ?	satisfied	more often	less often
Tell you what to expect?	satisfied	more often	less often
Help with chores, transport or childcare?	satisfied	more often	less often
Take over all your duties and do everything for you?	satisfied	more often	less often
Help with arrangements that are required as a consequence of your illness?	satisfied	more often	less often
Try to reassure you that everything would be all right ?	satisfied	more often	less often
Try to take your mind off your illness ?	satisfied	more often	less often

Which of the above types of support did you find most meaningful?

(MDSS)

Please think of one friend who you consider the most supportive to you

In the past month how much did your most supportive friend

Encourage you to talk about your emotional feelings about your illness ?	never	sometimes	often
Encourage you to talk about your illness experience ?	never	sometimes	often
Listen carefully to what you said and try to understand ?	never	sometimes	often
Tell you they loved you or make you feel loved ?	never	sometimes	often
Offer advice about how you could help yourself ?	never	sometimes	often
Suggest new ways of looking at your illness ?	never	sometimes	often
Offer advice about treatments available ?	never	sometimes	often
Tell you what to expect?	never	sometimes	often
Help with chores, transport or childcare?	never	sometimes	often
Take over all your duties and do everything for you?	never	sometimes	often
Help with arrangements that are required as a consequence of your illness?	never	sometimes	often
Try to reassure you that everything would be all right ?	never	sometimes	often
Try to take your mind off your illness ?	never	sometimes	often

(MDSS)

Were you satisfied with these expressions of concern from your most supportive friend or would you have preferred them more often or less often ?

Encourage you to talk about your emotional feelings about your illness ?	satisfied	more often	less often
Encourage you to talk about your illness experience ?	satisfied	more often	less often
Listen carefully to what you said and tried to understand ?	satisfied	more often	less often
Told you they loved you or made you feel loved ?	satisfied	more often	less often
Offer advice about how you could help yourself ?	satisfied	more often	less often
Suggest new ways of looking at your illness ?	satisfied	more often	less often
Offer advice about treatments available ?	satisfied	more often	less often
Tell you what to expect?	satisfied	more often	less often
Help with chores, transport or childcare?	satisfied	more often	less often
Take over all your duties and do everything for you?	satisfied	more often	less often
Help with arrangements that are required as a consequence of your illness?	satisfied	more often	less often
Try to reassure you that everything would be all right ?	satisfied	more often	less often
Try to take your mind off your illness ?	satisfied	more often	less often

Which of the above types of support did you find most meaningful?

(MDSS)

Please think of one health professional, either doctor or nurse, who you consider the most supportive to you.

In the past month how much did this most supportive health professional:

Encourage you to talk about your feelings about your illness ?	never	sometimes	often
Encourage you to talk about your illness experience ?	never	sometimes	often
Listen carefully to what you say and try to understand ?	never	sometimes	often
Offer advice about how you can help yourself ?	never	sometimes	often
Suggest new ways of looking at your illness ?	never	sometimes	often
Offer advice about treatments available ?	never	sometimes	often
Tell you what to expect?	never	sometimes	often
Answer all your questions?	never	sometimes	often
Try to reassure you that everything will be all right ?	never	sometimes	often
Try to take your mind off your illness ?	never	sometimes	often

(MDSS)

Were you satisfied with these expressions of concern from your most supportive health professional in the past month or would you have preferred them more often or less often ?

Encourage you to talk about your emotional feelings about your illness ?	satisfied	more often	less often
Encourage you to talk about your illness experience ?	satisfied	more often	less often
Listen carefully to what you say and tried to understand ?	satisfied	more often	less often
Offer advice about how you can help yourself ?	satisfied	more often	less often
Suggest new ways of looking at your illness ?	satisfied	more often	less often
Offer advice about treatments available ?	satisfied	more often	less often
Tell you what to expect?	satisfied	more often	less often
Answer all your questions?	satisfied	more often	less often
Try to reassure you that everything will be all right ?	satisfied	more often	less often
Try to take your mind off your illness ?	satisfied	more often	less often

Which of the above types of support did you find most meaningful?

(MAC Scale)

A number of statements are given below which describe people's reactions to having cancer. Please circle the appropriate number to the right of each statement, indicating how far it applies to you at present. For example, if the statement definitely does not apply to you then you should circle 1 in the first column.

	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
I have been doing things that I believe will improve my health, e.g., I changed my diet.	1	2	3	4
I feel I can't do anything to cheer myself up.	1	2	3	4
I feel that problems with my health prevent me from planning ahead.	1	2	3	4
I believe that my positive attitude will benefit my health.	1	2	3	4
I don't dwell on my illness.	1	2	3	4
I firmly believe that I will get better.	1	2	3	4
I feel that nothing I can do will make any difference.	1	2	3	4
I've left it all to my doctors.	1	2	3	4
I feel that life is hopeless.	1	2	3	4
I have been doing things that I believe will improve my health e.g., exercise.	1	2	3	4

(MAC Scale)

	Definitely does not apply to	Does not apply to me	Applies to me	Definitely applies to me
Since my cancer diagnosis I now realise how precious life is and I'm making the most of it.	1	2	3	4
I've put myself into the hands of God.	1	2	3	4
I have plans for the future, e.g., holidays.	1	2	3	4
I worry about the cancer getting worse	1	2	3	4
I've had a good life; what's left is a bonus.	1	2	3	4
I think my state of mind can make a lot of difference to my health.	1	2	3	4
I feel that there is nothing I can do to help myself.	1	2	3	4
I try to carry on my life as I've always done.	1	2	3	4
I would try to make contact with others in the same boat.	1	2	3	4
I have difficulty believing that this has happened to me.	1	2	3	4
I suffer great anxiety about it.	1	2	3	4
I am not very hopeful about the future.	1	2	3	4
At the moment I take one day at a time.	1	2	3	4
I feel like giving up.	1	2	3	4

(MAC Scale)

	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
I try to keep a sense of humour about it.	1	2	3	4
Other people worry more about me than I do.	1	2	3	4
I think of other people who are worse off.	1	2	3	4
I am trying to get as much information as I can about cancer.	1	2	3	4
I feel that I can't control what is happening.	1	2	3	4
I try to have a very positive attitude.	1	2	3	4
I keep quite busy, so I don't have time to think about it.	1	2	3	4
I avoid finding out more about it.	1	2	3	4
I see my illness as a challenge.	1	2	3	4
I feel fatalistic about it.	1	2	3	4
I feel completely at a loss about what to do.	1	2	3	4
I feel very angry about what has happened to me.	1	2	3	4
I don't really believe I have cancer.	1	2	3	4
I count my blessings.	1	2	3	4
I try to fight the illness.	1	2	3	4

(CEC Scale)

Listed below are some of the reactions people have to certain feelings or emotions. Please read through the items on each list and by circling an appropriate number on the scale indicate how far each describes the way you generally react.

For example:In reaction A, if you think that you <u>almost never</u> keep quiet when very annoyed, then you should circle 1

Please circle a number for every reaction listed. Work quickly and circle only one number on each line.

When I feel angry (very annoyed)	Almost Never	Some- times	Often	Almost Always
I keep quiet	1	2	3	4
I refuse to argue or say anything	1	2	3	4
I bottle it up	1	2	3	4
I say what I feel	1	2	3	4
I avoid making a scene	1	2	3	4
I smother my feelings	1	2	3	4
I hide my appearance	1	2	3	4

When I feel anxious (worried)	Almost Never	Some- times	Often	Almost Always
I let others see how I feel	1	2	3	4
I keep quiet	1	2	3	4
I refuse to say anything about it	1	2	3	4
I tell others about it	1	2	3	4
I say what I feel	1	2	3	4
I bottle it up	1	2	3	4
I smother my feelings	1	2	3	4

When I feel unhappy (miserable)	Almost Never	Some- times	Often	Almost Always
I refuse to say anything about it	1	2	3	4
I hide my unhappiness	1	2	3	4
I put on a bold face	1	2	3	4
I keep quiet	1	2	3	4
I let others see how I feel	1	2	3	4
I smother my feelings	1	2	3	4
I bottle it up	1	2	3	4

(RSCL)

In this questionnaire you are asked about your symptoms. Would you please, for any of the symptoms mentioned, indicate to what extent you have been bothered by it, by circling the answer most applicable to you. The questions relate to the past week.

