

Case Studies in Therapeutic SenseCam use aimed at Identity Maintenance in Early Stage Dementia.

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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of PhD is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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Abstract

Case Studies in Therapeutic SenseCam use aimed at Identity Maintenance in Early Stage Dementia

Paulina Piasek

In the absence of a medical cure for memory loss new technologies specialised in pervasive imaging are being incorporated into interventions for dementia. The practice of lifelogging is a digital capture of life experiences typically through mobile devices such as SenseCam. The lightweight wearable digital camera passively captures about 3,000 images a day. Lifelogging results in personal, recent prompts, potentially encouraging sharing of personal memories. This research investigated the incorporation of lifelogging technology into a therapeutic approach aimed to support people with dementia by using the Case Study method, an exploratory and descriptive approach. The case study is a method of empirical inquiry that enables investigation of phenomenon within its real life context. SenseCam therapy aimed to stimulate the cognition of a person with dementia, with support of their personal identity as its primary goal. SenseCam images were used as cues to meaningful discussions about the person's recent memories. The images enabled a construction of a particular version of the participants' identities mainly based in their recent past. On the contrary participants seemed to valorise their identity of their distant past. The SenseCam identity also contained uncensored details from participants' lives as revealed by review of SenseCam images. The exposing nature of SenseCam images posed risks to the users' privacy and showed the potential ethical risks of using lifelogging technology with people with dementia.

There is limited literature on the practical recommendations on how to use lifelogging devices and how they affect people with dementia. The results from this research indicate that a number of factors should be considered when using lifelogging technology with people with dementia. Firstly the contextual factors of people with dementia including the level of cognitive impairment, existing coping mechanisms and the interaction patterns with the carer need to be considered. Secondly the technology should be used within a therapeutic framework and tailored to suit the individual needs of both people with dementia and their carers. Lastly intimate and unexpected details from the participant's life should be discussed in an ethical and sensitive manner. Implications of not working within these boundaries show clear potential for risk of undermining the human rights and potentially the wellbeing of people with dementia.

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Chapter 1

Introduction

This research concerns the incorporation of a new lifelogging technology into a therapeutic approach aimed at supporting people in early stages of dementia in maintaining an awareness of their sense of identity in the present. The thesis explores and describes the processes associated with the design and use of ‘SenseCam Therapy’ with people with dementia and their carers. The therapy adopts person centred ethos and social constructivist approach to research involving people with dementia. Hence, the interests of the thesis are the subjective experiences of participants constructed through multifaceted social interactions throughout the research process as opposed to objective quantifiable results. This chapter situates the research within the dementia context, presents the personal and empirical motivation for conducting this research, sets out the aims and objectives of the investigation and describes the overall significance of this enquiry. Finally, it concludes with defining some of the key terms and outlines the thesis organization to guide the reader.

Diminishing identity is one of the most debilitating effects of dementia for the person and their family, occurring simultaneously to the disease progression (Post 2000, Mills 1997). A weakening sense of identity derives from the effects of dementia on both inner (memory and continuity) and outer (social interaction and communication) processes. The cognitive impairments in memory, language and decision making often cause confusion and can also lead to the person experiencing negative social interactions or even social withdrawal, in combination affecting the person’s sense of identity. As identity diminishes it complicates relationships and generally reduces the

person's quality of life perhaps leading to acceleration of the disease progression. However, recent research suggests that a sense of identity can be maintained long into the illness by engaging the person with dementia in various psychosocial interventions. Such interventions follow person centred ethos. They aim to stimulate the cognitive and social resources weakened by the disease in order to maintain the person's current level of functioning, and in turn help to slow down the diminishing identity (Kitwood 1997, Clare 2008). Providing access to these psychosocial interventions in the early stages of dementia can help the person to maintain their identity for a longer period in the disease trajectory. Hence, these interventions are most effective to supporting a person's sense of identity if accessed in the early stages of dementia (Moniz-Cook 2011). In order to have access to psychosocial interventions in the early stages of dementia it is necessary to have an early diagnosis. Without a diagnosis it can be challenging to seek interventions as it may be unclear what they are to intervene for. Once dementia is diagnosed one can engage in appropriate, dementia specific psychosocial and medical support. Therefore, receiving early diagnosis increases the chances of engaging in psychosocial interventions, which support the identity of people with dementia.

Early diagnosis and early intervention in dementia care is also an expressed aim of every current public policy on the disease. In the context of the current trend of an ageing population, there will be a continuous increase of dementia incidence, making it one of the biggest, global public health challenges facing our generation (Wimo and Prince 2010). Today, there is an estimated 41,740 people living with dementia in Ireland (Cahill, O'Shea and Pierce 2012) and 35.6 million people living with dementia worldwide (Wimo and Prince 2010). It is estimated that by the year 2026 the number of people with dementia in Ireland will increase to 52,000. Worldwide this number is set to increase to 65.7 million by 2030 and 115.4 million by 2050 (Wimo and Prince 2010). Dementia can be seen as a costly condition as it draws on a variety of public and private, formal and informal resources necessary to provide appropriate care (O'Shea and O'Reilly 2000). It is estimated the overall cost of dementia in Ireland is just over €1.69 billion per annum (Cahill, O'Shea and Pierce 2012). The total estimated worldwide costs of dementia for the year 2010 were US\$604 billion (Wimo and Prince 2010). The cost of care increases with the progression of the disease, as a person in the late stages usually requires admission into long-term care (Jönsson et al. 2006). As mentioned above timely diagnosis can

provide access to a pathway of evidence-based interventions aiming to maintain the person in the early stages of the disease and delaying long term care admission, which in turn can reduce this healthcare expenditure (Cahill, O'Shea and Pierce 2012). Thus, there is also a strong economic argument in favour of early diagnosis (Wimo and Prince 2010).

Like many other aspects of health systems, psychosocial interventions are influenced by current developments in technology. The practice of lifelogging, which is digital capture of life experiences typically through wearable sensors or devices, is one way the technology is incorporated into memory interventions for dementia. Lifelogging results in personal, recent and meaningful prompts, encouraging sharing of personal memories (Doherty and Smeaton 2008). Lifelogging devices are usually wearable and the data capture happens automatically. The device of particular interest to this research is SenseCam (Figure 1.1). This is a small camera worn around the neck by the use of a lanyard at chest level. It automatically captures images every 30 seconds, resulting in thousands of recorded images per day, each taken from a first person viewpoint, i.e. the images rarely include the wearer (Figure 1.2). SenseCam has been previously investigated by way of a clinical trial with a patient with severe memory impairment as a result of encephalitis (Berry et al. 2007). Following this, SenseCam received much attention from scientific researchers with numerous studies reporting promising results of SenseCam as prosthesis to memory impairments (Bengtsson and Kikhia 2010, Doherty et al. 2012).



Figure 1.1 SenseCam.

Although, there is no shortage of studies presenting the benefits of SenseCam use to support memory, the majority lack practical and in depth detail on how to use the device with people with dementia. The studies present very experimental and quantitative results in terms of improved memory recall, while they are less clear on

how such improvements affect the person with dementia. I choose research methods that address this gap and allow exploration of how the process of using SenseCam affects people with dementia in aspects broader than memory alone, including the person's identity and quality of life. This is an empirical study, which utilises case studies with the aim of grounding the SenseCam use in the context of the lives of people with dementia and their carers. The focus will be on the processes of therapeutic rather than experimental SenseCam use and the associated effects on the person's identity as well as other aspects like quality of life and depression. Furthermore, the previously unexploited practical details and ethical issues around lifelogging will also be explored, resulting in recommendations on SenseCam use with people with dementia. The thesis as a whole provides a novel understanding of therapeutic SenseCam use aimed at supporting the identity of people with dementia.



Figure 1.2 Sample SenseCam images.

1.1 Motivation

The motivation for this research came from empirical studies on technology, psychosocial interventions and identity in dementia as introduced above. Firstly the stimulation came from the connection between the early psychosocial interventions and how they can support the sense of identity of people with dementia. Secondly it arose from the advancements in information technologies and their use and embracement by dementia interventions. Finally, the motivation was also personal to the researcher as outlined below, subsequent to the empirically bound motivations.

There is increasing evidence of positive effects of psychosocial interventions for people with dementia. In particular the results of a Randomised Control Trial (RCT) of Cognitive Stimulation Therapy (CST) were comparable with currently licensed dementia medication (Salmon 2006). Following this in the UK, the National Institute for Clinical Health and Excellence (2006) recommend all people with mild to moderate dementia be offered CST. CST aims to optimise cognitive function using a range of mental activities. They include sensory stimulation, recognising people and

objects, word and number games, physical games and singing and orientation (Spector, Orrell and Woods 2010). These activities rely heavily on reminiscence which is another psychosocial intervention aiming to stimulate memories and communication through social interactions. The Cochrane review on reminiscence therapy for dementia indicated improvements in cognition, mood and general behavioural function. The results were very promising but the evidence was inconclusive suggesting more high quality RCTs are needed (Woods et al. 2005). Reminiscence therapy involves the sharing of memories often induced by cues like old photographs or postcards, songs or newspapers (Holden and Woods 1995) or even videos from YouTube (Bermingham et al. 2013). This sharing of memories of the past can reinforce the person's identity in the present (Oyebode and Clare 2008). The discourse on whether the identity of individuals with dementia can be maintained through psychosocial approaches is well established in dementia literature (Sabat and Collins 1999). With increasing body of research suggesting optimistic results (Caddell and Clare 2011b) and reporting that the relatives of people with dementia in long term care consider the failure to support the resident's identity as abuse (Harnett and Jönson 2010). The above empirical findings influenced the research to explore an early psychosocial intervention aimed at supporting the identity of people with dementia.

Furthermore, given recent advances it would be unjust to exclude investigation into how such the advances in technology changed the possibilities of dementia interventions (Mulvenna et al. 2010). Nowadays we are surrounded by technology in our daily lives from mobile phones, televisions, laptops, and tablet computers to more complex advancements becoming ubiquitous in our lives. Global Positioning System (GPS) are built into many devices and automatic face recognition tagging is ubiquitous in our Facebook photo albums. These new technologies can also be used to support more far-reaching aspects of our everyday life such that could support psychosocial stimulation (Mulvenna et al. 2010). As introduced earlier SenseCam is the device of particular interest in relation to psychosocial interventions. SenseCam is commonly used for lifelogging as it captures a large amount of images, which in turn can be used as cues to life experiences. Thus, SenseCam captures life experiences autonomously and digitally producing large sets of images that can potentially be used as cues to discussions about one's identity in a similar way to reminiscence. The prompts used in reminiscence are usually generic, however they may also include a

number of selected personal photographs. These photographs are usually limited in number and from the distant past. The memories from the distant past are usually impaired much later in the disease progression; thus using reminiscence taps into the strengths of people with dementia. The narratives cued through reminiscence may represent a person's life story, which highlights distant stages of the person's life. On the other hand the memories for recent events are usually impaired in the early stages of dementia, which can often be simultaneous with the beginning of a diminishing identity. Hence, cueing discussions about recent as oppose to distant events may support people with dementia to have an awareness of their identity in the present. Previous research suggests SenseCam images can provide recent, personal and meaningful prompts which may cue the sharing of more recent memories from the recent life stages (Loveday and Conway 2011).

The potential of SenseCam technology in supporting identity motivated the underlying concern of the thesis: Can reviewing SenseCam images within a therapeutic approach support people to share stories of their recent events and to express their identities in the present? It seemed worth exploring if reviewing SenseCam images can provide the essential cues to recent memories to enable re-living of the events of yesterday by people with failing memory. Furthermore, it was of interest to the present research if reviewing these images and re-living the events of yesterday are enough to evoke meaningful narratives about one's life and identity in the present moment. It was stimulating to explore if sharing of these narratives of recent past within social interactions can reinforce the person's identity in the present. Given literature and the theoretical foundations of identity seem to suggest a positive answer to these questions, there is a need to explore this new SenseCam technology from a perspective which is broader than testing memory recall in people with dementia. Embraced into a therapeutic intervention, SenseCam images may have the potential to stimulate the inner and outer processes necessary to help support one's sense of identity. This thesis aims to explore SenseCam use within a therapeutic intervention aimed at supporting the identity of people in early stage dementia.

In addition to these empirically bound motivations the researcher's prior experience, assumptions and pre-conceptions formed a personal motivation to undertake this research endeavour. Moreover, from this point my presence will be highlighted by the use of "I" throughout this thesis, situating me within the research.

I grew up in Poland, where in my experience older people were seen as very knowledgeable with strong roles within families and communities. Most elderly Poles survived at least one of the world wars and with they coped with things most people would nowadays find unimaginable. The general attitude was that they are people we admire and respect. My grandparents were no exception and living next door to them for fourteen years meant they played a key part in my upbringing and I developed a strong bond with them.

Since immigrating to Ireland I have missed the closeness and the everyday contact I used to share with them. Here I completed a B.Sc. in Psychology Applied to Information Technology. During my degree I completed many projects on the design and usefulness of technology based on the principles of psychology of human beings, including the design of assistive technology for people with dementia. In parallel to my degree I also worked in industry setting where I tested the usability of devices before they were released to the general public. I developed a growing interest in human-computer interaction, especially in how technology can benefit or can burden people.

As I continued my professional development in Ireland my grandparents aged and with that my grandmother developed memory problems. At the time when I came across an advertised post for a researcher to explore SenseCam use as an intervention for early stage dementia my family began suspecting my grandmother had dementia and began the process of seeking a diagnosis. Here, was an opportunity to somehow link my longing to support my grandmother or other people in her situation with an increasing interest in human computer interaction.

Having read everything that was available on using SenseCam to improve memory I was struck by how promising the results were. However I realized that at that time, most of the research was actually funded by companies promoting SenseCam – a common practice in industry settings - though this may have changed with the work in this area being done now. The work I have carried out in this Ph.D. thesis has not in any way been funded by industry thus guaranteeing that I was able to objectively and impartially explore the phenomenon of using the device within the context of participants of this study.

1.2 Problem Definition

Identity loss is one of the most feared symptoms associated with developing dementia (Post 2000). The condition undermines autobiographical memory and disrupts narratives, which are predominant to identity formation (Bruce and Schweitzer 2008). The practical ramifications of weakening identity include: reduced interaction, complications with familial relationships, social isolation, reduced quality of life and spoiled personhood. Nevertheless, previous research suggests a person's identity can be reinforced and maintained long into the illness through numerous psychosocial approaches (Kitwood 1997, Caddell and Clare 2010). These include approaches using a variety of cues like photographs, objects, or music for reminiscence and cognitive stimulation, as memories of the past contribute to identity in the present (Oyebode and Clare 2008). Combining this with emerging pervasive health technologies like the practice of lifelogging, there is an opportunity for innovative interventions aimed at identity support in dementia. Existing research on SenseCam has already shown that large-scale image sets can aid memory recall of people with dementia. There is a need to explore SenseCam technology from the viewpoint of supporting people with dementia to maintain an awareness of their sense of identity in the present. Therefore the problem addressed in this thesis is to explore SenseCam use as a therapeutic intervention aiming to support the sense of identity in early stage dementia.

1.3 Aims and Objectives

The main aim of the work reported in this thesis is to design, deliver and explore an innovative intervention that supports the identity of the person with early stage dementia. The objective includes providing an in-depth qualitative depiction of the processes so that success or failure of the intervention can be explored. A further objective is to present any effects of the intervention by illustrating the subjective experiences of people with dementia and carers throughout the research process. With these aims and objectives in mind, four specific research questions can be defined.

1. Will SenseCam therapy encourage discussions about recent memories as cued by SenseCam images within social interactions?
 - a. Will the images derived from SenseCam cue person's recent past and be meaningful and enjoyable for the person with dementia?

- b. Will viewing the images derived from SenseCam encourage rich opinion-based discussions?
 - c. Will viewing the images within the therapeutic setting support the social interaction between person with dementia and their carer and/or therapist?
- 2. Will SenseCam use be worthwhile in supporting people in early stage dementia in having a sense of identity?
- 3. Why and how should we use SenseCam as a therapeutic intervention for early stage dementia?
- 4. Will SenseCam therapy provide any other benefits to the people with early stage dementia?

The main goal of the intervention is to support people with dementia to continue to have an awareness of their identity in the present by providing cues to recent memories and encouraging social interaction. Thus, firstly I propose to explore how effective are the SenseCam images at cueing the persons' recent memories, encouraging discussions and supporting social interactions. The answer to this question will shape the overarching understanding of the usefulness of SenseCam to supporting identity in early stage dementia. I then propose to explore how to use SenseCam as a therapeutic intervention for early stage dementia. The final question attempts to evaluate the therapy by exploring whether there are any other benefits to the people with early stage dementia.

1.4 Research Significance

The central endeavour of this research is to add to the knowledge of meaningful interventions in early stage dementia care. In the recent research review for Ireland's national dementia strategy, one of the main goals was to increase early diagnosis of dementia and to develop new and expanded psychosocial approaches to complement existing medical and neurological models of service delivery (Cahill, O'Shea and Pierce 2012). The goal of increasing evidence base for psychosocial approaches is shared across most dementia strategies (Cahill, O'Shea and Pierce 2012, National Institute for Clinical Health and Excellence 2006). In the absence of such interventions, the diagnosis can be tragic to the individual (Berr, Wancata and Ritchie 2005).

This research also provides new insights on translating lifelogging technologies into clinical dementia applications. It explores SenseCam use with people with dementia from a new perspective of supporting the participant's sense of identity. Previous research concentrated on testing memory recall after SenseCam use. The results were promising indicating that SenseCam images can act as effective cue to episodic memory, as well as improving recall of an event reviewed using the SenseCam images (Loveday and Conway 2011, Berry et al. 2007). Earlier research also suggested that SenseCam images mimic episodic memory in being: personal and meaningful to the individual; of recent past; captured from the first person's point of view; and captured automatically without requiring mindful awareness (Doherty et al. 2012). However, there is limited literature from research on using SenseCam directly to support the identity of people with dementia. Thus, this thesis contributes to the existing literature by exploring SenseCam technology from a perspective broader than testing memory recall in people with dementia.

This research also provides a new understanding of SenseCam use in the context of people with dementia. Previous works in this area have mainly reported the promising results of SenseCam use with people with dementia from a quantitative perspective but until now there has been lack of in-depth descriptive reports from a qualitative perspective. Informed by detailed observations, interviews and participant diary keeping throughout the delivery of SenseCam therapy, new issues in need of consideration were highlighted. A novel way of using SenseCam has been proposed with some detailed recommendations, focusing on the individual, their identity and their life context.

1.5 Terms

Throughout the thesis, I refer to some key concepts that are open to varied interpretations. On this basis, it is worth explicitly clarifying the understandings of these terms for the purpose of this thesis. I begin by clarifying the meaning of the word 'case', which in this thesis is explicitly understood in a methodological sense as implied by Stake (1995) or Yin (2003). Hence, I certainly do not imply that the participants of this study are unusual, eccentric or odd personality 'cases'. The word case is explained methodologically as an inquiry into phenomena by exploring it in the context of individuals or organisations.

The term dementia can also be understood from various perspectives. For the purpose of this thesis I draw upon two principal understandings. Firstly, dementia is often defined from a biomedical perspective as an umbrella term for a range of complex diseases all of which have different aetiologies but share similar symptoms of multiple cognitive deficits, including impairment in memory, thinking, attention, and orientation. Dementia has also been defined from a more psychosocial approach signifying the perspective of the person with dementia and their social functioning (Kitwood 1997). Kitwood (1997) argued that the neuropathology of the brain alone is insufficient to explain the mental and emotional symptoms associated with dementia. Taken together the medical and psychosocial definitions of dementia present a more holistic understanding of the condition. I provide a more detailed rationale for adopting this combined understanding following detailed review of both perspectives in Chapter Two.

It is clear from the combined understanding of dementia that memory impairment is an unavoidable symptom of the global cognitive deterioration associated with dementia (American Psychiatric Association 2013). While many uncertainties related to memory impairment and dementia persist that are beyond the scope of this thesis, there are questions related to memory impairments in need of clarification for the purpose of this research. Firstly, given that memory impairments in early dementia seem to be connected to diminishing identity, it is of particular interest to clarify if any memory types in particular are of more value to the sense of identity and if there is a pattern of their impairment as a result of dementia. Secondly, given that SenseCam images will be used as cues to discussions about memories, it is a concern of this thesis to understand the processes associated with cueing and recalling of memories. I will seek to provide a brief clarification to the above memory concerns and to consider the implications in terms of impact on the identity of those in the early stages of dementia.

In order to better the understanding of memory and its connection to identity the overall concept of memory needs some clarification. Human memory can be seen as various systems and processes, where the systems refer to the way in which the memory is organized whereas the processes are the activities taking place within the memory systems (Eysenck 2000). There are many hypothetical constructs on the way which memory is structured or stored. One of the early models of memory system is the multi-store model (Atkinson and Shiffrin 1968). According to this model the basic

structure consists of: sensory store, short-term store and long-term store. Sensory memory results from our perceptions. It automatically and briefly holds visual perceptions in iconic sub-system or auditory perceptions in echoic sub-system (Atkinson and Shiffrin 1968). Short-term store is of very limited capacity, which holds information for short periods of time. Working memory is an advance over the short-term memory concept as it is concerned with both active processing and the brief storage of information. It is responsible for activities like mental arithmetic, verbal reasoning as well as traditional short-term memory tasks (Baddeley 1988). Long-term store is essentially of unlimited capacity and can hold information for extremely long periods of time. The theory argues that all information is received by sensory stores, of which some is processed further to short-term store and through rehearsal and importance of information some is transferred to the long-term store (Atkinson and Shiffrin 1968). Although it has been widely accepted that it is valuable to distinguish between long-term memory and short-term memory, more research suggests further fractionation of the long-term store (Baddeley 1988).

The initial multi-store model of memory proposed that long-term memory is a single store (Atkinson and Shiffrin 1968). However, Tulving (1983) suggests that it is improbable that all the knowledge is stored in a single long-term memory store. Tulving (1983) further suggested two separate memory types: episodic and semantic. The semantic memory serves a different function and operates in a different way from episodic memory. Episodic memory has an autobiographical or personal nature, where specific episodes or events are stored usually including information about that event. In contrast semantic memory contains organised knowledge about the world and about language (Tulving 1983). Episodic and semantic memories depend heavily on each other, where the episodes remembered form the basis for the semantic knowledge of concepts or symbols. Semantic memory is formed from episodic memory, as over time the emotional sensitivity to certain events or episodes is reduced and information can be stored as semantic knowledge.

Several theorists have proposed it is the episodic memory also known as autobiographical memory that is essential to the sense of identity (Conway and Pleydell-Pearce 2000, Rubin 1996, Addis and Tippett 2004). Therefore, it is significant to this thesis to clarify the concept of episodic memory and how it is affected in dementia. Episodic memory is memory for personally experienced events (Mayes and Roberts 2002). The person remembering consciously re-experiences these

events as an observer or an actor. The person who remembers is not only aware that he/she experienced the events but also has a conscious feeling the events are being remembered. The experience of remembering may just involve the feeling of personally having experienced the event even without any further memory of it. The episodic memories are not stored as fixed representations, but are reconstructed each time as guided by the person and the present moment perception and their awareness (Naylor 2006). Given the personal characteristics of episodic memory as presented above it can be assumed that its impairment could impact on sense of identity but also that changes in identity over time could also influence the particular version of memories constructed.

Given this brief overview of memory suggests episodic or autobiographical memories are of most value to identity, it is of further interest to identify any patterns in the impairments of episodic memories in early stage dementia. Autobiographical memory appears to develop in early childhood, with representations of events experienced more than one time progressing into the long-term store (Rubin 1996). Episodic memory is usually modelled by reflecting upon the different life phases. These models are important to understanding how episodic memories are affected in early dementia. Most models divide the personal memories formed and stored throughout one's lifespan into several distinct phases marked by specific age brackets including childhood (6-16), early adulthood (17-39), late adulthood (40-55) and a recent phase (last 5 years) (Kopelman, Wilson and Baddeley 1989, Ivanoiu et al. 2006). However, such divisions seem to leave a significant period between the late adulthood and a recent phase for anyone who lives past seventy or eighty years of age. Similarly the late adulthood phase can overlap with the recent phase in the case of someone still in his or her fifth decade. Thus, for the purpose of this thesis I broadly divide the memories of the past as recent and distant memories. The recent memories cover memories of immediate past events including the past few days or weeks as well as a broader recent period of a few years as indicated by participants of this study. The events captured by SenseCam throughout the study can be seen as cues to the memories of the recent past of the participants of this research. The distant memories cover all of the possible distant past phases including early and late adulthood as well as childhood. I further differentiate among them as distant memories, more distant memories and long distant past memories.

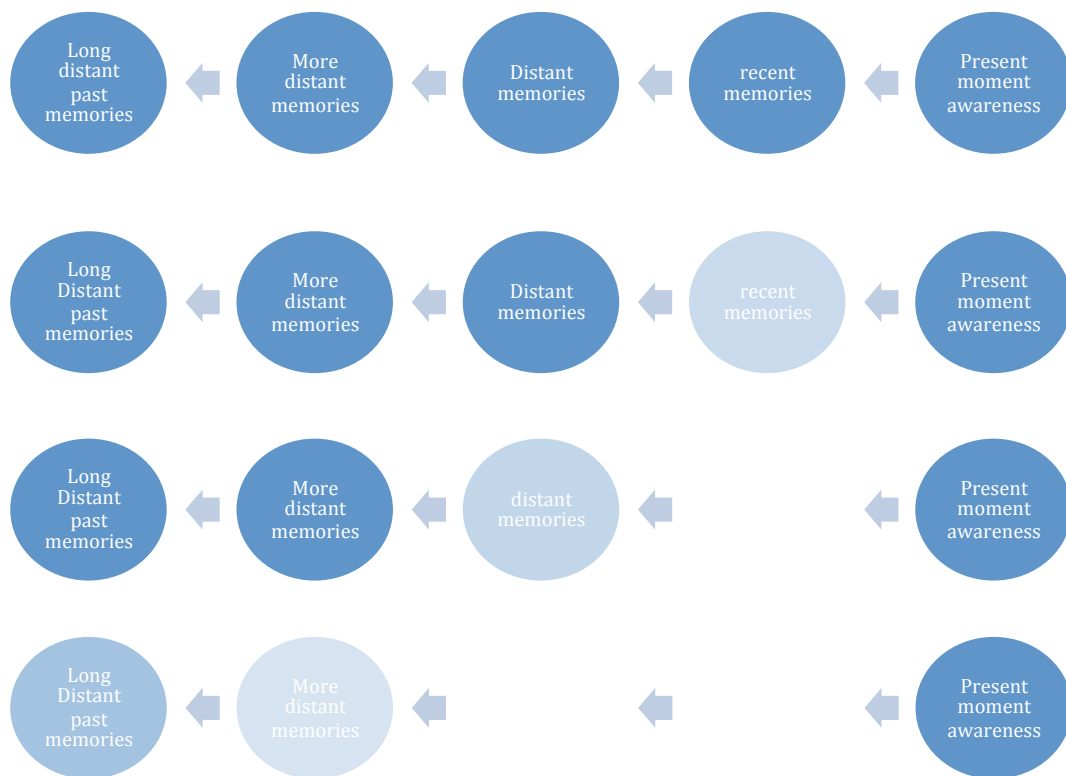


Figure 1.3 Pattern of memory impairment in dementia.

Several empirical studies report that the typical presentation of memory impairments in early stage dementia involves a disproportionate impairment of recent relative to distant memories (Ivanou et al. 2006, Graham and Hodges 1997). These findings exclude people with semantic dementia, a subcategory of Frontotemporal dementia where usually the opposite can be observed (Snowden, Griffiths and Neary 1996). The studies further suggest that as dementia progresses the memories continue to impair gradually in the order of “last in - first out”. In the initial stages usually only the recent memories are impaired but as the dementia progresses, distant and long distant past memories are also impaired (Figure 1.3). Given that the memories of most value to one’s sense of identity are impaired in a gradual process it can be assumed that a sense of identity may also be diminishing in a similar fragmentary progression. I provide a more detailed discussion of identity and its relation to memory in Chapter Three.

The second concern related to memory and in need of clarification for the purpose of this research is to understand the processes associated with cueing the recalling of memories. The memory systems involve three major processes: encoding, storage and retrieval. Given previous research suggests SenseCam images mimic episodic memories and that SenseCam images will be used as cues to discussions

about these memories, the theories on memory processes are discussed below with a particular focus on episodic memory (Berry et al. 2007).