Have you, during the past week, been bothered by:

Lack of appetite	not at all	a little	quite a bit	very much
Irritability	not at all	a little	quite a bit	very much
Tiredness	not at all	a little	quite a bit	very much
Worrying	not at all	a little	quite a bit	very much
Sore muscles	not at all	a little	quite a bit	very much
Depressed mood	not at all	a little	quite a bit	very much
Lack of energy	not at all	a little	quite a bit	very much
Low back pain	not at all	a little	quite a bit	very much
Nervousness	not at all	a little	quite a bit	very much
Nausea	not at all	a little	quite a bit	very much
Desperate feelings about the future	not at all	a little	quite a bit	very much
Difficulties sleeping	not at all	a little	quite a bit	very much
Headaches	not at all	a little	quite a bit	very much
Vomiting	not at all	a little	quite a bit	very much
Dizziness	not at all	a little	quite a bit	very much

(RSCL)

Decreased sexual interest	not at all	a little	quite a bit	very much
Tension	not at all	a little	quite a bit	very much
Abdominal ache	not at all	a little	quite a bit	very much
Anxiety	not at all	a little	quite a bit	very much
Constipation	not at all	a little	quite a bit	very much
Diarrhoea	not at all	a little	quite a bit	very much
Heartburn/ belching	not at all	a little	quite a bit	very much
Shivering	not at all	a little	quite a bit	very much
Tingling hands or feet	not at all	a little	quite a bit	very much
Difficulty concentrating	not at all	a little	quite a bit	very much
Sore mouth / pain when swallowing	not at all	a little	quite a bit	very much
Loss of hair	not at all	a little	quite a bit	very much
Burning (or sore) eyes	not at all	a little	quite a bit	very much
Shortness of breath	not at all	a little	quite a bit	very much
Dry mouth	not at all	a little	quite a bit	very much

(HAD Scale)

Please underline one statement in each section:

I feel tense or wound up:
most of the time
a lot of the time
from time to time, occasionally
not at all

I still enjoy the things I used to enjoy:
definitely as much
not quite as much
only a little
hardly at all

I get a sort of frightened feeling as if something awful is about to happen:
very definitely and quite badly
yes, but not too badly
a little, but it doesn't worry me
not at all

I can laugh and see the funny side of things:
as much as I always could
not quite so much now
definitely not so much now
not at all

Worrying thoughts go through my mind:
a great deal of the time
a lot of the time
from time to time but not too often
only occasionally

I feel cheerful:
not at all
not often
sometimes
most of the time

I can sit at ease and feel relaxed:
definitely
usually
not often
not at all

I feel as if I am slowed down
nearly all the time
very often
sometimes
not at all

I get a sort of frightened feeling like " butterflies " in the stomach:
not at all
occasionally
quite often
very often

I have lost interest in my appearance:
definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

I feel restless as if I have to be on the move
very much indeed
quite a lot
not very much
not at all

I look forward with enjoyment to things:
as much as I ever did
rather less than I used to
definitely less than I used to
hardly at all

I get sudden feelings of panic:
very often indeed
quite often
not very often
not at all

I can enjoy a good book or radio or T.V. programme
often
sometimes
not often
very seldom

What change has having cancer made to your life?

What has having cancer meant in loss terms?
(either: not at all, a little, quite a bit, very much)

physical strength

independence

role

physical restriction

social deficit

overall perceived loss

APPENDIX iii

Tables of analyses

NB. Due to the imbalance in numbers of participants recruited through the hospice and oncology centre, comparisons between these two groups on the various tests administered are not feasible

Hypothesis 1a. Average pain intensity is positively associated with received support within the social networks of patients with advanced cancer.

			Average Pain
Kendall's tau_b	Average Pain	Correlation Coefficient	1.000
		Sig. (2-tailed)	.
		N	98
	Received emotional support from family	Correlation Coefficient	.064
		Sig. (2-tailed)	.439
		N	98
	Received informational support from family	Correlation Coefficient	-.092
		Sig. (2-tailed)	.277
		N	98
	Received tangible support from family	Correlation Coefficient	.135
		Sig. (2-tailed)	.131
		N	98
	Received reassurance support from family	Correlation Coefficient	.009
		Sig. (2-tailed)	.919
		N	98
	Received overall support from family	Correlation Coefficient	.037
		Sig. (2-tailed)	.640
		N	98
	Received emotional support from friends	Correlation Coefficient	-.001
		Sig. (2-tailed)	.992
		N	98
	Received informational support from friends	Correlation Coefficient	-.132
		Sig. (2-tailed)	.132
		N	98
	Received tangible support from friends	Correlation Coefficient	.088
		Sig. (2-tailed)	.300
		N	98
	Received reassurance support from friends	Correlation Coefficient	.025
		Sig. (2-tailed)	.772
		N	98
	Received overall support from friends	Correlation Coefficient	.012
		Sig. (2-tailed)	.880
		N	98
	Received emotional support from HCPs	Correlation Coefficient	.223**
		Sig. (2-tailed)	.007
		N	98
	Received informational support from HCPs	Correlation Coefficient	.116
		Sig. (2-tailed)	.151
		N	98
	Received reassurance support from HCPs	Correlation Coefficient	.040
		Sig. (2-tailed)	.627
		N	98
	Received overall support from HCPs	Correlation Coefficient	.155*
		Sig. (2-tailed)	.048
		N	98

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

Hypotheses 1b and 1c. Average pain intensity is positively associated with psychological distress in patients with advanced cancer.

			Average Pain
Kendall's tau_b	Average Pain	Correlation Coefficient	1.000
		Sig. (2-tailed)	.
		N	98
	Irritability	Correlation Coefficient	.041
		Sig. (2-tailed)	.639
		N	98
	Worrying	Correlation Coefficient	-.011
		Sig. (2-tailed)	.901
		N	98
	Depressed Mood	Correlation Coefficient	.044
		Sig. (2-tailed)	.610
		N	98
	Nervousness	Correlation Coefficient	-.035
		Sig. (2-tailed)	.690
		N	98
	Desperate feelings about the future	Correlation Coefficient	.123
		Sig. (2-tailed)	.159
		N	98
	Tension	Correlation Coefficient	.097
		Sig. (2-tailed)	.265
		N	98
	Anxiety	Correlation Coefficient	.115
		Sig. (2-tailed)	.183
		N	98
	Difficulty concentrating	Correlation Coefficient	.095
		Sig. (2-tailed)	.272
		N	98
	HADS: Anxiety	Correlation Coefficient	.109
		Sig. (2-tailed)	.183
		N	92
	HADS:Depression	Correlation Coefficient	.037
		Sig. (2-tailed)	.654
		N	92

Hypotheses 1b and 1c. Average pain intensity is positively associated with perceived loss in patients with advanced cancer.

			Average Pain
Kendall's tau_b	Average Pain	Correlation Coefficient	1.000
		Sig. (2-tailed)	.
		N	98
	Physical Strength	Correlation Coefficient	.153
		Sig. (2-tailed)	.073
		N	98
	Independence	Correlation Coefficient	.112
		Sig. (2-tailed)	.188
		N	98
	Role	Correlation Coefficient	.036
		Sig. (2-tailed)	.674
		N	98
	Physical Restriction	Correlation Coefficient	.199*
		Sig. (2-tailed)	.024
		N	98
	Social Deficit	Correlation Coefficient	.109
		Sig. (2-tailed)	.209
		N	98
	Perceived Loss Total Score	Correlation Coefficient	.137
		Sig. (2-tailed)	.098
		N	90

*. Correlation is significant at the .05 level (2-tailed).

Hypothesis 1d. Average pain intensity is positively associated with coping deficit in patients with advanced cancer.

			Average Pain
Kendall's tau_b	Average Pain	Correlation Coefficient	1.000
		Sig. (2-tailed)	.
		N	98
	MAC :Anxious preoccupation	Correlation Coefficient	.022
		Sig. (2-tailed)	.804
		N	80
	MAC :Fatalism	Correlation Coefficient	-.010
		Sig. (2-tailed)	.913
		N	80
	MAC: Helplessness/hopelessness	Correlation Coefficient	.048
		Sig. (2-tailed)	.597
		N	80
	MAC: Fighting spirit	Correlation Coefficient	-.155
		Sig. (2-tailed)	.078
		N	80
	MAC: Avoidance	Correlation Coefficient	.243*
		Sig. (2-tailed)	.013
		N	80

*. Correlation is significant at the .05 level (2-tailed).

Hypothesis 1e. Average pain intensity is negatively associated with perceived support within the social networks of patients with advanced cancer.

			Average Pain rated as high
Kendall's tau_b		Sig. (2-tailed)	.
	Perceived emotional support from family	Correlation Coefficient	.051
		Sig. (2-tailed)	.589
		N	98
	Perceived informational support form family	Correlation Coefficient	.120
		Sig. (2-tailed)	.198
		N	98
	Perceived tangible support from family	Correlation Coefficient	.152
		Sig. (2-tailed)	.101
		N	98
	Perceived reassurance support from family	Correlation Coefficient	.095
		Sig. (2-tailed)	.311
		N	98
	Perceived overall support from family	Correlation Coefficient	-.112
		Sig. (2-tailed)	.216
		N	98
	Perceived emotional support from friends	Correlation Coefficient	-.001
		Sig. (2-tailed)	.990
		N	98
	Perceived informational support from friends	Correlation Coefficient	.008
		Sig. (2-tailed)	.932
		N	98
	Perceived tangible support from friends	Correlation Coefficient	.026
		Sig. (2-tailed)	.782
		N	98
	Perceived reassurance support from friends	Correlation Coefficient	.061
		Sig. (2-tailed)	.511
		N	98
	Perceived overall support from friends	Correlation Coefficient	-.044
		Sig. (2-tailed)	.630
		N	98
	Perceived emotional support from HCPs	Correlation Coefficient	.171
		Sig. (2-tailed)	.067
		N	98
	Perceived informational support from HCPs	Correlation Coefficient	.113
		Sig. (2-tailed)	.224
		N	98
	Perceived reassurance support from HCPs	Correlation Coefficient	.192*
		Sig. (2-tailed)	.039
		N	98
	Perceived overall support from HCPs	Correlation Coefficient	-.151
		Sig. (2-tailed)	.088
		N	98

*. Correlation is significant at the .05 level (2-tailed).

Hypothesis 2a. Average pain intensity rated as moderate to high is positively associated with received support within the social networks of patients with advanced cancer

			Average Pain rated as high
Kendall's tau_b		Sig. (2-tailed)	.
	Received emotional support from family	Correlation Coefficient	.057
		Sig. (2-tailed)	.641
		N	53
	Received informational support from family	Correlation Coefficient	-.109
		Sig. (2-tailed)	.390
		N	53
	Received tangible support from family	Correlation Coefficient	.098
		Sig. (2-tailed)	.469
		N	53
	Received reassurance support from family	Correlation Coefficient	.113
		Sig. (2-tailed)	.370
		N	53
	Received overall support from family	Correlation Coefficient	.082
		Sig. (2-tailed)	.484
		N	53
	Received emotional support from friends	Correlation Coefficient	.240
		Sig. (2-tailed)	.054
		N	53
	Received informational support from friends	Correlation Coefficient	-.020
		Sig. (2-tailed)	.878
		N	53
	Received tangible support from friends	Correlation Coefficient	.000
		Sig. (2-tailed)	1.000
		N	53
	Received reassurance support from friends	Correlation Coefficient	.225
		Sig. (2-tailed)	.078
		N	53
	Received overall support from friends	Correlation Coefficient	.187
		Sig. (2-tailed)	.109
		N	53
	Received emotional support from HCPs	Correlation Coefficient	.245*
		Sig. (2-tailed)	.047
		N	53
	Received informational support from HCPs	Correlation Coefficient	.171
		Sig. (2-tailed)	.155
		N	53
	Received reassurance support from HCPs	Correlation Coefficient	.128
		Sig. (2-tailed)	.299
		N	53
	Received overall support from HCPs	Correlation Coefficient	.207
		Sig. (2-tailed)	.077
		N	53

*. Correlation is significant at the .05 level (2-tailed).

Hypotheses 2b and 2c. Average pain intensity rated as moderate to high is positively associated with psychological distress in patients with advanced cancer.

			Average pain rated as high
Kendall's tau_b		Sig. (2-tailed)	.
	Irritability	Correlation Coefficient	-.030
		Sig. (2-tailed)	.822
		N	53
	Worrying	Correlation Coefficient	.082
		Sig. (2-tailed)	.523
		N	53
	Depressed Mood	Correlation Coefficient	.121
		Sig. (2-tailed)	.349
		N	53
	Nervousness	Correlation Coefficient	-.076
		Sig. (2-tailed)	.566
		N	53
	Desperate feelings about the future	Correlation Coefficient	-.031
		Sig. (2-tailed)	.813
		N	53
	Tension	Correlation Coefficient	-.003
		Sig. (2-tailed)	.983
		N	53
	Anxiety	Correlation Coefficient	.067
		Sig. (2-tailed)	.600
		N	53
	Difficulty concentrating	Correlation Coefficient	.075
		Sig. (2-tailed)	.561
		N	53
	HADS: Anxiety	Correlation Coefficient	.137
		Sig. (2-tailed)	.254
		N	51
	HADS:Depression	Correlation Coefficient	.086
		Sig. (2-tailed)	.481
		N	51

Hypotheses 2b and 2c. Average pain intensity rated as moderate to high is positively associated with perceived loss in patients with advanced cancer.

			Average Pain rated as high
Kendall's tau_b		Sig. (2-tailed)	.
	Physical Strength	Correlation Coefficient	.075
		Sig. (2-tailed)	.559
		N	53
	Independence	Correlation Coefficient	-.069
		Sig. (2-tailed)	.586
		N	53
	Role	Correlation Coefficient	.059
		Sig. (2-tailed)	.640
		N	53
	Physical Restriction	Correlation Coefficient	.130
		Sig. (2-tailed)	.322
		N	53
	Social Deficit	Correlation Coefficient	.028
		Sig. (2-tailed)	.828
		N	53
	Perceived Loss Total Score	Correlation Coefficient	.037
		Sig. (2-tailed)	.758
		N	50

Hypothesis 2d. Average pain intensity rated as moderate to high is positively associated with coping deficit in patients with advanced cancer.

			Average Pain rated as high
Kendall's tau_b		Sig. (2-tailed)	.
	MAC :Anxious preoccupation	Correlation Coefficient	.079
		Sig. (2-tailed)	.555
		N	41
	MAC :Fatalism	Correlation Coefficient	-.296*
		Sig. (2-tailed)	.027
		N	41
	MAC: Helplessness/hopelessness	Correlation Coefficient	.033
		Sig. (2-tailed)	.809
		N	41
	MAC: Fighting spirit	Correlation Coefficient	-.074
		Sig. (2-tailed)	.582
		N	41
	MAC: Avoidance	Correlation Coefficient	-.047
		Sig. (2-tailed)	.752
		N	41

*. Correlation is significant at the .05 level (2-tailed).

Hypothesis 2e. Average pain intensity rated as moderate to high is negatively associated with perceived support within the social networks of patients with advanced cancer.

			Average Pain rated as high
Kendall's tau_b		Sig. (2-tailed)	.
	Perceived emotional support from family	Correlation Coefficient	.188
		Sig. (2-tailed)	.175
		N	53
	Perceived informational support form family	Correlation Coefficient	.188
		Sig. (2-tailed)	.175
		N	53
	Perceived tangible support from family	Correlation Coefficient	.235
		Sig. (2-tailed)	.090
		N	53
	Perceived reassurance support from family	Correlation Coefficient	.212
		Sig. (2-tailed)	.126
		N	53
	Perceived overall support from family	Correlation Coefficient	-.256
		Sig. (2-tailed)	.055
		N	53
	Perceived emotional support from friends	Correlation Coefficient	-.284*
		Sig. (2-tailed)	.041
		N	53
	Perceived informational support from friends	Correlation Coefficient	-.279*
		Sig. (2-tailed)	.044
		N	53
	Perceived tangible support from friends	Correlation Coefficient	-.284*
		Sig. (2-tailed)	.041
		N	53
	Perceived reassurance support from friends	Correlation Coefficient	-.154
		Sig. (2-tailed)	.266
		N	53
	Perceived overall support from friends	Correlation Coefficient	.253
		Sig. (2-tailed)	.062
		N	53
	Perceived emotional support from HCPs	Correlation Coefficient	.012
		Sig. (2-tailed)	.933
		N	53
	Perceived informational support from HCPs	Correlation Coefficient	.088
		Sig. (2-tailed)	.526
		N	53
	Perceived reassurance support from HCPs	Correlation Coefficient	.088
		Sig. (2-tailed)	.526
		N	53
	Perceived overall support from HCPs	Correlation Coefficient	-.074
		Sig. (2-tailed)	.578
		N	53

*. Correlation is significant at the .05 level (2-tailed).