Encoding is a process where perception of physical input through the senses such as a sound or a word is transformed into a representation, which can be stored in memory. Storage is the retaining of encoded information into one of the memory stores and the maintenance of that information. The more the information is repeated the likelihood of transferring in into a long-term store increases. After the process of consolidation memories are stored as groups of neurons in the long-term stores (Gazzaniga and Bizzi 1995). The encoding of episodes usually involves representations of events, which occurred over a short period of time. The representations are always from the observer's or the experiencing perspective. These representations combine perceptual and semantic information of objects and environments and how these are located in space, in time and relate to the observer. The encoding of episodes also much depends on the experiencer. Depending on the amount of attention deployed to an aspect of episode determines whether or not it is represented in consciousness (Tulving 1983). Memory retrieval or recall is the accessing of information from a memory store and the moving them into consciousness for use in active cognitive processing. The recall is a reconstruction of elements of events. As memories are stored as grouped neurons, recall requires activating in the same nerve pattern that created the original experience. These neurons allow re-living a memory, and the speed of accessing them depends on their strength. Episodic memory must involve re-experiencing or reliving the original episode. One usually associates certain feelings and emotions related to reliving an episode, however remains uncertain how much this derives from being able to retrieve the information and how much it derives from personal semantic knowledge (Mayes and Roberts 2002). The retrieval of episodes typically involves a directed search for a target memory. The process may take several stages in which the person retrieves cues which then reactivate further memories until eventually it is judged that the memory corresponds to the correct episode. Usually the recall of an experienced episode is associated with the feeling of *déjà-vu* (Mayes and Roberts 2002). The three main types of recall include free, cued and serial recall. Free recall is when a list of information is remembered without particular order, which usually results in primacy, recency or contiguity effect. The primacy effect is when the items from the start of the list are remembered; the recency effect is displayed through memory of just the last

items on the list, and the contiguity effect when items positioned next to each other are remembered. Serial recall is the ability to remember items in the order in which they occurred (Gazzaniga and Bizzi 1995). This research is interested whether SenseCam images will be effective in cued recall – whether the images are meaningful enough to evoke a feeling of having experienced an event. More importantly, will the participant be able to discuss items or events once given a cue, but would not be able to without the cue. Discussions about the images are critical as the ability to organise an event into a story means the memories are organised coherently and can possibly be stored for extended periods of time. The ability to share one's past experiences with others through language provides several new opportunities for memory enhancement including events reorganisation (Fivush 2002). This ability is also known as creating a narrative, which is a story that will remain memorable and is key to identity formation. Prior to the more detailed discussion on the importance of language and narrative to identity in Chapter Three, the term identity requires some clarification.

The term identity is also central to the thesis and can have various interpretations. While, the complex, philosophical debate on the theory and significance of identity to humans is beyond the scope of this thesis, Chapter Three presents a detailed discussion of selected theories and empirical studies informing the subject of identity loss and maintenance in dementia. In this instance I will introduce the concept of identity and clarify the way it is understood for the purpose of this thesis. I will also briefly compare the use of the terms identity and personhood in dementia.

Identity is often defined as individuality, personality or continuity of a person. In other words who the person is and what makes them same person over time. While, these definitions may seem straightforward they can be complicated and vary in their underlying assumptions. Identity is a commonly studied subject with roots in different theoretical and disciplinary traditions including among others psychology, sociology and anthropology (Schwartz, Luyckx and Vignoles 2011, Smith 2002, Lemert 2014). Different approaches and models of how to address the concept are often used to explain the same term - identity. The multiple understandings are usually divisive from one another by focusing on identity as dependent on either inner or outer human processes. They also differentiate in their assumptions of identity being personally or

socially constructed or discovered and whether identity remains stable or fluid and constantly changing (Vignoles, Schwartz and Luyckx 2011).

The approaches to understanding identity through its inner processes usually focus on memories, self-continuity, self-consciousness and self-awareness. The relation between memory and identity formation has been a long debated subject. Locke (1690/2012) first described identity as a continuous concept largely dependent on a person's ability to remember his/her past in the present. "*...as far as this consciousness can be extended backwards to any past or action or thought, so far reaches the identity of that person; it is the same self now it was then*" (Locke 1690/2012). It is believed the construction of identity is rarely a deliberate, self-conscious process (Lemert 2014). People seldom set about to create a sense of self as a good or a bad person or a good or a bad citizen. Rather they simply find themselves over time thinking and feeling about themselves in certain ways. Identity is a sense of ourselves over a life span (Erikson and Erikson 1998). Thus, in some sense a feeling of continuity and in some sense generated in hindsight using only selective memories. Early in life, a sense of identity is associated with the security, protection, and acceptance that infants feel when effectively cared for by adults to whom they feel an attachment. Over the years, other social values also become influential in how people think about themselves. Belonging to a group and social roles become important components of identity construction.

Hence, the outer processes associated with living in the social world influence the same identity that develops unconsciously within our mind and throughout our lives. Thus, identity can be understood as an entity, which is constructed through engaging in everyday interpretive activities, the complex process of remembering, telling and local knowing. Social life is an essential feature in identity construction. However, identity is not just a responsive social entity to be filled with meaning, rather it is more actively socially formulated, or artfully constructed in various dimensions necessary for the different context in which it may be located (Holstein and Gubrium 2000). To have an identity means "*having a sense of continuity with the past; and hence a narrative, a story to present to others*" (Kitwood 1997, pg. 83). Hence, identity seems to be created through a mixture of both inner and outer human process.

This understanding is in keeping with recent literature on identity, which also suggests the differences between the inner, and outer approaches to understanding

identity are somehow artificial and propose viewing identity from an integrated approach (Wetherell 2010, Vignoles, Schwartz and Luyckx 2011). This integrated view of identity suggests that the value and meaning of life reside at the level of both the individual and their social network and identity is at once psychological and sociological (Wetherell 2010). Individuals form their identities based on their inner processes such as memories and thinking. However, these same individuals are acting in the societal world and can only form and maintain these identities as embedded and supported in social systems (Lemert 2014). Similarly this thesis accepts an integrated view of identity. Identity is viewed as a dynamic concept that changes as influenced by the inner processes including memories as well as outer process of being situated in the world. Thus, for the purpose of this thesis identity is understood as a momentarily awareness in the present moment, one that does not remain true but constantly evolves with the person as situated in the world.

In dementia research it is often assumed that the term identity is the same concept as personhood (Cohen-Mansfield, Golander and Arnheim 2000, Caddell and Clare 2010). The factors leading to acquiring identity and personhood are to an extent similar however the two concepts are distinctively different from a theoretical perspective. Personhood was defined by Kitwood (1997) as a *“standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood and the failure to do so have consequences that are empirically testable.”*

Despite grounding personhood in relations and social being, Kitwood defined it as a status implying it has a fixed state, which can be activated or deactivated through the social relationships. Contrarily, identity is understood as a dynamic concept that fluctuates as influenced by the inner and outer human processes.

Furthermore, Kitwood’s definition of personhood may be interpreted in a way that excessively empowers the care providers as the only means to support the personhood of people with dementia. This perceives the person with dementia and their ability to deny and fight against negative interactions or perceptions of them as a result of their condition as minimal. Despite Kitwood’s emphasis on improving quality of care, the person with dementia is depicted somehow helpless to take any action about his or her individual perception of personhood, as it is imparted upon them through the interrelations. In comparison, to an extent identity also depends on social interactions, however it is understood it is composed of variety of resources

with some independent of social interactions. These include personal memories and self-awareness. Mead and Morris (1934) argued that inner thought might be understood as an interpersonal dialogue, sufficient to social interaction and to create a version of reality crucial to support identity awareness in the present. Therefore, divergent to personhood, identity does not depend merely on social interaction and as long as resources from other areas are available, identity will evolve and alter in quality over time, but can't be taken away solely by neurological impairment or negative interactions. Additionally, identity is one of the components needed to form personhood as explained by Kitwood (1997). Hence, diminishing identity can impact on overall personhood. However, if the person is supported to maintain a strong sense of identity it may also be challenging to take away their personhood. Thus, the focus on supporting people in maintaining an awareness of their sense of identity may be more empowering to people with dementia. It thus follows that this research focuses on exploration of supporting an awareness of a sense of identity rather than upholding of personhood through therapeutic SenseCam use. Nevertheless, it is recognised that by following Kitwood's person centred care principles and his definition of personhood, which sees identity as one of its components, personhood will also be supported intuitively.

It is also important to clarify the meaning of the term "*therapeutic*" as it is understood for the purpose of this research. Similarly to the concept of dementia, the term therapeutic is open to various interpretations. Given this research is grounded in a more holistic understanding of dementia, which highlights the impact psychosocial factors have on the disease progression, the meaning of therapeutic is also influenced by this understanding. Thus, the concept is understood, as a non-pharmacological approach focusing on the use of psychosocial factors to improve the quality of life for the person with dementia. Furthermore, following the principles of person centred care, a therapeutic approach is understood as guided by the individual's experience of dementia inclusive of the personal network, including family and care staff. It also needs to be stressed that the evaluation of therapeutic intervention as based on the psychosocial understanding differs from the means of pharmacological therapeutic intervention analysis. While pharmacological interventions are usually standardised, with clear, measurable outcomes, non-pharmacological interventions are more challenging to evaluate. The pharmacological interventions are usually evaluated through number of RCTs, in which groups receiving the pharmacological treatment

are compared with control groups receiving no treatment. As the non-pharmacological understanding of the term therapeutic implies individually tailored intervention, it is difficult to measure its generalizable effectiveness in a quantifiable standardised way. The focus of evaluation lies in exploration and depiction of the therapeutic process of delivering the intervention and individual differences between people with dementia, rather than generalisation of uniform measurable outcomes.

1.6 Thesis Organisation

This thesis is presented in 9 chapters including this Introduction chapter. The outline of the thesis is as follows:

Chapter 2 explores the complexity behind understanding and diagnosing dementia as influenced by the biomedical and psychosocial approaches. Moreover, this provides the rationale for predominately grounding this research in the ethos of a psychosocial perspective while accepting that the biomedical approach has yielded important insights to dementia aetiologies and treatments.

Chapter 3 discusses identity from selected philosophical perspectives and the potential impact of dementia on one's identity. Particular attention is given to the inner and outer processes involved in having a sense of identity in the present. The chapter concludes by presenting an understanding of identity as an integrated identity awareness in the present.

Chapter 4 provides an overview of existing early psychosocial and technological interventions aimed at stimulating cognition and social interaction in dementia. I then outline a rationale, by merging together the theoretical assumptions of identity and the existing interventions to illustrate how SenseCam therapy was designed as an intervention to support identity in early stage dementia.

Chapter 5 outlines the philosophical assumptions of constructivism guiding this research. The theoretical rationale for the use of case study methodology to best answer the research questions is then provided. The main focus of this chapter is to demonstrate an understanding of this methodology as influenced by constructivism and its relevance to the research topic. I then outline the data collection and data analysis methods used. Lastly the chapter describes the process of seeking an ethical approval for the present research and outlines some ethical considerations related to dementia and lifelogging.

Chapter 6 presents the findings for each of the three case studies. Each account commences with the first impressions of the participants and their contexts.

Observational data, interview data and journal entries are combined to present chronological accounts of the delivery of SenseCam therapy and its effects on the persons' identity. Each account ends with emerging issue questions.

Chapter 7 is the findings report from cross case analysis. The data from the three cases were triangulated and put under analysis with common themes described. They were organised around the main aim of this study: delivering the intervention to people with early stage dementia and its usefulness to supporting the persons' identity.

In **Chapter 8**, I return to the original research questions and address them in the light of the findings reported in Chapter Six and Seven. I also provide a general discussion around the ethical implications of using SenseCam with people with dementia.

Finally, **Chapter 9** concludes the thesis by reflecting upon its strengths and limitations. Based on the findings, I provide recommendations for future research and therapeutic SenseCam use.

1.7 Summary

In this introduction, the importance of delivering psychosocial interventions in the early stages of dementia has been presented from the perspective of supporting a person's identity. The potential of incorporating SenseCam technology into therapeutic intervention for people with early stage dementia has been presented as motivation for the study. I have also stated the aims and objectives of the research and described the overall significance of this enquiry. Finally I have clarified some of the key concepts and referred to thesis organization to guide the reader.

Chapter 2

Understanding Early Stage Dementia

This chapter presents a discussion on the influence of psychosocial and biomedical perspectives to the understanding of dementia. Correspondingly, the complexity of making early diagnosis and the meaning of the early stages of dementia are also explored through the underpinnings of two distinct approaches. While exploring multiple perspectives is useful for creating a more holistic understanding of the condition, these philosophies provide the reasoning for predominately grounding this research in the ethos of a psychosocial perspective. Nevertheless, the important insights to dementia aetiologies and medical treatments made through the biomedical approach are appreciated.

2.1 Understanding Dementia

The introductory chapter briefly defined dementia from biomedical and psychosocial perspectives. It was then suggested that these two definitions should be synthesised in order to gain a more eclectic and holistic understanding of dementia. Investigating the nuances of these perspectives is useful as they enable us to appreciate their influence on other factors associated with dementia. Of particular interest are the impacts of dementia diagnosis, and the resulting treatments and care, and their positioning to support the identity of the person with dementia. Thus, for the purposes of this thesis, these two perspectives are used to conceptualise and understand dementia and will underpin the empirical research.

2.1.1 The biomedical understanding of dementia

In the past, dementia was predominantly understood from the biomedical perspective, which focused principally on neuropathological causes, possible medical treatments and cure. The scientific research influenced by this perspective enabled identification of different types of dementia based on their underlying causes, signs and symptoms. Furthermore, it also led to development of some pharmacological treatments. This progress played a key role in yielding important insights about dementia. However, it is important to note that these findings are in a continuous state of flux reflecting new theories, counter-theories, the lack of a medical cure, and the emergence of a psychosocial understanding of dementia.

The biomedical view influenced the processes by which dementia is diagnosed, as well as the connotations of receiving such a diagnosis by ascribing medical viewpoints to its assessment and treatment. The biomedical approach to diagnosis usually involves the use of standardised psychometric tests which assess memory and cognitive impairment. It also suggests conducting laboratory tests to eliminate any other conditions that may mimic dementia, as well as neurological assessments including many forms of brain scans such as non-contrast computed tomography (CT scan), or magnetic resonance imaging (MRI scans).

The different types of dementia identified by the biomedical approach to dementia diagnosis can be broadly divided into those that are of neurodegenerative causes and those that are of non-neurodegenerative causes. Neurodegenerative aetiologies are a result of processes in the brain which speed up cell (neuron) death and impair the function of the remaining cells, leading to progressive and incurable cognitive decline (McKeith and Fairbairn 2001). The types of dementia that result from neurodegeneration include Alzheimer's disease (AD), Diffuse Lewy body disease, and Frontotemporal dementia (American Psychiatric Association 2013).

The scientific research into neurodegenerative dementia claims that there are distinguishable neuropathological changes including neuron loss, intra-cellular neurofibrillary tangle and extracellular senile plaque. Externally, an extensive loss of the grey matter and dilatation of ventricles, often seen as a shrinking of the brain, are evident signs of the neuropathology in AD. The brain changes associated with AD consist of two core cellular pathologies. The first type is the senile plaque pathology, which is composed of a protein called beta-amyloid that is abnormally deposited into

insoluble fibrils. The plaque surrounds external neurons and their connecting fibres and causes inflammation of the brain. The second cellular pathology in AD is neurofibrillary tangle, which develops within the nerve cell rather than in its surroundings. It is associated with a loss of hippocampal neurons and it correlates with dementia more strongly than senile plaque. Neurofibrillary tangle is caused by abnormalities in proteins called tau, which appear to be present from an early stage (Allen 2007). With regard to genetic influences to the above neuropathologies, the rare familial type of AD can be recognised by mutation of the genes on chromosomes 1, 14 and 21. This mutation occurs specifically in a protein called amyloid precursor protein, in the form of a higher frequency of the protein than normal, leading to the formation of beta-amyloid A β . Allen (2007) argues that A β plays a major part in the initiations of neurodegenerative processes in AD. Anyone who inherits this gene from a parent will inherit the disorder, usually with an early onset. The more common, non-familial type of gene mutation which is potentially a factor in AD aetiology is Apo lipoprotein E-4 (Apo E-4) on chromosome 19. Some cases with late onset are also associated with chromosome 12 abnormalities (Clare 2008).

Table 2.1 Possible dementia aetiologies adapted from (American Psychiatric Association 2013).

Dementia aetiologies	Prevalence	The most common non-neurodegenerative cause of dementia is damage to blood vessels in the brain, also known as cerebrovascular damage or disease. Such damage occurs with strokes and is often accompanied by a narrowing of the blood vessels supplying the brain with blood and oxygen, resulting in localised areas of the brain being demolished due to poor blood supply. Cerebrovascular disease usually affects people who are elderly or have a history of
Alzheimer's disease	50-75%	
Frontotemporal dementia	5-10%	
Diffuse Lewy body disease	5%	
Vascular dementia	20-30%	
Traumatic brain injury		
Substance medication use		
HIV infection		
Prion disease		
Parkinson's disease		
Huntington's disease		
Another medical condition		
Multiple aetiologies		
Unspecified		

diabetes, smoking, or heart disease. The type of dementia that results from such cerebrovascular disease is called vascular dementia, although Alzheimer's disease is associated with similar risk factors. Additional non-neurodegenerative causes of dementia include traumatic dementia (following a head injury), toxic exposure dementia, and infectious dementia as in AIDS dementia complex (Clare 2008). A

recent list of different dementia aetiologies and their prevalence among all dementia cases is presented in Table 2.1.

Nevertheless, despite the identification of dementia subtypes, differential diagnosis is challenging. Biomedical research into physiological causes has, to date, only yielded modest knowledge about the underlying causes of the neuropathology in people with various types of dementia (Whitehouse and Daniel 2008).

“Different types of dementia are historically associated with distinct symptom patterns and distinguishing microscopic brain abnormalities. Increasing evidence from long-term epidemiological observation and autopsy studies suggests these distinctions are somewhat artificial. Symptoms and pathologies frequently overlap, and can be further complicated by coexisting health conditions” (Alzheimer's Association 2007, pg. 2)

There is growing evidence to suggest that confirmative diagnoses of AD can only be carried out through a post mortem examination where two core lesions of the brain are identified (Whitehouse and Daniel 2008, Clare 2008, Snowden 2003). Whitehouse and Daniel (2008) state that the diagnosis of Alzheimer's is only ever probable, and even during a post-mortem, it is hard to differentiate between the brain of a so-called Alzheimer's *sufferer* and a brain where the person has aged normally. Furthermore, Whitehouse and Daniel (2008) state that the biomedical theory of beta-amyloid protein plaques and neurofibrillary tangles is not precise enough to define this as the pathology causing dementia. Furthermore, it is still not understood how exactly beta-amyloid kill neurons, and recently, new hypotheses have emerged stating they may be the brain's defence mechanism against ageing (Whitehouse and Daniel, (2008). This is further supported by the findings that beta-amyloid protein plaques are found in all aged brains. Some pathological studies have demonstrated that people with dementia sometimes show lower levels of beta-amyloid protein plaques than brains where the person has aged normally. Thus, the boundaries between aetiologies are inherently arbitrary, and in recent years, people often receive a diagnosis of dementia due to multiple aetiologies (American Psychiatric Association 2013).

Although highly individual, regardless of the cause of dementia, it is a progressive and terminal condition, with deterioration likely to occur in all cognitive domains. The disease disturbs the cognitive functioning of memory, language, the ability to communicate, mood and personality. These discoveries have led to extensive scientific and pharmacological research efforts to discover disease-

modifying treatments. Unfortunately, the pharmacological cure for dementia remains non-existent. Some medications, however, can temporarily ease symptoms and improve functioning, and may slow the progression of the basic disease process. However, they are limited because they are type-specific, with the majority of drugs developed to treat Alzheimer's disease; their effects on other types of dementia are uncertain. There are many randomised control trials aimed at measuring the effectiveness of dementia drugs using cognition scales. However, their efficacy remains difficult to evaluate. Recently, it has been argued that other psychosocial interventions occurring simultaneously to drug therapies can also have an effect on the symptoms of dementia (Spector et al. 2003, Moniz-Cook and Manthorpe 2009).

Thus, despite the biomedical approach to dementia allowing for the possibility of differential diagnoses, pharmacological treatment, and a hope that medications will improve or stop failing cognitive function, there is a level of scientific uncertainty and as yet a lack of the promised cure for dementia. The biomedical drive to view dementia as a physiological illness, which is currently incurable, poses the danger of instilling a fear of dementia diagnosis, or worse, promising false hope in terms of treatment. *"False hopes proffered to gain scientific recognition or commercial profit can leave people with greater suffering than when they started"* (Whitehouse and Daniel 2008, pg. 22).

There are numerous authors who argue that viewing dementia from a biomedical perspective is at least partially responsible for creating the stigma associated with dementia and for instilling fear of an incurable illness among the general public (Post 2006, Beard and Fox 2008, Kitwood 1997). Stigma is a process of disqualification from society, whereby a 'normal' person is reduced to a person with whom something is wrong (Goffman 1963). Within the biomedical perspective, dementia is viewed as an illness, and the *"slow death of the mind"* to which a medical cure isn't available at present but will eventually be found (Beard and Fox 2008). The main focus remains on the disease and not the person, which often results in the person with dementia being labelled as a patient or a sufferer with a need for pharmacological treatment. Furthermore, too much focus on neuropathology is distracting from the many psychosocial opportunities that enable people to live well, even with dementia. Given that the largest risk factor for dementia is age, the stigma associated with dementia is also interwoven with ageism. *"Older people with dementia have to overcome the double stigma of age and dementia, both of which*

inevitably affect the quality of their lives, the services that support them and the national policies that underpin these services.” (Moniz Cook and Manthorpe 2009, pg. 19).

While the biomedical perspective has increased understanding of the condition by differentiating dementia types, causes and symptoms, the initial focus on biological causes and a medical cure or lack thereof is also viewed as a product of stigma and fear of developing the condition among society. Nevertheless, it was this scientific enquiry into dementia, driven by the biomedical perspective, which improved understanding of the condition, including its trajectory. Biomedical research plays a key role in developing some pharmacological treatments and emphasises their efficacy in the early stages of dementia. This in turn encouraged the establishment of memory clinics and increased the number of early diagnoses (Passmore and Craig 2004). Larger numbers of people diagnosed in the early stages of dementia has led to recognition that other psychosocial services throughout the illness could also be helpful.

2.1.2 The psychosocial understanding of dementia

It is unfortunate that, until recent years, psychosocial factors were almost completely neglected in light of the overwhelming biomedical focus on neuropathology. Kitwood (1997) challenged the influence of this perspective in the 1990s by introducing new ways of thinking about dementia, placing the person and their individual experience of the disease at centre stage. Following this re-conceptualisation of dementia, several social and behavioural scientists have further developed a psychosocial understanding of dementia. In principle, while the biomedical view focuses on searching for the causes of, and cure for, dementia, the psychosocial perspective considers that it might be time to accept that some types of dementia may be incurable. Therefore, rather than allocating large efforts to the search for a medical cure, one should concentrate on enhancing the quality of life for people with dementia and offsetting the associated neurological damage by prolonging the functionality of basic skills such as communication (Whitehouse and Daniel 2008). Accordingly, understanding dementia as a psychosocial disorder allows for the inclusion of psychological and sociological factors, which may affect the progression of the disease (Adams and Manthorpe 2003). Nonetheless, the psychosocial view of dementia recognises that a biological neuropathology is the

primary cause of the disorder. It argues, however, that psychosocial factors should not be underestimated in relation to their influence on the progression of the disease. Thus, the psychosocial view presents dementia as a two-sided progression, where the gradual failure of cognitive processes such as memory, reasoning and comprehension are accompanied by changes in relationships, interaction and identity. The former can be attributed to the brain being less efficient, with a decline and degeneration of its structure, whereas the latter is attributed to the socio-psychological environment (Kitwood 1997). Thus the main objectives of the psychosocial understanding are to recognise and reinforce each person's unique experience, and ultimately to support their identity through the use of psychosocial factors despite the weakening effects of the disease (Kitwood 1997, Spector and Orrell 2010, Whitehouse and Daniel 2008).

The pioneering theory for understanding dementia as something more than just a disease caused by an organic neurological problem follows Kitwood's (Kitwood 1993) dialectic model of dementia. The model presents dementia as a dialectical inter-relationship between neurological damage and psychological factors. Kitwood (Kitwood 1997) diverges from the medical or organic mental model of dementia, labelling it a "standard paradigm" which has a narrow perspective and ignores larger human issues. He believes that putting a purely medical label on the disease leads to personal exclusion and discrimination through categorising of people as incompetent and burdensome. Kitwood (1993) aims to present an understanding of dementia that accommodates a richer range of evidence than that of the biomedical model and takes an approach to dementia care that focuses more on the human than the medical solutions. Kitwood (1993) formulated dementia (D) as having five key factors: $D=P+B+H+NI+SP$, where P stands for personality, B is biography, H is physical health, NI is neurological impairment, and SP is the social psychology surrounding the person (Kitwood 1997). He argues that psychological factors can have either a positive or a negative effect on neuropathology, in turn slowing down the disease or speeding it up. The main psychological factor referred to in the model affecting the well-being of a person with dementia is "personhood", which can be undermined by "malignant psychology" or maintained through "person-centred care" (Kitwood 1997).

This dialectic model strongly argues that essential to an understanding of dementia as a biopsychosocial disease, is a viewpoint of personhood as a relational process. Kitwood provides a relational view of personhood that emphasises the

interdependence of care providers and the personhoods of people in their care. Personhood is defined as a status given to a person by others through relationships and social interactions. “*It implies recognition, respect and trust*” (Kitwood 1997). It should be viewed as central to relationships and to the uniqueness of a person. Kitwood also states that it is essential to penetrate social and personal history in order to develop a deeper understanding and to generate sensitivity to areas of need in order to provide appropriate person-centred care.

Kitwood (1997) suggests that positive approaches to dementia care (in which social psychology plays a major part) help offset neurological decline. He argues that each advance in neurological impairment should be compensated for by person-centred care. The greater the neurological impairment, the more positive person-centred care should be provided. Kitwood (1997) introduced the person-centred approach to dementia in order to maintain personhood and to stop discrimination and neglect of people diagnosed with the disease. The most influential change, which is the point of reference in many therapeutic approaches, is to see a PERSON-with-dementia rather than a person-with-DEMENTIA (Kitwood 1997). This theory points out that it is the person who should come first rather than the diagnosis; however, in many cases, the personhood of an individual might be challenged soon after their diagnosis is known. Kitwood (1997) outlined the positive interactions which should be considered while providing care in order to enhance the personhood of a person with dementia. These include:

- Recognition of the person,
- Negotiation of choices,
- Collaboration or co-operation,
- Play rather than work,
- Timalation – referring to sensual experiences,
- Celebration of pleasure,
- Relaxation,
- Validation of emotions,
- Holding – referring to providing a safe psychological space where anxiety can be explored,

- Facilitation – referring to the enabling of a person to make his or her own rational decisions, created and provided by the person with dementia.

Kitwood's ideas of person-centred care are practiced in various therapy approaches including Cognitive Stimulation Therapy, reminiscence, and validation (Holden and Woods 1995, Moniz-Cook and Manthorpe 2009, Spector et al. 2003).

As mentioned earlier, it can be argued that the biomedical model of dementia has led to an undermining in the personhood of people with dementia.

“Neither from the standard paradigm, nor from the majority of the research affiliated to it, do we get any sense of the real people, in the diversity of their backgrounds, personalities and ordinary lives, who develop a dementing condition...Implicitly, then, the standard paradigm feeds into an extremely negative and deterministic view, which can be summed up in the popular image of ‘the death that leaves the body behind’ (Kitwood 1997, pg.37).

The standard paradigm holds the view that the mental and emotional processes associated with diagnosis are a direct result of the neuropathology of the brain. Kitwood (1997) argues against this view and states that social and interpersonal factors play a vital role in either adding to the difficulties arising from neurological impairment, or lessening their effects. Kitwood (1997) developed a list of behaviours, which he named “malignant social psychologies”. The word malignant represents something harmful and depersonalising towards the person with dementia. It represents a social environment where personhood is damaged and even physical well-being might be undermined. The list of behaviours includes:

- Treachery - deception used to distract or manipulate,
- Disempowerment - not allowing the use of abilities one may have,
- Infantilisation – patronising treatment,
- Intimidation - inducing fear in a person,
- Labelling - categorising people as demented,
- Stigmatisation - treating a person as if they were an alien,
- Outpacing - interacting at a rate too fast for the person,
- Invalidation - failing to take feelings into account,
- Banishment - excluding, objectification - treating a person like an object,

- Disparagement - telling a person they are useless,
- Other behaviours: ignoring, imposing, withholding, accusing, disrupting, and mockery.

Kitwood (1997) further argues that all events in human interaction play their part at a neurological level. Exclusion or discrimination of a person with dementia may actually damage nerve tissue, whereas positive caring interactions may be conducive to nerve growth, therefore offsetting neurological decline.

In conclusion, Kitwood's theory presents the process of dementia as a continuous interplay between neuropathology and social factors. This model is described as a spiral, which portrays the person with dementia as moving through states, where, in each state, factors of neurological impairment are reacted to through social psychology factors. If these social psychology factors are negative (malignant social psychology), they will negatively affect neurological impairment and work together to undermine personhood. However, personhood can be supported if the social psychology is more positive (person-centred care), enabling the offsetting of the effects of neuropathology and even promoting some degree of structural regeneration of the neurons. Therefore, contrary to the standard paradigm, the dialectical model of dementia emphasises the importance of person-centred care, which impacts on one's "personhood" (Kitwood 1997).