Hypothesis 3a. Present pain intensity is positively associated with received support within the social networks of patients with advanced cancer.

			Present Pain
Kendall's tau_b		Sig. (2-tailed)	.
	Received emotional support from family	Correlation Coefficient	.031
		Sig. (2-tailed)	.715
		N	98
	Received informational support from family	Correlation Coefficient	.024
		Sig. (2-tailed)	.786
		N	98
	Received tangible support from family	Correlation Coefficient	.233*
		Sig. (2-tailed)	.012
		N	98
	Received reassurance support from family	Correlation Coefficient	-.058
		Sig. (2-tailed)	.507
		N	98
	Received overall support from family	Correlation Coefficient	.071
		Sig. (2-tailed)	.384
		N	98
	Received emotional support from friends	Correlation Coefficient	.095
		Sig. (2-tailed)	.273
		N	98
	Received informational support from friends	Correlation Coefficient	.006
		Sig. (2-tailed)	.948
		N	98
	Received tangible support from friends	Correlation Coefficient	.189*
		Sig. (2-tailed)	.033
		N	98
	Received reassurance support from friends	Correlation Coefficient	.107
		Sig. (2-tailed)	.230
		N	98
	Received overall support from friends	Correlation Coefficient	.158
		Sig. (2-tailed)	.052
		N	98
	Received emotional support from HCPs	Correlation Coefficient	.036
		Sig. (2-tailed)	.677
		N	98
	Received informational support from HCPs	Correlation Coefficient	-.039
		Sig. (2-tailed)	.638
		N	98
	Received reassurance support from HCPs	Correlation Coefficient	-.110
		Sig. (2-tailed)	.202
		N	98
	Received overall support from HCPs	Correlation Coefficient	-.019
		Sig. (2-tailed)	.811
		N	98

*. Correlation is significant at the .05 level (2-tailed).

Hypotheses 3b. Present pain intensity is positively associated with psychological distress in patients with advanced cancer.

			Present Pain
Kendall's tau_b		Sig. (2-tailed)	.
	Irritability	Correlation Coefficient	.139
		Sig. (2-tailed)	.128
		N	98
	Worrying	Correlation Coefficient	.053
		Sig. (2-tailed)	.550
		N	98
	Depressed Mood	Correlation Coefficient	.139
		Sig. (2-tailed)	.123
		N	98
	Nervousness	Correlation Coefficient	.127
		Sig. (2-tailed)	.166
		N	98
	Desperate feelings about the future	Correlation Coefficient	.161
		Sig. (2-tailed)	.075
		N	98
	Tension	Correlation Coefficient	.160
		Sig. (2-tailed)	.077
		N	98
	Anxiety	Correlation Coefficient	.147
		Sig. (2-tailed)	.100
		N	98
	Difficulty concentrating	Correlation Coefficient	.100
		Sig. (2-tailed)	.265
		N	98
	HADS: Anxiety	Correlation Coefficient	.248**
		Sig. (2-tailed)	.003
		N	92
	HADS:Depression	Correlation Coefficient	.011
		Sig. (2-tailed)	.896
		N	92

**. Correlation is significant at the .01 level (2-tailed).

Hypotheses 3c. Present pain intensity is positively associated with perceived loss in patients with advanced cancer.

			Present Pain
Kendall's tau_b	Present Pain	Correlation Coefficient	1.000
		Sig. (2-tailed)	.
		N	98
	Physical Strength	Correlation Coefficient	.055
		Sig. (2-tailed)	.532
		N	98
	Independence	Correlation Coefficient	.025
		Sig. (2-tailed)	.781
		N	98
	Role	Correlation Coefficient	.030
		Sig. (2-tailed)	.730
		N	98
	Physical Restriction	Correlation Coefficient	.049
		Sig. (2-tailed)	.588
		N	98
	Social Deficit	Correlation Coefficient	.067
		Sig. (2-tailed)	.457
		N	98
	Perceived Loss Total Score	Correlation Coefficient	.095
		Sig. (2-tailed)	.273
		N	90

Hypothesis 3d. Present pain intensity is positively associated with coping deficit in patients with advanced cancer.

			Present Pain
Kendall's tau_b		Sig. (2-tailed)	.
	MAC :Anxious preoccupation	Correlation Coefficient	.001
		Sig. (2-tailed)	.988
		N	80
	MAC :Fatalism	Correlation Coefficient	.039
		Sig. (2-tailed)	.670
		N	80
	MAC: Helplessness/hopelessness	Correlation Coefficient	.085
		Sig. (2-tailed)	.360
		N	80
	MAC: Fighting spirit	Correlation Coefficient	-.081
		Sig. (2-tailed)	.372
		N	80
	MAC: Avoidance	Correlation Coefficient	.087
		Sig. (2-tailed)	.395
		N	80

Hypothesis 3e. Present pain intensity is negatively associated with perceived support within the social networks of patients with advanced cancer.

			Present Pain
Kendall's tau_b		Sig. (2-tailed)	
	Perceived emotional support from family	Correlation Coefficient	.047
		Sig. (2-tailed)	.631
		N	98
	Perceived informational support form family	Correlation Coefficient	-.054
		Sig. (2-tailed)	.578
		N	98
	Perceived tangible support from family	Correlation Coefficient	-.065
		Sig. (2-tailed)	.497
		N	98
	Perceived reassurance support from family	Correlation Coefficient	-.047
		Sig. (2-tailed)	.631
		N	98
	Perceived overall support from family	Correlation Coefficient	.035
		Sig. (2-tailed)	.710
		N	98
	Perceived emotional support from friends	Correlation Coefficient	-.071
		Sig. (2-tailed)	.462
		N	98
	Perceived informational support from friends	Correlation Coefficient	-.057
		Sig. (2-tailed)	.555
		N	98
	Perceived tangible support from friends	Correlation Coefficient	-.129
		Sig. (2-tailed)	.183
		N	98
	Perceived reassurance support from friends	Correlation Coefficient	-.133
		Sig. (2-tailed)	.168
		N	98
	Perceived overall support from friends	Correlation Coefficient	.105
		Sig. (2-tailed)	.269
		N	98
	Perceived emotional support from HCPs	Correlation Coefficient	.124
		Sig. (2-tailed)	.201
		N	98
	Perceived informational support from HCPs	Correlation Coefficient	.042
		Sig. (2-tailed)	.666
		N	98
	Perceived reassurance support from HCPs	Correlation Coefficient	.150
		Sig. (2-tailed)	.119
		N	98
	Perceived overall support from HCPs	Correlation Coefficient	-.110
		Sig. (2-tailed)	.232
		N	98

Hypothesis 4a. Overall evaluated pain experience is positively associated with received support within the social networks of patients with advanced cancer

			Overall Evaluated Pain Experience
Kendall's tau_b		Sig. (2-tailed)	.
	Received emotional support from family	Correlation Coefficient	.006
		Sig. (2-tailed)	.939
		N	98
	Received informational support from family	Correlation Coefficient	-.106
		Sig. (2-tailed)	.193
		N	98
	Received tangible support from family	Correlation Coefficient	.102
		Sig. (2-tailed)	.234
		N	98
	Received reassurance support from family	Correlation Coefficient	-.045
		Sig. (2-tailed)	.579
		N	98
	Received overall support from family	Correlation Coefficient	-.023
		Sig. (2-tailed)	.764
		N	98
	Received emotional support from friends	Correlation Coefficient	-.045
		Sig. (2-tailed)	.576
		N	98
	Received informational support from friends	Correlation Coefficient	-.151
		Sig. (2-tailed)	.073
		N	98
	Received tangible support from friends	Correlation Coefficient	.063
		Sig. (2-tailed)	.440
		N	98
	Received reassurance support from friends	Correlation Coefficient	-.079
		Sig. (2-tailed)	.340
		N	98
	Received overall support from friends	Correlation Coefficient	-.050
		Sig. (2-tailed)	.503
		N	98
	Received emotional support from HCPs	Correlation Coefficient	.165*
		Sig. (2-tailed)	.037
		N	98
	Received informational support from HCPs	Correlation Coefficient	.102
		Sig. (2-tailed)	.190
		N	98
	Received reassurance support from HCPs	Correlation Coefficient	.035
		Sig. (2-tailed)	.664
		N	98
	Received overall support from HCPs	Correlation Coefficient	.120
		Sig. (2-tailed)	.113
		N	98

*. Correlation is significant at the .05 level (2-tailed).