Whitehouse and Daniel (2008) provide an even more progressive theory on understanding dementia, which argues that Alzheimer's disease does not exist and rather signifies an attempt to understand the normal processes of uncontrollable brain ageing. In their book "The Myth of Alzheimer's", the authors state that everyone ages differently and therefore some people experience more severe mental cognitive decline than others. Similarly, some people age more gracefully than others, and do not develop any cognitive difficulties (Whitehouse and Daniel 2008).

Whitehouse and Daniel, similarly to Kitwood, argue against the biomedical, neurological model of dementia (Kitwood 1997, Whitehouse and Daniel 2008). They criticise the labelling of dementia as a disease, which results in false promises that science will one day find a cure for dementia. However, if one accepts that Alzheimer's disease is a myth of the medical and pharmacological industry, one assumes that finding a cure must result in the cessation of normal, natural brain ageing. Similar to the dialectical model of dementia, this model has faith in a more

humanistic approach to dealing with dementia. Seeing Alzheimer's disease as a myth allows for the view that memory loss and other functional slowdowns are natural components of ageing that do not necessitate a disease label. This implies that individuals with cognitive challenges are still vital human beings with a high quality of life who can remain active, social family members. This theory also follows Kitwood's framework of maintaining the personhood and honour of each individual (Kitwood 1993, Whitehouse and Daniel 2008).

In line with person-centred care, Whitehouse and Daniel (2008) also provide their own version of how to avoid severe neurological impairment and maintain psycho-social factors as we age. They label it "*a prescription for successful aging*" (Whitehouse and Daniel 2008). According to Whitehouse and Daniel (2008), the prescription for successful ageing lies in incorporating the following factors into lifestyles:

- Diet - fewer saturated fats,
- Restricting daily calorie intake,
- Protecting young minds - promoting breast feeding,
- Exercise – three times a week,
- Environmental exposure – eating less fish known to carry toxins,
- Reduce stress – surrounded with calming people,
- Building cognitive reserve – getting as much education as possible education, staying vital in later years, taking up new hobbies,
- Protecting against infections – avoiding infections in earlier life.

This view of Alzheimer's disease as a myth may be unacceptable to some. However, it does redirect the focus from a biomedical view of finding a cure for a neurological disease, to finding, providing and enhancing quality-of-life interventions. Simultaneously, this proposes a change in monetary investments from research seeking a medical cure to research on dementia intervention or even prevention, and the care of ageing people (Whitehouse and Daniel 2008).

Another development from Kitwood's dialectical model in understanding dementia as more than a disease caused solely by neuropathology in the brain, is the biopsychosocial model (Spector and Orrell 2010). This model follows Kitwood's understanding of dementia as an interrelationship between biological and psychosocial factors (Kitwood 1997, Spector and Orrell 2010). However, both factors

are divided further into fixed factors and tractable factors. Fixed factors are aspects that relate to history and therefore are unresponsive to change, whereas tractable factors may be amenable to change. This approach encourages the viewing of dementia as something that is not a causal disease, but instead something where change, adaptation and improvement are possible (Spector and Orrell 2010). This model argues that tractable factors may be influenced both by fixed factors, such as age or personality, and by interventions, whether medical or psychosocial. This theory also acknowledges that a person with dementia may experience “excess disability” where, instead of reaching potential functioning through appropriate interventions and support, the person’s current functioning may be below their capabilities (Spector and Orrell 2010).

The aforementioned psychosocial theories of understanding dementia emphasise the importance of recognising the person and supporting the maintenance of their identity through psychological and social factors. Furthermore, they affirm that psychosocial factors such as biography, social and emotional history as well as their encountered social interactions may develop a person’s sickness or well being. This perspective shows potential to move emphasis to positive interactions and high-quality support for people living with dementia, regardless of medical advancement and treatments. Furthermore, the psychosocial view emphasises the necessity to support people to remain active within their community networks and in wider society, despite their illness (Irving et al. 2013).

Both biomedical and psychosocial perspectives offer advantages for understanding the condition. Yet, if viewed independently, they can influence a partial and rather incomplete view of dementia. Thus, for the purposes of this thesis, dementia is understood as a condition caused predominantly by physiological causes. However, it is also implied that dementia should be viewed from the perspective of the person, and that its trajectory is largely dependant on psychosocial factors such as a good quality of life, support and care, positive social interactions and psychosocial interventions.

Unfortunately, this holistic view of dementia is currently more of an exception than a common understanding. Usually, dementia is viewed from either a biomedical or a psychosocial perspective, and this divided view influences and affects the processes of diagnosis, the meaning of early diagnoses, and of early stage dementia. Given that the research in this thesis explores an intervention for people in the early

stages of dementia, it is important to explore in more detail how this *early* phase in particular is understood and influenced by both biomedical and psychosocial understandings.

2.2 Early stage dementia

Given that dementia is not a dichotomous condition with linear impairments, understanding and diagnosing dementia in general can in itself be a complex process, as highlighted by the above discourse. Dementia is an insidious condition with cognitive impairments proceeding in a gradual, subtle manner, but with progressively damaging effects. Therefore, establishing a diagnosis of dementia at an early stage of its trajectory is even more problematic. As mentioned in the previous chapter, early diagnosis is desirable so that appropriate treatment strategies can be implemented earlier in the course of the disease. Despite this recognition, there seems to be a lack of clarity regarding the meaning of the early stages of dementia and at which point in the disease's trajectory is a diagnosis necessary, as well as what is considered early.

Along with past clinical experience, medical professionals may draw from a variety of sources to evaluate the progression of symptoms in patients with dementia. Medical scans depicting physiological damage in the brain may be one of those sources. However, as discussed earlier, there can often be little commonality between the severity of the neuropathology and its observed symptoms. There are other clinical tools that medical professionals can refer to in order to determine the severity of a person's dementia. Some of the more commonly used tools include the Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria, the Mini Mental State Examination (MMSE), and the Clinical Dementia Rating (CDR) (American Psychiatric Association 2013, Folstein, Folstein and McHugh 1975, Hughes 1982).

The most recent fifth edition of the DSM criteria subsumed the diagnoses of dementia under a new heading of “neurocognitive disorders (NCD)”. This new category recognises a less severe level of memory impairment. The NCD are divided into mild and major neurocognitive disorders, with the former describing modest cognitive problems and the latter representing major cognitive problems. The CDR outlines five stages of progressive dementia on a scale from 0 to 3, with increasing scores indicating a worsening in functioning. The lowest score of 0 represents a healthy person with no dementia present. The next score of 0.5 on the CDR scale

represents very slight impairments with some minor memory inconsistencies. CDR guidelines state that the person in question might struggle to solve challenging problems and can have trouble with timing. A score of 1 indicates that the person with dementia is noticeably impaired in each area, but that the changes are still mild. The person's short-term memory is significantly impaired and disrupts some aspects of their day. People in this category have started to become disoriented geographically and may have trouble with directions and getting from one place to another. The person may also start to have trouble functioning independently at events and activities outside the home. At home, chores may start to get neglected, and the person may need to be reminded to take care of their personal hygiene. The CDR score of 0.5, titled as questionable dementia, and a score of 1, mild dementia, can both be perceived as early stages of the condition. It is commonly perceived in scientific research studies as well as by medical professionals that people with scores of either 0.5 or 1 have early stage dementia. There is, however, a substantial difference in the possible symptoms in people with a score of 0.5 and 1 as mentioned above. This alone suggests that people who are broadly classified as in the early stages may have quite different levels of functionality.

The MMSE is a brief screening tool to provide a quantitative assessment of cognitive impairment and to record cognitive changes over time. An MMSE score of less than 24 is generally the accepted cut-off, as evidence of the presence of a cognitive impairment (Dick et al. 1984). Tombaugh & McIntyre (1992) classified three levels of impairment. The first level indicates no impairment, marked by a score of between 24 and 30. The next level indicates mild impairment, scored between 18 and 24. The last level indicates severe impairment, marked by a score of between 0 and 17.

Apart from the CDR's score of 0.5 indicating potential dementia, there is little emphasis on identifying the very early stages of the condition among the other clinical tools. Both the MMSE and DSM seem to focus on the mild and severe stages. Based on these psychometric tools, some clinicians may refuse to diagnose someone until they present with mild to moderate symptoms, whereas others may diagnose people as soon as they present with what are considered questionable symptoms. It is also possible that dementia can go unnoticed in the very early stages, due to the affected person developing effective coping and denial mechanisms. A study examining the obstacles to timely diagnosis in Europe reported that guidelines on diagnosing

dementia for medical professionals, as well as GP education, enhanced the diagnosis of dementia (Vernooij-Dassen et al. 2005). However, bespoke dementia training for medical professionals was only present in four out of eight participating countries. As a result, the level of cognitive impairment and functioning in people diagnosed with early stage dementia can vary, depending on the perceptiveness of their clinicians.

Another factor influencing the understanding of early stages of dementia is the time at which a person presents to their clinician. A common barrier to early diagnosis and treatment includes late presentation, and there could be several reasons for a delay in seeking and receiving a diagnosis. There are numerous studies indicating that the stigma initiated by the biomedical understanding of dementia still persists among the general public (McParland et al. 2012, Beard and Fox 2008, Corner and Bond 2004, Vernooij-Dassen et al. 2005). A Northern Irish study into knowledge of dementia by the general public suggests that deeply stigmatised attitudes towards people with dementia continue to exist (McParland et al. 2012). Another study examining the factors affecting timely recognition and early diagnosis of dementia among medical professionals in eight European countries concluded that dementia-related stigma was a major obstacle to early diagnosis in all countries (Vernooij-Dassen et al. 2005).

One study on dementia and its associated anxieties discovered that a loss of self-identity and dignity, and concerns about long term care, were among the biggest fears faced by elderly people (Corner and Bond 2004). Moreover, another study reported that, in the view of people who have received them, a dementia diagnosis often redefines everyday forgetfulness into a medical problem (Beard and Fox 2008). Some people receiving an early diagnosis do not perceive their experiences as pathological but rather as age- related forgetfulness (Clare, Goater and Woods 2006). Nevertheless, they are often persuaded, by the medicalisation of dementia and a stigmatised societal awareness, to view their forgetfulness as symbolic of a disease. Additionally, research suggests that receiving an early diagnosis and recommendations from medical professionals may, in some cases, cause people to feel disempowered and can damage their identity, as they are still capable of making independent decisions (Iliffe and Manthorpe 2004). This is especially true in cases where a person is capable of carrying out occupational or leisure activities like driving or participating in sports, whereas their cessation is recommended at the time of diagnosis (Iliffe, Manthorpe and Eden 2003). Iliffe and Manthorpe (2004) suggest that

unless cognitive impairments exceed existing capabilities and coping mechanisms, the benefit of making and disclosing this diagnosis remains unclear.

Thus, viewing dementia solely from the biomedical perspective as a physiological illness poses a risk of stigmatising forgetful adults into “dementia patients”, which in turn leads to these individuals being challenged by these new diseased identities (Beard and Fox 2008). People with dementia can be confronted by negative identities ascribed to them by society following their diagnosis (Preston, Marshall and Bucks 2007). Among other things, they include being classed as disabled, insane, childish, or stupid (Preston, Marshall and Bucks 2007).

Studies investigating how individuals cope with these associated challenges after receiving a dementia diagnosis suggest that people with dementia often develop coping mechanisms to manage their identity. These coping mechanisms can be broadly divided as “self-maintaining” or “self-adjusting” (Clare 2003). The former relates to individuals attempting to minimise their difficulties by relating to their pre-diagnosis identity, whereas the latter relates to individuals attempting to tackle their difficulties and adapt their identity reflectively (Clare 2003). Self-maintaining strategies are often a sign of denial of the condition and of a response to the stigma associated with the disease, and can include states of denial and a lack of unawareness about the disease (Preston, Marshall and Bucks 2007, Clare 2003, Beard and Fox 2008). This often leads to discontinuity between past and present identities (Preston, Marshall and Bucks 2007). Some individuals indicate that they perceive dementia as completely unrelated to their identity, which can also be seen as a protection of their prior sense of self. In these cases, individuals often acknowledge positive aspects of their lifelong identities, including achievements, as a means of compensating for the new diseased identities imposed on them by societal stigma (Preston, Marshall and Bucks 2007).

Thus, the way people cope with dementia and its associated challenges including stigma can have a profound impact on an individual’s decision-making processes about whether or not to seek a diagnosis. Stigma can result in people seeking a diagnosis only to confirm their failing capacities and the need for services due to increased dependence on their carers. The initial large numbers of diagnoses of dementia in moderate to late stages of progression created a misleading understanding in the past that the condition is debilitating and that treatment is largely palliative, even immediately following diagnosis, limiting rehabilitative possibilities. This

misleading perception about the diagnosis of dementia offering limited value to the person with the condition often leads to the generation of even more stigma and fear among the public.

Therefore, the biomedical model may be seen to be somewhat responsible for the stigma associated with dementia, which has led to fears of developing the condition and avoidance of diagnoses. However, it can also be argued that medical advances play a part in de-stigmatising the condition. As mentioned earlier, the biomedical developments in physiological causes has led to better understanding of the disease's trajectory and in turn has improved the likelihood of its identification in its early stages. Along with establishing an evidence base for pharmacological treatments in early stages, many governments and dementia strategies focus on early detection and diagnosis (Moniz Cook and Manthorpe 2009). Taken together, this has promoted the opening of a large number of memory clinics and an increase in the number of people diagnosed with dementia in its earliest stages.

This increasing number of early diagnoses has led to the identification of people living with dementia who have very low cognitive impairment and a high level of functionality. Research into the experiences of people with early diagnoses, who have a lot more insight into their condition, presents a contrasting picture to existing depictions of individuals in later stages of the condition. Furthermore, one study reports that *"people with dementia do not, however, typically view themselves as having an illness"* (Clare, Goater and Woods 2006). This has had a huge impact on the de-stigmatisation of the condition and shows how providing the right supports can enable people with dementia to continue to live well following their diagnosis.

Additionally, the shift from biomedical to psychosocial understandings of the condition implies a change of focus from testing for neuropathology and cognitive impairments to a person-centred assessment of capabilities (Irving and Lakeman 2010). Through this assessment, interventions and resources are identified which maximise a person's strengths, in order to enable them to live well with dementia. The move away from the biomedical perspective has enabled a range of such interventions – aimed at supporting and maintaining the preserved abilities of the person with dementia, while taking into account their context including factors such as social status, health, well being, and mental and spiritual functioning. This divergent approach to identifying dementia promotes self-management and aims to maximise the functioning of the person, especially in the early stages of the condition.

Furthermore, person-centred assessment emphasises individual experiences of dementia and considers existing coping mechanisms. Thus, the growing evidence base for early psychosocial interventions working alongside the advancements in pharmacological treatments offers hope for and value to early diagnosis (Moniz Cook and Manthorpe 2009).

In summary, both biomedical and psychosocial perspectives influence early diagnoses of dementia. This in turn complicates the meaning of what constitutes as the early stages of dementia. Given that perceptions of dementia vary and that they are currently in a state of flux, some people still view dementia from a biomedical perspective while others see it as psychosocial matter. As a result, there is no one common time point in the trajectory of dementia at which people may seek or receive a diagnosis. There might be people who seek diagnosis very early on (as encouraged by recent de-stigmatisation and growing evidence from psychosocial interventions), and there might be others who still fear a dementia diagnosis due to continuing stigma. In addition, dementia is a very individual illness and people perceive and cope with their initial symptoms differently. All of the above factors can influence when a person might decide to seek and receive a diagnosis. Similarly, there seems to be no clarity among clinicians as to when a diagnosis should be made, and the process of making a diagnosis itself can also be a complex and prolonged process.

As a result, it is problematic to say what exactly is considered “early” stage dementia. This would suggest that people with an early diagnosis of dementia might vary significantly in their day-to-day functioning and in the severity of their symptoms. This alone can be problematic in understanding the meaning of the “early stages of dementia”, and the use of such a term as a screening criterion to take part in this study. In turn, it is possible that potential participants in this study may theoretically fulfil the criterion of having early stage dementia, but each individual may vary in their actual level of impairment and functioning.

2.3 Summary

This chapter presented two distinctive perspectives to understanding dementia and the influences these have on how a person with dementia, and his or her identity, is perceived in terms of treatment and support. The biomedical perspective places a strong emphasis on underlying causes and treatments, resulting in the person with dementia being positioned as secondary to the disease. A person with dementia is

situated as a patient or sufferer, which in turn can be seen to cause stigma about having dementia. Furthermore, by viewing dementia as an illness, people are often portrayed as helpless victims whose behaviours, actions and expressions are seen as a symptom of the disease, and that should be treated with additional medications which are usually prescribed without consideration of any psychosocial interventions. In the late stages of dementia, this view often depicts the person's identity as lost during the progression of dementia and does not encourage the enabling of self need-fulfilment or expression.

Complementarily, the psychosocial perspective places emphasis on the person living with the condition and discourages viewing dementia solely as a neuropathological condition with necessary medical treatments (Kitwood 1997, Spector and Orrell 2010, Whitehouse and Daniel 2008). The goals of care-giving are to recognise and reinforce each person's unique experience and ultimately to preserve personhood despite the weakening effects of the disease. The main implication of the psychosocial view of dementia is thus that the personhood of the person with dementia is recognised, preserved and respected through many psychosocial factors (Kitwood 1997, Spector and Orrell 2010, Whitehouse and Daniel 2008).

Moreover, these diverse perspectives also influence the diagnosis of dementia, resulting in the creation of early diagnosis as a complex process, and with the meaning of early stage dementia open to various interpretations. The consequences of this categorisation result in a broad category of people, ranging from people with autonomous decision-making capacities and occupational capabilities, to people in more advanced stages with memory spans of less than a few hours, all being classified under the same label. Thus, early diagnosis or early stage dementia is a complex category which fluctuates depending on adopted perspectives of the condition. The biomedical view implies that the presence of a neuropathology is sufficient for someone to be labelled with the disease, prescribed medical treatment and potentially advised to cease activities of daily living, whereas more recent advancements in the psychosocial perspective suggest that early dementia should only be identified at a point where cognitive impairments begin to exceed coping mechanisms (Iliffe and Manthorpe 2004). It is once cognitive impairments begin to exceed coping mechanism that the identity of the person with dementia is at risk of diminishing. New methods that prioritise the capabilities rather than the impairments of people with dementia are necessary to underpin early dementia diagnoses. There is evidence

from a number of studies to suggest that early psychosocial interventions supporting peoples' capabilities can help to extend the time a person remains in the early stages of the disease (Moniz-Cook and Manthorpe 2009). This in turn can enable the person to maintain their sense of identity longer into the disease's progression (Caddell and Clare 2011a). In the absence of such interventions, diagnosis can have tragic consequences for the individual (Berr, Wancata and Ritchie 2005).

For the purposes of this thesis, it is accepted that the biomedical perspective has played a key role in yielding important insights into identifying the neuropathology of the brain associated with dementia, as well as diagnosis of the disorder and providing helpful medical treatments. However, current research is not restricted by the understandings set out in the biomedical approach. The influences of psychosocial understandings which value the perspective of people with the disease and which support them through psychosocial factors, are also incorporated into understandings of dementia. As dementia is likely to be experienced differently by each individual, not all symptoms and causes can be assumed to be due to the dementia label (O'Shea 2007). Although both the biomedical and psychosocial perspectives were used to conceptualise and understand dementia, it is the latter which will primarily underpin the empirical research conducted as part of this thesis. The psychosocial perspective allows recognition of the person and their identity, allowing for individual symptoms and associated needs to be addressed within a therapeutic intervention. Accordingly, supporting the identity of people with dementia through therapeutic intervention is the focus of this research.

Chapter 3

Identity and Dementia

The focus of this chapter is to philosophically situate the idea of a person's identity and to situate those underpinnings alongside the impact that dementia has on a person's ability to continue to have a sense of identity. Two main theoretical approaches to understanding identity are reviewed, namely the *inner* and *outer* identity perspectives. Particular attention is given to the theoretical foundations of identity in terms of memory, language, and social interaction, and how these are impacted by dementia. The chapter concludes by considering the implications of this review of identity and dementia when using SenseCam as a means of supporting people with dementia to maintain a sense of identity.

3.1 Identity and Dementia

There is no doubt that something happens to the identities of people with dementia. There are reports from families claiming that the person's identity changes completely and that they become someone else as the condition progresses. Others say that the person's ability to express themselves, their preferences and characteristics is weakened and they possess less insight into familial relationships and environments. Many argue that identity slowly diminishes as the condition progresses. Others yet contend that identity disappears completely and that all that is left of a person is an outer shell with nothing inside.

“That some sort of identity is lost when dementias ravage the brain seems indisputable. But what kind of identity is lost and what unchanged aspect of the person other than the endurance of the body, might at least for some time be retained?” (Radden and Fordyce 2006, p.71).

There is much debate about whether identity can be entirely lost or whether some of it can be retained by people with dementia (Clare 2003, Caddell and Clare 2013, Mills 1997, Addis and Tippet 2004, Cohen-Mansfield, Golander and Arnhem 2000). To gain insight into what might be happening to their identity when a person gets dementia, broad theories of identity were reviewed. As mentioned in the introduction, a complex interdisciplinary debate on the theory and significance of identity to humans is beyond the scope of this thesis. However, selected theoretical and empirical perspectives inform the subject of identity loss and maintenance in dementia. This review is divided by two distinct discourses identified within the theories relating to identity in humans. The first discourse is referred to as “*inner identity*” and the second as “*outer identity*”.

The discourse on inner identity focuses on philosophical debates concerning issues such as what makes a person the same person over time and what criteria should be used to decide this. These philosophical disputes include metaphysical theories of identity based on the physical continuity of the body and brain, and theories of identity which propose the continuity of some mental entity capable of surviving bodily death. This highly philosophical discourse on identity in humans is mainly concerned with identifying the inner human processes necessary to form and maintain identity. These processes are usually interrelated to memories and include, among other things, self-continuity, self-consciousness and self-awareness.

The discourse on outer identity moves away from an abstract philosophical self to a more real-world understanding of identity. The focus is on the externalism of the mind, or, in other words, on people located in the outer world. This discourse argues that the crucial element of identity is in seeing a person as a situated human being who engages with the world in a mental and bodily way to show desires, choices, drives, emotions, needs and attachments.

3.2 Inner Identity

The origins of the inner views of identity are often attributed to the writings of Rene Descartes, a sixteenth century French philosopher. Descartes (1641/1984)

situates identity within the mind and body of a human being. He contemplated whether it is the physical existence of the body that enables humans to have an identity. Descartes considered whether identity remains the same despite its possible transformations in physical existence. He illustrated his reasoning by describing the possible physical transformations of a piece of beeswax. He described how beeswax is liquid when hot and solid when cold. Descartes (1641/1984) established that it is possible for any subject to completely transform in its physical existence, yet maintain the continuity of being the same subject. He questioned thus what is the cue that informs us that something is the same (has the same identity), despite its physical transformations. Given this, he concluded that there must be something other than physical existence that enables one to be aware of this sameness. He settled that it must be the internal processes of the mind that know by intuition whether an object is the same thing over time, as it is not always the physical existence that maintains its sameness.

Descartes therefore asserted that identity is a thing that thinks: *“But what then am I? A thing that thinks. What is that? A thing that doubts, understands, affirms, denies, is willing, is unwilling, and also imagines and has sensory perceptions.”* (Descartes 1641/1984).

He concluded that the body and mind are separate, and ratified that it is his mind that gives him a better idea of himself, not his body. This conventionalisation of a split between mental and physical existence became known as Cartesian Dualism. Descartes further claimed it is the intellect alone which maintains one's identity. He summarised his theory in one well-known notion, “I think therefore I am”.

The progression of dementia usually results in an increased neuropathology and a worsening of mental functioning to a degree, which can be perceived as a lack of an ability to think for oneself (American Psychiatric Association 2013). The cognitive impairments arising from dementia and damaging the brain can be seen as a loss of the mind. If taking Descartes' philosophy at face value and applying it to dementia, this loss of the mind would also mean a loss of identity in people with dementia. Furthermore, accepting Descartes' notion of “I think therefore I am” would consequently imply it is possible to lose an identity completely in the very late stages of dementia, when cognition is severely impaired.

However, Descartes' philosophy was about *“the nature of the human mind, and how it is better known than the body.”* As such, one can only contemplate what

Cartesian¹ insights imply for the issue of identity loss in dementia. While in the past Cartesian Dualism focused the medical world on curating pathological symptoms, it does not necessarily help us move forward with the issue of identity loss in dementia. Unlike some other medical conditions, dementia does not impair cognition in a dichotomous way. People with dementia do not lose the ability to think instantly at the point of receiving the diagnosis. Instead, as mentioned in the previous chapter, dementia is an insidious condition with cognitive impairments proceeding in a gradual, subtle way, but with progressively damaging effects.

Thus, Descartes' dualistic approach of identity being constructed in the mind and independent of the body must be taken with a considerable amount of thought when applying it to the issue of diminishing identity in dementia. If not, Cartesian dualism would imply that a person with dementia who no longer has the capacity to think is just a remaining living bodily shell and does not require any moral or ethical treatment as their identity is gone (Shewmon 1985). The only treatment this view necessitates for the remaining outer shell would involve acute physical needs. This understanding would consequently undermine any psychosocial support for the person with dementia and would instead emphasise care of the physical body (Lyman 1989, Kitwood 1997).

While Descartes, as well as others philosophies reviewed below, provided us with insight into the theoretical constructs of identity in humans, we need to keep in mind that these early philosophers were not thinking directly about diminishing identity in dementia.

Similarly to Descartes, Locke (1690 2012) concentrates on the inner mind as a source of identity formation but develops this thinking further by identifying the processes responsible for the continuity of identity despite transformations in physical existence. He first introduced the idea of identity consisting of memory over time. Locke explained the connection between memory and identity by arguing that identity is only the same if the present identity remembers the events of the past identity.

"...as far as this consciousness can be extended backwards to any past or action or thought, so far reaches the identity of that person; it is the same self now as it was then" (Locke 1690/2012).

¹ Cartesian means of, or relating to, Descartes—from his Latinised name *Cartesius*.

Locke (1690/2012) claimed that as long a person has the cognitive ability to perceive himself as the same person in different times and places, his identity is continuous. Hence, in contrast to Descartes who considers identity at any given moment, Locke implies that in order for a person to have an identity, they must know it is the same thing as it was earlier, even if there is a physical change. Identity, thus, can be interpreted as a continuous concept largely dependent on a person's ability to remember his or her past in the present moment.

Applying Locke's theory on continuity of identity to dementia can offer some explanation to the ill-understood process of what happens to the identity of people with the condition. Given that our ability to remember is impaired even in the early stages of dementia, this factor clearly threatens the identity of the person with dementia. Locke's proposition of a person's identity being composed of accessible memories implies that a person in the late stages of dementia, with presumably poor access to memories, can also result in that person having little identity. Thus, accepting the Lockean view of identity at face value and applying it directly to dementia would, similarly to Descartes' view, imply identity loss is probable in dementia but that it is conditional on memory decline.

Philosophies of the continuity of identity were explored further (Hume 1748/2014, Luntley 2006). While Locke implied that in order to maintain the same identity, one must know whether one is the same as at an earlier stage, Luntley (2006) probed the possibility of identity being the same (continuous) as itself at any given point in time. However, many philosophers including Luntley (2006) came to the conclusion that it is simply impossible to discover whether identity is the same as itself in any given moment (Hume 1748/2014, Murdoch 1993). Hume (1748/2014) saw identity as momentary perception; he claimed humans are designed to forget what our identity was like before a point in time, but to remember the events around which the identity formed. He asserts that identity is purely a perception at any given time point, and that when we search for our identities, it may be that all we can find at one time is a bundle of perceptions and associated thoughts. More recent philosophers have also reflected on the idea of identity being unobtainable, both in people with and without dementia (Hughes, Louw and Sabat 2006, Murdoch 1993).

"Our moment-to-moment existence in normal life passes by without grasping it... What seems to be lost is not only the stream that binds the moments together but also the point of view at each moment" (Hughes, Louw and Sabat 2006, p. 30).

The ungraspable nature of identity suggests that it is not a static thing, but rather that it is constantly changing, never true or accurate but simply based on perceptions and memories available to us at any given point in time. These understandings are represented as inner identity in Figure 3.1. This visual attempts to depict how a person's awareness of a sense of continuity between past memories and the present moment is key to their perceived sense of identity in the present.