Hypotheses 4b. Overall evaluated pain experience is positively associated with psychological distress in patients with advanced cancer.

			Overall Evaluated Pain Experience
Kendall's tau_b		Sig. (2-tailed)	.
	Irritability	Correlation Coefficient	.114
		Sig. (2-tailed)	.180
		N	98
	Worrying	Correlation Coefficient	.057
		Sig. (2-tailed)	.488
		N	98
	Depressed Mood	Correlation Coefficient	.115
		Sig. (2-tailed)	.169
		N	98
	Nervousness	Correlation Coefficient	-.030
		Sig. (2-tailed)	.723
		N	98
	Desperate feelings about the future	Correlation Coefficient	.186*
		Sig. (2-tailed)	.027
		N	98
	Tension	Correlation Coefficient	.157
		Sig. (2-tailed)	.061
		N	98
	Anxiety	Correlation Coefficient	.167*
		Sig. (2-tailed)	.044
		N	98
	Difficulty concentrating	Correlation Coefficient	.118
		Sig. (2-tailed)	.156
		N	98
	HADS: Anxiety	Correlation Coefficient	.186*
		Sig. (2-tailed)	.018
		N	92
	HADS:Depression	Correlation Coefficient	.090
		Sig. (2-tailed)	.255
		N	92

*. Correlation is significant at the .05 level (2-tailed).

Hypotheses 4c. Overall evaluated pain experience is positively associated with perceived loss in patients with advanced cancer.

			Overall Evaluated Pain Experience
Kendall's tau_b		Sig. (2-tailed)	.
	Physical Strength	Correlation Coefficient	.181*
		Sig. (2-tailed)	.027
		N	98
	Independence	Correlation Coefficient	.113
		Sig. (2-tailed)	.169
		N	98
	Role	Correlation Coefficient	.065
		Sig. (2-tailed)	.431
		N	98
	Physical Restriction	Correlation Coefficient	.200*
		Sig. (2-tailed)	.018
		N	98
	Social Deficit	Correlation Coefficient	.130
		Sig. (2-tailed)	.120
		N	98
	Perceived Loss Total Score	Correlation Coefficient	.197*
		Sig. (2-tailed)	.014
		N	90

*. Correlation is significant at the .05 level (2-tailed).

Hypothesis 4d. Overall evaluated pain experience is positively associated with coping deficit in patients with advanced cancer.

			Overall Evaluated Pain Experience
Kendall's tau_b		Sig. (2-tailed)	.
	MAC :Anxious preoccupation	Correlation Coefficient	.042
		Sig. (2-tailed)	.619
		N	80
	MAC :Fatalism	Correlation Coefficient	.045
		Sig. (2-tailed)	.596
		N	80
	MAC: Helplessness/hopelessness	Correlation Coefficient	.172*
		Sig. (2-tailed)	.047
		N	80
	MAC: Fighting spirit	Correlation Coefficient	-.279**
		Sig. (2-tailed)	.001
		N	80
	MAC: Avoidance	Correlation Coefficient	.183
		Sig. (2-tailed)	.054
		N	80

*. Correlation is significant at the .05 level (2-tailed).

**. Correlation is significant at the .01 level (2-tailed).

Hypothesis 4e. Overall evaluated pain experience is negatively associated with perceived support within the social networks of patients with advanced cancer.

			Overall Evaluated Pain Experience
Kendall's tau_b		Sig. (2-tailed)	.
	Perceived emotional support from family	Correlation Coefficient	.116
		Sig. (2-tailed)	.196
		N	98
	Perceived informational support form family	Correlation Coefficient	.101
		Sig. (2-tailed)	.259
		N	98
	Perceived tangible support from family	Correlation Coefficient	.221*
		Sig. (2-tailed)	.013
		N	98
	Perceived reassurance support from family	Correlation Coefficient	.127
		Sig. (2-tailed)	.158
		N	98
	Perceived overall support from family	Correlation Coefficient	-.204*
		Sig. (2-tailed)	.019
		N	98
	Perceived emotional support from friends	Correlation Coefficient	.019
		Sig. (2-tailed)	.832
		N	98
	Perceived informational support from friends	Correlation Coefficient	.032
		Sig. (2-tailed)	.723
		N	98
	Perceived tangible support from friends	Correlation Coefficient	.070
		Sig. (2-tailed)	.438
		N	98
	Perceived reassurance support from friends	Correlation Coefficient	.107
		Sig. (2-tailed)	.233
		N	98
	Perceived overall support from friends	Correlation Coefficient	-.070
		Sig. (2-tailed)	.426
		N	98
	Perceived emotional support from HCPs	Correlation Coefficient	.149
		Sig. (2-tailed)	.097
		N	98
	Perceived informational support from HCPs	Correlation Coefficient	.092
		Sig. (2-tailed)	.305
		N	98
	Perceived reassurance support from HCPs	Correlation Coefficient	.125
		Sig. (2-tailed)	.162
		N	98
	Perceived overall support from HCPs	Correlation Coefficient	-.111
		Sig. (2-tailed)	.191
		N	98

*. Correlation is significant at the .05 level (2-tailed).

Hypothesis 5a. Within the over-59-years old group, the older patients are, the more likely they will be to receive insufficient support from their social networks.

			Age in years
Kendall's tau_b		Sig. (2-tailed)	.
	Received emotional support from family	Correlation Coefficient	.079
		Sig. (2-tailed)	.495
		N	43
	Received informational support from family	Correlation Coefficient	.071
		Sig. (2-tailed)	.548
		N	43
	Received tangible support from family	Correlation Coefficient	-.011
		Sig. (2-tailed)	.929
		N	43
	Received reassurance support from family	Correlation Coefficient	.086
		Sig. (2-tailed)	.465
		N	43
	Received overall support from family	Correlation Coefficient	.020
		Sig. (2-tailed)	.858
		N	43
	Received emotional support from friends	Correlation Coefficient	-.098
		Sig. (2-tailed)	.398
		N	43
	Received informational support from friends	Correlation Coefficient	.024
		Sig. (2-tailed)	.848
		N	43
	Received tangible support from friends	Correlation Coefficient	-.308**
		Sig. (2-tailed)	.010
		N	43
	Received reassurance support from friends	Correlation Coefficient	-.155
		Sig. (2-tailed)	.196
		N	43
	Received overall support from friends	Correlation Coefficient	-.174
		Sig. (2-tailed)	.112
		N	43
	Received emotional support from HCPs	Correlation Coefficient	.065
		Sig. (2-tailed)	.569
		N	43
	Received informational support from HCPs	Correlation Coefficient	.013
		Sig. (2-tailed)	.907
		N	43
	Received reassurance support from HCPs	Correlation Coefficient	.021
		Sig. (2-tailed)	.856
		N	43
	Received overall support from HCPs	Correlation Coefficient	.056
		Sig. (2-tailed)	.613
		N	43

**. Correlation is significant at the .01 level (2-tailed).

Hypothesis 5b. Within the over-59-years old group, the older patients are, the more likely they will be to perceive a support deficit from their social network

			Age in years
Kendall's tau_b		Sig. (2-tailed)	
	Perceived emotional support from family	Correlation Coefficient	-.112
		Sig. (2-tailed)	.390
		N	43
	Perceived informational support form family	Correlation Coefficient	-.056
		Sig. (2-tailed)	.665
		N	43
	Perceived tangible support from family	Correlation Coefficient	-.129
		Sig. (2-tailed)	.315
		N	43
	Perceived reassurance support from family	Correlation Coefficient	-.174
		Sig. (2-tailed)	.181
		N	43
	Perceived overall support from family	Correlation Coefficient	.137
		Sig. (2-tailed)	.279
		N	43
	Perceived emotional support from friends	Correlation Coefficient	.008
		Sig. (2-tailed)	.950
		N	43
	Perceived informational support from friends	Correlation Coefficient	.026
		Sig. (2-tailed)	.840
		N	43
	Perceived tangible support from friends	Correlation Coefficient	-.022
		Sig. (2-tailed)	.864
		N	43
	Perceived reassurance support from friends	Correlation Coefficient	-.022
		Sig. (2-tailed)	.867
		N	43
	Perceived overall support from friends	Correlation Coefficient	.009
		Sig. (2-tailed)	.944
		N	43
	Perceived emotional support from HCPs	Correlation Coefficient	-.294*
		Sig. (2-tailed)	.024
		N	43
	Perceived informational support from HCPs	Correlation Coefficient	-.286*
		Sig. (2-tailed)	.028
		N	43
	Perceived reassurance support from HCPs	Correlation Coefficient	-.111
		Sig. (2-tailed)	.395
		N	43
	Perceived overall support from HCPs	Correlation Coefficient	.212
		Sig. (2-tailed)	.088
		N	43

*. Correlation is significant at the .05 level (2-tailed).