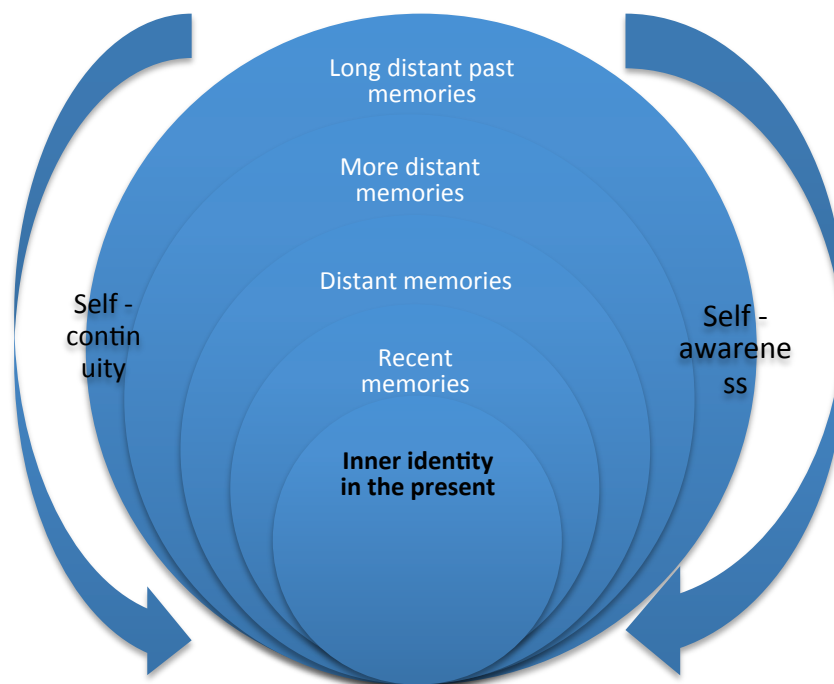


Figure 3.1 Inner identity.

Thus, Locke initiated the idea of a fluctuating identity by firstly identifying the importance of self-continuity based on our awareness of past memories. This notion was further developed in the sense that identity remembers events but cannot remember itself, or as Luntley (2006) describes it, identity is something which “...keeps track of things” but “...cannot be tracked itself”. Combined, these philosophical insights suggest that grasping identity at any given moment may be impossible.

“It is this transcendental identity that passes by too quickly to be recalled at any particular moment. It is the extreme of our empirical reach and cannot be grasped, neither in health nor dementia (Hughes, Louw and Sabat 2006, p. 30).

Seeing identity as something that cannot be tracked may imply that people with dementia do not lose track of themselves or forget themselves, as this is an impossible task in the first place. It may be possible to forget who we were in the past but philosophical insights seem to suggest it is impossible to forget oneself in any given moment. Unfortunately, this does not imply that the person with dementia is spared from the threat of losing their identity; instead it merely suggests that people with dementia may not be consciously aware of their identity loss. Thus, this insight alone may not be sufficient to offer some reassurance to people with dementia and the general public who fear forgetting themselves. Dementia erodes the capacity to remember or track external things and if the loss of this capacity is severe, then, according to Locke, this will amount to a loss of identity.

Nevertheless, accepting the notion that the continuity of identity depends largely on our access to memories can also have positive implications for upholding the thought that people with dementia can retain some identity. The fact that memory is usually impaired in a progressive way implies that losing your identity in dementia is also a gradual process. Therefore, as long as some memories are accessible, some sensation of having an identity is also retained as the condition progresses.

Furthermore, as mentioned in Chapter One, dementia usually impairs memories in the order of “last in - first out”. Thus, usually most recent memories are impaired first, followed by memories of the distant past and the long distant past. Accepting that identity is continuous with accessible memories in the present implies that any inaccessible memories to a person with dementia are no longer part of their perceived identity in the present moment. The identity of a person with dementia in the present moment is composed of their remaining accessible memories. In other words, if memories do not reach one’s consciousness and one is simply unaware of them, identity is only shaped by the last available memories. Figure 3.2 attempts to depict this point. Despite recent memories becoming inaccessible in early stages of dementia, the identity of the person does not disappear; instead, it achieves a sense of continuity with memories from a more distant past.

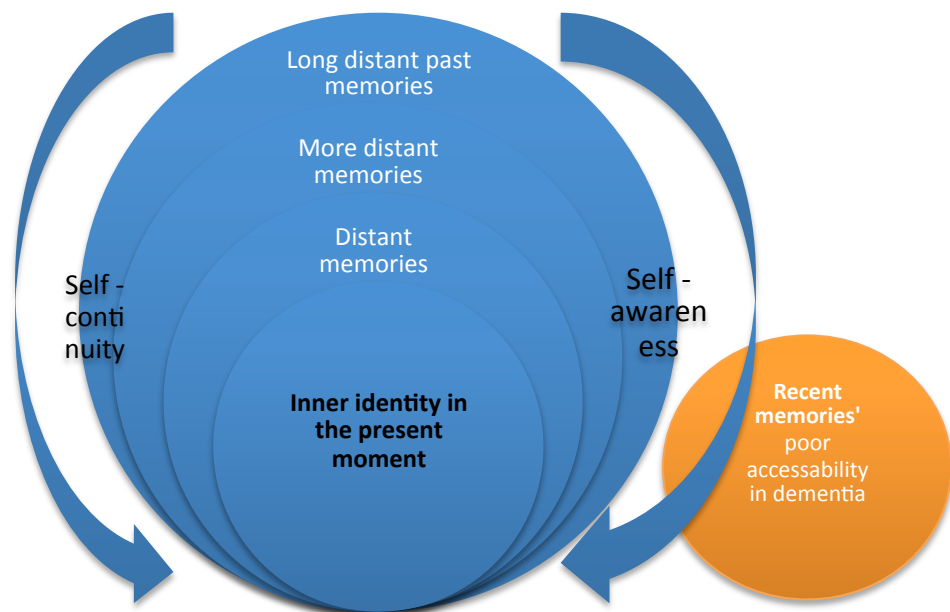


Figure 3.2 Inner identity in early stage dementia.

The view of losing identity as a gradual process seems to be in line with the view of people with dementia themselves. Robert Davis, diagnosed with Alzheimer's disease, wrote,

"The loss of self, which I was experiencing, the helplessness to control this insidious thief who was little by little taking away my most valued possession, my mind, had made me especially wary of the rest of my possessions in an unreasonable way"

(Davis and Davis 1989, p. 91)

"I'm slipping away a bit at a time... and all I can do is watch it happen."
(Pratchett 2008)

Thus, following Locke's proposition that identity is strongly dependent on our memories and that these are impaired gradually in dementia indicates that identities are also impaired gradually. This is in contrast with Descartes who sees identity as an all or nothing matter meaning a person can either have an identity or not. Nevertheless, his thinking brings back the notion that even though identity diminishes gradually, it is possible for a person with dementia to lose their *inner* identity completely if memories become completely inaccessible. This in turn would imply that there is only a transient time period in dementia progression in which a person is aware of their diminishing identity and can be supported to continue to evolve their self-continuity in the present moment. Furthermore, it would be of interest to this study, which aims at supporting identity by providing access to recent memories, to

explore if there is a critical threshold between identity loss and retaining an identity, even in a diminished state.

There are a number of empirical studies which provide some insight into the boundaries between a diminished identity and a complete lack of a sense of identity, by examining the impact of memory impairment on the sense of identity in people with dementia. These studies propose that autobiographical memory is fundamental to self-knowledge and self-narratives, enabling the association of past and present identities and contributing to a sense of continuity in identity (Addis and Tippett 2004). Addis and Tippett (2004) examined this relationship by administering two measures of autobiographical memory (the Autobiographical Memory Interview and autobiographical fluency), and two measures of identity (the Twenty Statements Test and selected identity components from the Tennessee Self Concept Scale). The scores from these scales were then correlated. The results show evidence for just six out of a possible 48 correlations between memory and the self-concept scale. The study concluded that only some aspects of identity in dementia may be directly affected by impairments in autobiographical memory.

Another study examined the relationship between autobiographical memory, identity and additionally, awareness of memory functioning, in people with dementia. The measures used also included the AMI and the Tennessee Self-Concept Scale, in addition to the Memory Awareness Rating Scale. The results suggest that lower levels of memory functioning awareness correlate with a poorer memory of the mid-life period; however, these contributed to a more positive and definitive sense of identity (Naylor and Clare 2008). The findings from both studies do not show a strong correlation between autobiographical memory and identity in dementia. However, this could be due to the very experimental approach to eliciting both memories of past events, and a sense of identity. This experimental structure of the measures used may not concord with the nature of autobiographical memory. The theoretical assumptions of autobiographical memory suggest that it is through a natural narrative about past events that people create their sense of identity (Naylor and Clare 2008).

Mills (1997) studied people with moderate to severe dementia in a longitudinal study through individual interviews. She found that the emotional memories recalled during interviews formed fragments of each person's identity. The participants recalled self-centred stories during interviews giving them a sense of narrative identity that gradually dissolved as the stories faded from memory with the

progression of the illness. Some participants whose memories were not so badly affected by dementia were able to retain their sense of identity (Mills 1997). Mills (1997) concluded that as memory loss progresses, the person's identity is further weakened, leading to a total loss of self.

Further support for the theoretical assumptions of the identity's origins in memory was presented by a study exploring the contributions of both the episodic and semantic memory to identity (Haslam et al. 2011). This study considered the impact of impairments in both semantic and episodic memory on one's identity. The semantic memory serves a different function and operates in a different way to episodic memory. Episodic memory has an autobiographical or personal nature, where specific episodes or events are stored, usually including information about that event. In contrast, semantic memory contains organised knowledge about the world and about language (Tulving 1983). The study found that both autobiographical and semantic components, with a dominance of the latter, were associated with the integrity of identity. Poorer retrieval of semantic self-knowledge was associated with lower identity strength (Haslam et al. 2011).

Thus, both the philosophical and empirical research reviewed support the assumption that memory is one of the resources necessary to retain a sense of identity in dementia. As empirical studies suggest, there is correlation between a deteriorating memory and diminishing identity in people with dementia, with an inevitable loss of a sense of self in the latter stages due to a lack of access to any memories (Haslam et al. 2011, Mills 1997).

This suggests that the transient time period in dementia progression, when a person is aware of their diminishing identity and can be supported to evolve their self-continuity in the present moment, is limited to the early stages of dementia. Yet again, some people may not even have insight into their diminishing identity. Given this point, this study aims to support identity by discussing recent events cued by images of recent memories. The boundaries for inclusion should be limited to those people in the early stages of dementia possessing an awareness of their condition or its symptoms. People in the early stages of dementia are still likely to have access to some memories and may be aware of their diminishing identity. People in the latter stages may no longer have access to recent memories and reviewing thousands of images captured in their recent past may be confusing to their identity, which is probably continuous with distant memories.

The above review thus confines potential participants who may benefit from SenseCam therapy to people in the early stages of dementia. The clarification of common memory impairment in dementia discussed in Chapter One suggests that dementia usually impairs memories in the order of last in - first out. This then infers that people in the early stages of dementia have limited access to their recent memories. Given that SenseCam captures recent events and is said to mimic episodic memories of recent events, it may be an ideal tool to support people with dementia accessing their otherwise poorly-accessible recent memories. A technical question is whether providing access to these recent memories externally can help extend an internal sense of continuity between present identity from recent inaccessible memories and from accessible distant past memories.

In summary, the discourse on inner identity reviewed some of the philosophical constructs of identity in humans. The Cartesian and Lockean theories of identity both focus on the mind as opposed to the body, and both explain personal identity in terms of inner thinking although they only consider persistent thought. Descartes asserts that identity is present solely in one's intellect at any given time point. In contrast, Locke gives an account of memory and explains identity in terms of the continuity of consciousness based on memories (Locke 1690/2012). Locke's account of identity does not seem to be directly in conflict with Descartes, rather it is a further development of the theoretical perspectives on inner identity.

While these philosophical perspectives were not theorised in terms of diminished identity relating to dementia, they still offer some insights into the question of identity loss in dementia. Directly accepting Descartes' notion "I think therefore I am" would imply that dementia diminishes a person's identity by impairing their ability to think. Similarly, applying the Lockean ideology of identity, in terms of the continuity of consciousness based on memory, to the condition of dementia directly also implies that identity can be lost entirely when people with dementia can no longer access their memories. Thus, if we philosophically consider from this perspective the question of whether it is possible for a person with dementia to lose their identity entirely, the answer is "yes", it is. These perspectives are only contemplations in terms of dementia and the issue of diminishing identity.

Acknowledging early philosophical theories on identity in humans also offers some perspectives in terms of supporting identity in dementia. Firstly, there may be some reassurance for people in the fact that identity can never be grasped at any given

moment, and therefore it is impossible to forget oneself and be aware of it. Secondly, the perhaps-renowned notion of identity, where its continuity depends on access to memories, emphasises that people with dementia should be supported in making inaccessible memories accessible again in order to extend continuity between recent events and the present moment. Thirdly, given that identity loss is a gradual process driven by progression in memory impairments, it seems more plausible to use SenseCam images of recent events to support people in the early stages of dementia that are aware of their diminishing identities and with whom some memories are still accessible. Furthermore, if supporting people with early stage dementia, the focus should be on facilitating them in accessing memories of recent events, as these are impaired first in early dementia, as opposed to distant past memories. This isn't to say that people in later stages of dementia should not be supported in their having a sense of identity. People in later stages may still be supported by upholding a sense of identity; however, other cues, perhaps from the more distant past, may be more suitable at reflecting their identity through a sense of continuity with more distant memories.

The key inferences from the above discourse provide direct insight into this study aiming to support people with early dementia in maintaining their sense of identity. As such, philosophical theory suggests that we should focus on recent memories in order to support people with early dementia in having a sense of identity. In this light, the characteristic features of SenseCam to capture these recent memories sound promising. The concern of this thesis is whether SenseCam can act as an external prosthesis for recent memories and extend the continuity link between present identity in the present moment to that of the recent and more distant past.

3.3 Outer Identity

While the discourse on inner identity suggests that it is possible for identity to become eroded and lost in dementia, there is evidence in human sentience and in the body, or remaining “outer shell”, that the concept of identity may be more complex than just a location in the mind. The discourse on inner identity offers some hope for the idea of supporting people with dementia in maintaining their sense of identity. However, that hope is confined to only those people in the early stages of dementia with a diminished identity, as opposed to people further along the dementia spectrum with severely eroded thought and memory processes. Furthermore, the opportunity to

support people in the early stages in maintaining their sense of identity is limited to progressing memory impairments. The philosophical discourses deriving from Descartes and Locke imply that identity is dependent on the inner processes of the very thinking and memory whose failures are signs of dementia. Thus, applying the theoretical basis of inner identity directly to dementia would suggest that, with progression of the condition, inner identity disappears.