Hypotheses 5c. Within the over-59-years old group, the older patients are, the more likely they will be to experience psychological distress.

			Age in years
Kendall's tau_b		Sig. (2-tailed)	.
	Irritability	Correlation Coefficient	-.042
		Sig. (2-tailed)	.739
		N	43
	Worrying	Correlation Coefficient	.214
		Sig. (2-tailed)	.078
		N	43
	Depressed Mood	Correlation Coefficient	.206
		Sig. (2-tailed)	.094
		N	43
	Nervousness	Correlation Coefficient	-.030
		Sig. (2-tailed)	.814
		N	43
	Desperate feelings about the future	Correlation Coefficient	.151
		Sig. (2-tailed)	.219
		N	43
	Tension	Correlation Coefficient	.090
		Sig. (2-tailed)	.470
		N	43
	Anxiety	Correlation Coefficient	.169
		Sig. (2-tailed)	.164
		N	43
	Difficulty concentrating	Correlation Coefficient	.085
		Sig. (2-tailed)	.484
		N	43
	HADS: Anxiety	Correlation Coefficient	.026
		Sig. (2-tailed)	.823
		N	40
	HADS:Depression	Correlation Coefficient	.072
		Sig. (2-tailed)	.539
		N	40

Hypotheses 5d. Within the over-59-years old group, the older patients are, the more likely they will be to perceive loss.

			Age in years
Kendall's tau_b		Sig. (2-tailed)	.
	Physical Strength	Correlation Coefficient	.028
		Sig. (2-tailed)	.814
		N	43
	Independence	Correlation Coefficient	.134
		Sig. (2-tailed)	.260
		N	43
	Role	Correlation Coefficient	-.030
		Sig. (2-tailed)	.803
		N	43
	Physical Restriction	Correlation Coefficient	-.006
		Sig. (2-tailed)	.963
		N	43
	Social Deficit	Correlation Coefficient	-.032
		Sig. (2-tailed)	.791
		N	43
	Perceived Loss Total Score	Correlation Coefficient	-.067
		Sig. (2-tailed)	.566
		N	39

Hypothesis 5e. Within the over-59-years old group, the older patients are the more likely they will be to report a coping deficit.

			Age in years
Kendall's tau_b		Sig. (2-tailed)	.
	MAC :Anxious preoccupation	Correlation Coefficient	-.156
		Sig. (2-tailed)	.211
		N	35
	MAC :Fatalism	Correlation Coefficient	-.069
		Sig. (2-tailed)	.577
		N	35
	MAC: Helplessness/hopelessness	Correlation Coefficient	-.143
		Sig. (2-tailed)	.262
		N	35
	MAC: Fighting spirit	Correlation Coefficient	-.020
		Sig. (2-tailed)	.875
		N	35
	MAC: Avoidance	Correlation Coefficient	.071
		Sig. (2-tailed)	.603
		N	35

Hypothesis 5f. Within the over-59-years old group, the older patients are the more likely they will be to report that they suppress emotions.

			Age in years
Kendall's tau_b		Sig. (2-tailed)	.
	ANGRY	Correlation Coefficient	-.100
		Sig. (2-tailed)	.410
		N	36
	ANXIOUS	Correlation Coefficient	.085
		Sig. (2-tailed)	.456
		N	43
	UNHAPPY	Correlation Coefficient	.053
		Sig. (2-tailed)	.674
		N	36

Hypothesis 6a. Within the under-60-year old group the younger patients are, the more likely they will be to receive insufficient support from their social network.

			Age in years
Kendall's tau_b		Sig. (2-tailed)	.
	Received emotional support from family	Correlation Coefficient	.022
		Sig. (2-tailed)	.830
		N	55
	Received informational support from family	Correlation Coefficient	-.162
		Sig. (2-tailed)	.117
		N	55
	Received tangible support from family	Correlation Coefficient	-.039
		Sig. (2-tailed)	.724
		N	55
	Received reassurance support from family	Correlation Coefficient	-.012
		Sig. (2-tailed)	.908
		N	55
	Received overall support from family	Correlation Coefficient	-.103
		Sig. (2-tailed)	.284
		N	55
	Received emotional support from friends	Correlation Coefficient	.066
		Sig. (2-tailed)	.525
		N	55
	Received informational support from friends	Correlation Coefficient	-.055
		Sig. (2-tailed)	.605
		N	55
	Received tangible support from friends	Correlation Coefficient	-.148
		Sig. (2-tailed)	.158
		N	55
	Received reassurance support from friends	Correlation Coefficient	.148
		Sig. (2-tailed)	.160
		N	55
	Received overall support from friends	Correlation Coefficient	-.037
		Sig. (2-tailed)	.704
		N	55
	Received emotional support from HCPs	Correlation Coefficient	-.207*
		Sig. (2-tailed)	.041
		N	55
	Received informational support from HCPs	Correlation Coefficient	-.062
		Sig. (2-tailed)	.532
		N	55
	Received reassurance support from HCPs	Correlation Coefficient	-.127
		Sig. (2-tailed)	.217
		N	55
	Received overall support from HCPs	Correlation Coefficient	-.151
		Sig. (2-tailed)	.118
		N	55

*. Correlation is significant at the .05 level (2-tailed).

Hypothesis 6b. Within the under-60-year old group, the younger patients are the more likely they will be to perceive a support deficit from their social network

			Age in years
Kendall's tau_b		Sig. (2-tailed)	
	Perceived emotional support from family	Correlation Coefficient	-.160
		Sig. (2-tailed)	.162
		N	55
	Perceived informational support form family	Correlation Coefficient	-.162
		Sig. (2-tailed)	.153
		N	55
	Perceived tangible support from family	Correlation Coefficient	-.160
		Sig. (2-tailed)	.159
		N	55
	Perceived reassurance support from family	Correlation Coefficient	-.091
		Sig. (2-tailed)	.428
		N	55
	Perceived overall support from family	Correlation Coefficient	.188
		Sig. (2-tailed)	.089
		N	55
	Perceived emotional support from friends	Correlation Coefficient	.097
		Sig. (2-tailed)	.395
		N	55
	Perceived informational support from friends	Correlation Coefficient	.082
		Sig. (2-tailed)	.475
		N	55
	Perceived tangible support from friends	Correlation Coefficient	.082
		Sig. (2-tailed)	.475
		N	55
	Perceived reassurance support from friends	Correlation Coefficient	.025
		Sig. (2-tailed)	.826
		N	55
	Perceived overall support from friends	Correlation Coefficient	.025
		Sig. (2-tailed)	.820
		N	55
	Perceived emotional support from HCPs	Correlation Coefficient	.141
		Sig. (2-tailed)	.218
		N	55
	Perceived informational support from HCPs	Correlation Coefficient	.023
		Sig. (2-tailed)	.841
		N	55
	Perceived reassurance support from HCPs	Correlation Coefficient	.051
		Sig. (2-tailed)	.653
		N	55
	Perceived overall support from HCPs	Correlation Coefficient	-.087
		Sig. (2-tailed)	.421
		N	55

Hypotheses 6c. Within the under-60-years old group, the younger patients are the more likely they will be to experience psychological distress.

			Age in years
Kendall's tau_b		Sig. (2-tailed)	.
	Irritability	Correlation Coefficient	-.067
		Sig. (2-tailed)	.528
		N	55
	Worrying	Correlation Coefficient	-.006
		Sig. (2-tailed)	.957
		N	55
	Depressed Mood	Correlation Coefficient	-.036
		Sig. (2-tailed)	.733
		N	55
	Nervousness	Correlation Coefficient	-.022
		Sig. (2-tailed)	.840
		N	55
	Desperate feelings about the future	Correlation Coefficient	-.045
		Sig. (2-tailed)	.674
		N	55
	Tension	Correlation Coefficient	-.079
		Sig. (2-tailed)	.451
		N	55
	Anxiety	Correlation Coefficient	-.084
		Sig. (2-tailed)	.425
		N	55
	Difficulty concentrating	Correlation Coefficient	.033
		Sig. (2-tailed)	.751
		N	55
	HADS: Anxiety	Correlation Coefficient	.034
		Sig. (2-tailed)	.733
		N	52
	HADS:Depression	Correlation Coefficient	.119
		Sig. (2-tailed)	.238
		N	52

Hypotheses 6d. Within the under-60-years old group, the younger patients are the more likely they will be to perceive loss.

			Age in years
Kendall's tau_b		Sig. (2-tailed)	.
	Physical Strength	Correlation Coefficient	.017
		Sig. (2-tailed)	.868
		N	55
	Independence	Correlation Coefficient	.116
		Sig. (2-tailed)	.267
		N	55
	Role	Correlation Coefficient	.038
		Sig. (2-tailed)	.717
		N	55
	Physical Restriction	Correlation Coefficient	.014
		Sig. (2-tailed)	.899
		N	55
	Social Deficit	Correlation Coefficient	.017
		Sig. (2-tailed)	.876
		N	55
	Perceived Loss Total Score	Correlation Coefficient	.037
		Sig. (2-tailed)	.718
		N	51

Hypothesis 6e. Within the under-60-years old group, the younger patients are the more likely they will be to report a coping deficit

			Age in years
Kendall's tau_b		Sig. (2-tailed)	.
	MAC :Anxious preoccupation	Correlation Coefficient	-.021
		Sig. (2-tailed)	.844
		N	45
	MAC :Fatalism	Correlation Coefficient	.216*
		Sig. (2-tailed)	.045
		N	45
	MAC: Helplessness/hopelessness	Correlation Coefficient	.100
		Sig. (2-tailed)	.362
		N	45
	MAC: Fighting spirit	Correlation Coefficient	-.051
		Sig. (2-tailed)	.636
		N	45
	MAC: Avoidance	Correlation Coefficient	.001
		Sig. (2-tailed)	.991
		N	45

*. Correlation is significant at the .05 level (2-tailed).

Hypothesis 6f. Within the under-60-years old group, the younger patients are the more likely they will be to report that they do not suppress emotions

			Age in years
Kendall's tau_b		Sig. (2-tailed)	.
	ANGRY	Correlation Coefficient	.078
		Sig. (2-tailed)	.480
		N	43
	ANXIOUS	Correlation Coefficient	-.039
		Sig. (2-tailed)	.700
		N	55
	UNHAPPY	Correlation Coefficient	.037
		Sig. (2-tailed)	.747
		N	42

Hypothesis 7a. Gender will influence the provision of social support for patients with advanced cancer.

Z	Received emotional support from family	-.294
	Received informational support from family	-3.070
	Received tangible support from family	-.781
	Received reassurance support from family	-.117
	Received overall support from family	-1.349
	Received emotional support from friends	-1.715
	Received informational support from friends	-.138
	Received tangible support from friends	-.210
	Received reassurance support from friends	-.504
	Received overall support from friends	-.917
	Received emotional support from HCPs	-2.112
	Received informational support from HCPs	-1.495
	Received reassurance support from HCPs	-1.561
	Received overall support from HCPs	-2.007
Asymp. Sig. (2-tailed)	Received emotional support from family	.769
	Received informational support from family	.002
	Received tangible support from family	.435
	Received reassurance support from family	.907
	Received overall support from family	.177
	Received emotional support from friends	.086
	Received informational support from friends	.890
	Received tangible support from friends	.833
	Received reassurance support from friends	.614
	Received overall support from friends	.359
	Received emotional support from HCPs	.035
	Received informational support from HCPs	.135
	Received reassurance support from HCPs	.119
	Received overall support from HCPs	.045

Hypothesis 7b. Gender will influence the perception of social support for patients with advanced cancer.

Z	Perceived emotional support from family	-1.762
	Perceived informational support form family	-.449
	Perceived tangible support from family	-.545
	Perceived reassurance support from family	-1.060
	Perceived overall support from family	-1.929
	Perceived emotional support from friends	-.100
	Perceived informational support from friends	-1.210
	Perceived tangible support from friends	-.804
	Perceived reassurance support from friends	-.775
	Perceived overall support from friends	-.359
	Perceived emotional support from HCPs	-.337
	Perceived informational support from HCPs	-.722
	Perceived reassurance support from HCPs	-1.319
	Perceived overall support from HCPs	-.993
Asymp. Sig. (2-tailed)	Perceived emotional support from family	.078
	Perceived informational support form family	.653
	Perceived tangible support from family	.586
	Perceived reassurance support from family	.289
	Perceived overall support from family	.054
	Perceived emotional support from friends	.920
	Perceived informational support from friends	.226
	Perceived tangible support from friends	.422
	Perceived reassurance support from friends	.439
	Perceived overall support from friends	.719
	Perceived emotional support from HCPs	.736
	Perceived informational support from HCPs	.470
	Perceived reassurance support from HCPs	.187
	Perceived overall support from HCPs	.321

Hypotheses 7c. The gender of participants will influence their experience of psychological distress.

Z	Irritability	-2.582
	Worrying	-1.241
	Depressed Mood	-1.487
	Nervousness	-.610
	Desperate feelings about the future	-.931
	Tension	-.963
	Anxiety	-.878
	Difficulty concentrating	-.549
	HADS: Anxiety	-1.429
	HADS:Depression	-.575
Asymp. Sig. (2-tailed)	Irritability	.010
	Worrying	.214
	Depressed Mood	.137
	Nervousness	.542
	Desperate feelings about the future	.352
	Tension	.335
	Anxiety	.380
	Difficulty concentrating	.583
	HADS: Anxiety	.153
	HADS:Depression	.565

Hypotheses 7d. The gender of participants will influence their perception of loss

	Physical Strength	Independence	Role	Physical Restriction	Social Deficit	Perceived Loss Total Score
Z	-.341	-2.298	-1.427	-1.310	-1.788	-1.922
Asymp. Sig. (2-tailed)	.733	.022	.154	.190	.074	.055

Hypothesis 7e. The gender of participants will influence their coping attitudes

	MAC :Anxious preoccupation	MAC :Fatalism	MAC: Helplessness/hopelessness	MAC: Fighting spirit	MAC: Avoidance
Z	-1.512	-.707	-.306	-.850	-1.050
Asymp. Sig. (2-tailed)	.130	.479	.760	.395	.294

Hypothesis 7f. Participants' suppression of emotions will be influenced by gender.

	ANGRY	ANXIOUS	UNHAPPY
Z	-1.197	-.950	-1.443
Asymp. Sig. (2-tailed)	.231	.342	.149

Hypothesis 8a. Satisfaction with overall support given by their family is associated with the use of positive coping mechanisms in patients with advanced cancer.

			Satisfaction with overall support from family
Kendall's tau_b		Sig. (2-tailed)	.
	MAC :Anxious preoccupation	Correlation Coefficient	-.245**
		Sig. (2-tailed)	.008
		N	80
	MAC :Fatalism	Correlation Coefficient	-.033
		Sig. (2-tailed)	.721
		N	80
	MAC: Helplessness/hopelessness	Correlation Coefficient	-.282**
		Sig. (2-tailed)	.003
		N	80
	MAC: Fighting spirit	Correlation Coefficient	.196*
		Sig. (2-tailed)	.034
		N	80
	MAC: Avoidance	Correlation Coefficient	-.073
		Sig. (2-tailed)	.486
		N	80

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

Hypothesis 8b. Satisfaction with overall support given by their friend(s) is associated with the use of positive coping mechanisms in patients with advanced cancer.

			Satisfaction with overall support from friends
Kendall's tau_b		Sig. (2-tailed)	.
	MAC :Anxious preoccupation	Correlation Coefficient	-.064
		Sig. (2-tailed)	.493
		N	80
	MAC :Fatalism	Correlation Coefficient	.193*
		Sig. (2-tailed)	.038
		N	80
	MAC: Helplessness/hopelessness	Correlation Coefficient	-.048
		Sig. (2-tailed)	.617
		N	80
	MAC: Fighting spirit	Correlation Coefficient	.105
		Sig. (2-tailed)	.262
		N	80
	MAC: Avoidance	Correlation Coefficient	-.038
		Sig. (2-tailed)	.714
		N	80

*. Correlation is significant at the .05 level (2-tailed).

Hypothesis 8c. Satisfaction with overall support given by their health care professional(s) is associated with the use of positive coping mechanisms in patients with advanced cancer.

			Satisfaction with overall support from HCPs
Kendall's tau_b		Sig. (2-tailed)	.
	MAC :Anxious preoccupation	Correlation Coefficient	-.287**
		Sig. (2-tailed)	.001
		N	80
	MAC :Fatalism	Correlation Coefficient	-.092
		Sig. (2-tailed)	.304
		N	80
	MAC: Helplessness/hopelessness	Correlation Coefficient	-.265**
		Sig. (2-tailed)	.004
		N	80
	MAC: Fighting spirit	Correlation Coefficient	.106
		Sig. (2-tailed)	.239
		N	80
	MAC: Avoidance	Correlation Coefficient	.050
		Sig. (2-tailed)	.623
		N	80

**. Correlation is significant at the .01 level (2-tailed).

Hypothesis 9a. Satisfaction with overall support given by their family is negatively associated with (i) psychological distress and (ii) perceived loss in patients with advanced cancer.

			Satisfaction with overall support from family
Kendall's tau_b		Sig. (2-tailed)	.
	Irritability	Correlation Coefficient	-.270**
		Sig. (2-tailed)	.004
		N	98
	Worrying	Correlation Coefficient	-.143
		Sig. (2-tailed)	.115
		N	98
	Depressed Mood	Correlation Coefficient	-.217*
		Sig. (2-tailed)	.017
		N	98
	Nervousness	Correlation Coefficient	-.098
		Sig. (2-tailed)	.293
		N	98
	Desperate feelings about the future	Correlation Coefficient	-.041
		Sig. (2-tailed)	.659
		N	98
	Tension	Correlation Coefficient	-.199*
		Sig. (2-tailed)	.030
		N	98
	Anxiety	Correlation Coefficient	-.225*
		Sig. (2-tailed)	.013
		N	98
	Difficulty concentrating	Correlation Coefficient	-.164
		Sig. (2-tailed)	.071
		N	98
	HADS: Anxiety	Correlation Coefficient	-.300**
		Sig. (2-tailed)	.001
		N	92
	HADS:Depression	Correlation Coefficient	-.192*
		Sig. (2-tailed)	.028
		N	92
	Physical Strength	Correlation Coefficient	-.152
		Sig. (2-tailed)	.091
		N	98
	Independence	Correlation Coefficient	-.090
		Sig. (2-tailed)	.316
		N	98
	Role	Correlation Coefficient	-.117
		Sig. (2-tailed)	.193
		N	98
	Physical Restriction	Correlation Coefficient	-.133
		Sig. (2-tailed)	.151
		N	98
	Social Deficit	Correlation Coefficient	-.043
		Sig. (2-tailed)	.635
		N	98
	Perceived Loss Total Score	Correlation Coefficient	-.185*
		Sig. (2-tailed)	.035
		N	90

Hypothesis 9b. Satisfaction with overall support given by their friend(s) is negatively associated with (i) psychological distress and (ii) perceived loss in patients with advanced cancer.

			Satisfaction with overall support from friends
Kendall's tau_b		Sig. (2-tailed)	.
	Irritability	Correlation Coefficient	-.106
		Sig. (2-tailed)	.257
		N	98
	Worrying	Correlation Coefficient	-.082
		Sig. (2-tailed)	.370
		N	98
	Depressed Mood	Correlation Coefficient	-.157
		Sig. (2-tailed)	.088
		N	98
	Nervousness	Correlation Coefficient	.014
		Sig. (2-tailed)	.880
		N	98
	Desperate feelings about the future	Correlation Coefficient	-.109
		Sig. (2-tailed)	.242
		N	98
	Tension	Correlation Coefficient	-.096
		Sig. (2-tailed)	.298
		N	98
	Anxiety	Correlation Coefficient	-.110
		Sig. (2-tailed)	.231
		N	98
	Difficulty concentrating	Correlation Coefficient	-.031
		Sig. (2-tailed)	.736
		N	98
	HADS: Anxiety	Correlation Coefficient	-.082
		Sig. (2-tailed)	.347
		N	92
	HADS:Depression	Correlation Coefficient	-.122
		Sig. (2-tailed)	.164
		N	92
	Physical Strength	Correlation Coefficient	-.035
		Sig. (2-tailed)	.695
		N	98
	Independence	Correlation Coefficient	.055
		Sig. (2-tailed)	.546
		N	98
	Role	Correlation Coefficient	.016
		Sig. (2-tailed)	.861
		N	98
	Physical Restriction	Correlation Coefficient	-.028
		Sig. (2-tailed)	.767
		N	98
	Social Deficit	Correlation Coefficient	-.058
		Sig. (2-tailed)	.530
		N	98
	Perceived Loss Total Score	Correlation Coefficient	-.090
		Sig. (2-tailed)	.308

Hypothesis 9c. Satisfaction with overall support given by their health care professional(s) (HCPs) is negatively associated with (i) psychological distress and (ii) perceived loss in patients with advanced cancer

			Satisfaction with overall support from HCPs
Kendall's tau_b		Sig. (2-tailed)	.
	Irritability	Correlation Coefficient	-.087
		Sig. (2-tailed)	.335
		N	98
	Worrying	Correlation Coefficient	-.166
		Sig. (2-tailed)	.060
		N	98
	Depressed Mood	Correlation Coefficient	-.088
		Sig. (2-tailed)	.325
		N	98
	Desperate feelings about the future	Correlation Coefficient	-.066
		Sig. (2-tailed)	.465
		N	98
	Tension	Correlation Coefficient	-.133
		Sig. (2-tailed)	.140
		N	98
	Anxiety	Correlation Coefficient	-.152
		Sig. (2-tailed)	.087
		N	98
	Difficulty concentrating	Correlation Coefficient	.013
		Sig. (2-tailed)	.888
		N	98
	HADS: Anxiety	Correlation Coefficient	-.201*
		Sig. (2-tailed)	.017
		N	92
	HADS:Depression	Correlation Coefficient	-.060
		Sig. (2-tailed)	.481
		N	92
	Physical Strength	Correlation Coefficient	.031
		Sig. (2-tailed)	.727
		N	98
	Independence	Correlation Coefficient	-.026
		Sig. (2-tailed)	.768
		N	98
	Role	Correlation Coefficient	-.009
		Sig. (2-tailed)	.915
		N	98
	Physical Restriction	Correlation Coefficient	-.044
		Sig. (2-tailed)	.630
		N	98
	Social Deficit	Correlation Coefficient	.043
		Sig. (2-tailed)	.633
		N	98
	Perceived Loss Total Score	Correlation Coefficient	-.045
		Sig. (2-tailed)	.598
		N	90

APPENDIX iv

Means and standard deviations for the MAC, HAD, CECS and RSCL Scales

Means and standard deviations for:

(1) The MAC Scale

	:Anxious preoccupation	:Fatalism	Helplessness/hopelessness	Fighting spirit	Avoidance
Mean	21.85	21.54	9.64	52.05	1.94
Std. Deviation	5.43	4.90	4.08	5.84	1.26

(2) The HAD Scale

	Anxiety	:Depression
Mean	5.55	4.60
Std. Deviation	4.51	3.98

(3) The CECS

	ANGRY	ANXIOUS	UNHAPPY
Mean	16.33	12.48	13.88
Std. Deviation	5.04	7.12	4.29

(4) the RSCL

	Irritability	Worrying	Depressed Mood	Nervousness	Desperate feelings about the future	Tension	Anxiety	Difficulty concentrating
								98
								0
Mean	1.49	1.81	1.62	1.39	1.53	1.61	1.68	1.65
Std. Deviation	.98	1.27	1.14	.99	1.15	1.09	1.15	1.14