However, even if this inner identity is eroded and lost in dementia, the “outer shell” still remains. Even if inner identity has been eroded, an individual’s sentience, and their ability to feel things such as pain and comfort remain. People in the late stages of dementia with severely impaired memories and thinking show they are still human beings with motivations, longings and desires, humour, emotion, embarrassment and love (Feil 1993). These emotions, needs and attachments persist into the very late stages, long after the loss of inner identity. Thus, being a human suggests that identity goes beyond purely cognitive abilities. More recent philosophers have developed theories in contrast to the basis of this inner identity ideology.

The sole focus on inner cognitive processes dominating the discourse on inner identity has been criticised and even referred to as “hypercognitivism” (Post 2000, Whitehouse and Daniel 2008). Post (2006) questions why human identity should be so restricted. Also, where does this inner identity view leave us ethically and morally in the cases of people in the very late stages of dementia? It seems reasonable to question the notion that a person’s identity is merely based on their cognitive abilities and on continuity or self-consciousness.

The discourse on outer identity explores the emphasis of a person as a being in the world. This notion of outer identity is a broad one accommodating the rich multi-textured, multi-layered ways in which an individual can be in the world.

“The person is in a world just as the mind is constantly world involving. The person occupies public space: bodily but also by the use of language, which involves relationships with others. The person is situated and constituted by its situatedness.” (Hughes, Louw and Sabat 2006, p.34)

Thus, discussing outer identity moves the discourse beyond whether identity is maintained by the body, the mind, the brain, or some mixture of these. The crucial point is that they all belong to a person who is deeply embedded in the multi-layered context of human interaction. This is what Kitwood introduced by emphasising the

importance of personhood in the care of people with dementia. Personhood was defined by Kitwood (1997) as a *“standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.”*

The outer identity perspective highlights the importance of the world outside the head, in which real people participate, including people with dementia (Hughes, Louw and Sabat 2006). While some philosophers, naturally enough, engage with Locke’s work, those who also work in practice look more naturally at the work of Kitwood in thinking about personhood (Hughes, Louw and Sabat 2006).

“This is because the experience of practical engagement with people with dementia cannot but emphasize how it is that the person’s identity is more than simply the connections between their memories” (Hughes, Louw and Sabat 2006, p. 29).

Outer identity is therefore about the relation between the mind and the world. It is all about what constitutes meaningful and emotional experiences such as sadness, happiness, being in love, remembering you love someone.

“...mind and world are not according to externalism metaphysically independent categories, sliding smoothly past each other.” (Hughes, Louw and Sabat 2006, p.16)

These understandings are represented in Figure 3.3. This visual attempts to depict how a person’s situatedness in the world changes in everyday life in light of their emotions and sentience.

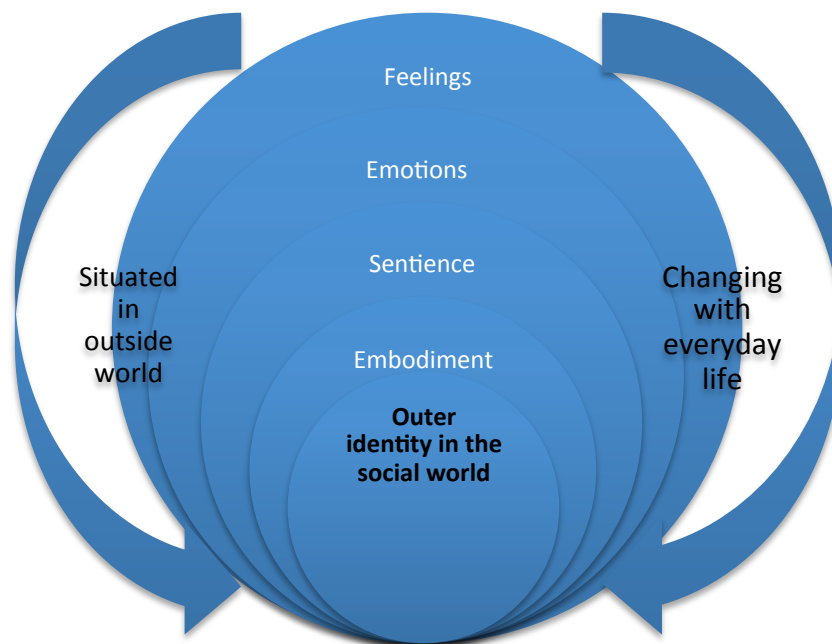


Figure 3.3 Outer identity.

Thus, by emphasising the role of other people in identity formation and evolution, outer identity highlights the importance of social interaction. The modern world presents many social encounters to individuals so as to confirm that their identity may not be formed independently of them. Through face-to-face interactions and media encounters, one can see who an individual is and what the individual can be (Holstein and Gubrium 2000). Outer identity is socially constructed, derived from and changing with everyday life.

The significance of social interactions to identity formation and maintenance has not been ignored in philosophical theories. Mead and Morris (1934) proposed that identity formation is a dynamic, never-ending process where identity constantly engages in an internal dialogue between the “I” (unique individuality) and the “Me” (social identity formed based on interactions with others). Mead suggested that individuals cannot establish identities without reflecting on their social interactions, thus suggesting that any new social endeavour affects one’s sense of established inner identity. In this way, the identity of individuals is seen as fluid and open to change, but also deeply reflexive and mirroring the surrounding social world. This leads to an understanding of identity as a phenomenon characterised by interpretation, variability, relativity, fluctuation and difference. Mead’s ideas were the beginning of a new perspective which viewed identity through a symbolic interactionist approach. Symbolic interactionism focuses on the way identity is formed and maintained

through interactions that take place with other people. It suggests that individuals can learn about their identities from their social group, or that they can learn independently by reflecting upon these social interactions. The actions of individuals are based on meanings that they create when interacting with other people or objects. Thinking is seen as an inner conversation with oneself, similar to social interaction such as a conversation with others. Mead and Morris (1934) argue that both forms of communication are interactive, reflexive and of equal value in forming identity.

Mead's assertions concerning the importance of internal dialogue and inner identity being influenced by social interactions have implications for the way we should support people with dementia in making meaning of their identities. Namely, people with dementia should not only be supported in accessing their recent memories, but also given opportunities to discuss them with others. In other words, people with dementia need to share their memories with themselves and with other people around them in order for their identity to become established within the social world. This finding has a direct influence on this study. Explicitly, the importance of sharing and reflecting upon memories within social interactions would suggest that value is not necessarily in SenseCam images per se, as they are merely the way to access unavailable recent memories. Instead, the value is in the interactive way these images are reviewed in conjunction with the person who has dementia.

Furthermore, it has been argued that in order for a person to establish their identity within the outer world, social interactions should enable them to form a narrative based on their memories. Narrative is defined as a spoken or written account of experiences or events. The basis of identity in memory conjoins with the narrative approach when theorising about identity creation and maintenance. The theoretical foundations of identity in memory suggest that narrative is necessary to extract autobiographical memories and to re-live recalled experiences. The narrative is therefore seen as an indispensable link to memory and social interaction when constructing and making sense of our identity.

It has thus been suggested that the ability of a person to construct and communicate a narrative is essential to their construction and updating of identity (McAdams 2004). The personal stories or narratives that people tell represent, in some way, who they are. Without the enquiry of a personal narrative, a full understanding of a person's identity does not seem possible (Singer and Blagov 2004). McAdams proposes a life story theory of narrative identity. Individuals

comprehend their lives in evolving narratives that situate them within particular interpersonal, ideological and cultural contexts (McAdams 2004, McAdams 1996). He further argues that these stories speak directly about identity, and states that “identity is itself a life story” (McAdams 2004). The life story theory of identity is usually shaped into life chapters moving in and out from particular episodes that stand out to an individual and finally moves into accounts of future goals and plans. These life chapters can be seen as reconstructed memories of the past, and the future goals as representations of an anticipated future (McAdams 2004). The self-defining narrative or life story therefore links together the past, present and future. Singer and Blagov (2004) build on this theory and argue that a narrative allows individuals to intertwine both future goals and accumulated past memories into a self-understanding, coherent picture of self.

However, the use of narratives for communication, and in turn, for the formation of identity, is a complex process. Personal narratives can inform us about identity through the way they are constructed and by what they contain (Holstein and Gubrium 2000). The storyteller carefully selects events to form a story of their life experiences from all available resources. The resources can be any and all experiences or biographical particulars that can be incorporated into a life story. There is a consistent interplay between what resources are available and which ones are chosen to form a narrative whose assembly depends on the availability of these resources. Biographical events are the most readily available resources for identity construction. The self is to some extent constructed from what an individual decides to notice from their immediate and distant past. However, identity is not fully predefined by the autobiographical past, and it is through the process of careful selection and narration of specific events that it is assembled. Biography is therefore one of the resources used for assembling identity. It is through the selection of past events to form a coherent story that these experiences and the associated identity gains meaning and understanding.

The content of a narrative is also locally constrained by cultural contexts and time (Holstein and Gubrium 2000). Narrative identity is therefore occasioned, always influenced by particular places and times, circumstances and local relevancies (Holstein and Gubrium 2000). The stories of self do not simply just happen; they are actively composed through relationships with others. The storyteller often edits the narrative according to the audience. As a result, a narrative identity can show

diversity depending on the context in which the stories are told. The way that narrative is constructed depends on the space given in an ordinary discussion for identity narration. Discussion is both retrospective and prospective in nature, as one needs to take into account what has been said previously and what is anticipated to follow (Holstein and Gubrium 2000). A narrative, however, takes more than a single sentence; therefore, the listener needs to allow the storyteller to talk over a longer period of time. Stories emerge from an on-going flow of talk and usually fit into what has preceded them. Anything can trigger a narrative during a discussion, especially a memory of a particular event. However, the emergence, meaning and relevance of a story to the self are not pre-given; rather, they could be best perceived as a complex social activity that is managed as a discussion unfolds (Holstein and Gubrium 2000). Thus, to understand identity, one needs to carefully examine both the content put into a story and also the way in which it is introduced, developed and completed within the interaction.

The above theoretical perspectives suggest that narrative is key to identity formation and, combined with memory and social interaction, intertwines to form the core of human experience (Beike, Lampinen and Behrend 2004, McAdams 2004). This in turn implies that the deterioration in memory and language skills that is inevitable in dementia may affect someone's ability to have a strong awareness of their sense of identity. The narrative necessary for identity maintenance is based on recalling memories from the past and it is the very memory of this immediate past that is most threatened by dementia. Furthermore, a person with dementia may experience difficulties in their language skills due to the progressive deterioration of their working memory. People with dementia may experience an inability to hold and use information during communication with others. Consequently, the narrative of the person with dementia may become repetitive and difficult to follow.

Thus, realising that the impairments associated with dementia have significant impacts on identity loss unravels more of the unknown of what happens to identity in people with dementia. Consequently, it also informs the way we should support people with the condition to maintain their sense of identity. Namely, the goal of any intervention aiming to support people with dementia to maintain a sense of identity should be to elicit personal narratives about recent memories, from within social interactions. While appreciating the extent of how challenging this may be, the aim of SenseCam therapy is to elicit narratives about recent memories as captured and cued

by SenseCam images, from within social interactions alongside the researcher and carer. This in turn should support the person with dementia to continue evolving their identity.

Similar studies have been carried out using a participatory story-telling approach, where all the significant people in the life of a person with dementia were interviewed (Crichton and Koch 2007). The social network of the person with dementia tells the stories about, for and with them. Crichton and Koch (2007) suggest that such interactions reproduce and reconfirm the person's identity. They call this phenomenon "curating" identity. The authors also reflect on how the process of curating identity draws on the linguistic and interactional nature of a narrative (Crichton and Koch 2007). As curating identity is prompted by the loss of memories from the recent past, social networks are responsible for remembering these events for the person with dementia. Following that, the linguistic nature of the narrative enables the curation process to recreate and reinterpret past experiences of an individual with dementia. The narrative enables the social network to present the identity of the person with dementia through past events included in the story, but also through the character represented. The interactive nature of the narrative allows the person with dementia to participate in the story-telling process to confirm parts of the story told by the social network. The interaction can also serve different roles depending on what is desired, whether this is to evoke, justify memories, share funny stories or seek support (Crichton and Koch 2007).

In summary, the discourse on outer identity has reviewed some of the theoretical and more practical perspectives of human identity. Predominantly it outlined that there is more to identity than the mere inner cognitive abilities of a person. The inner identity of a person is embedded in an outer world composed of society and various social interactions.

"People sometimes say that the human brain is the most complex item in the universe. But the whole person of whom that brain is part is necessarily a much more complex item than the brain alone. And whole people can't be understood without knowing a good deal both about their inner lives and about the other people around them. Indeed, they can't be understood without a fair grasp of the whole society that they belong to, which is presumably more complex still." (Midgley 2001, p. 35)

The discourse on outer identity explored the complex ways in which an

individual can be in the world. Two key processes through which a person establishes and maintains their inner identity within the world were considered. In particular, the processes of social interaction and narrative formation through communication were reviewed. Outer identity requires relationships with another person, preferably through the same language, which enables a discursive community where meanings can be conveyed, understandings can be achieved and intentions can be shared. Furthermore, understanding the basic processes of identity as lived in the outer world implies that identity can survive right to the final stages of dementia. Social interaction and communication can happen despite an inability to remember or think. We can interact by comforting an individual, which they may respond to with a smile to show their enjoyment or with some other less pleasing response. This implies that identity remains long into the progression of dementia and every effort should be made to maintain the personhood of people with dementia. This thus seems very relevant to people with dementia whose “inner identities” are at such risk (Hughes, Louw and Sabat 2006). This discourse extends Descartes’ notion from “I think therefore I am ” to “I think, I feel and I relate, and therefore I am” (Post 2006).

This opens up possibilities through which a person with dementia can be supported in maintaining their sense of identity. Specifically, any intervention aimed at supporting people in the continuance of identity should emphasise the importance of social interaction and communication to upholding a person’s identity. Kitwood highlighted the importance of social interaction in relation to personhood as introduced in Chapter One. He suggested that it is the manner of social interaction that is of relevance to upholding one’s personhood. Kitwood first introduced the idea of malignant social psychology discussed in detail in Chapter Two. According to Kitwood (1997), engaging in negative interactions can be damaging to the personhood of people with dementia. Similarly, engaging in positive interactions can be beneficial to the personhood of people with dementia. Accordingly, in this research the role of the therapist is not undermined but instead seen as part of the process of reviewing SenseCam images and supporting participants to maintain their sense of identity. The processes of SenseCam therapy should thus support participants in reflecting upon their recent memories by enabling them to form narratives about these. This in turn should support the person with dementia with continuity of their awareness of their sense of identity.

3.4 Summary

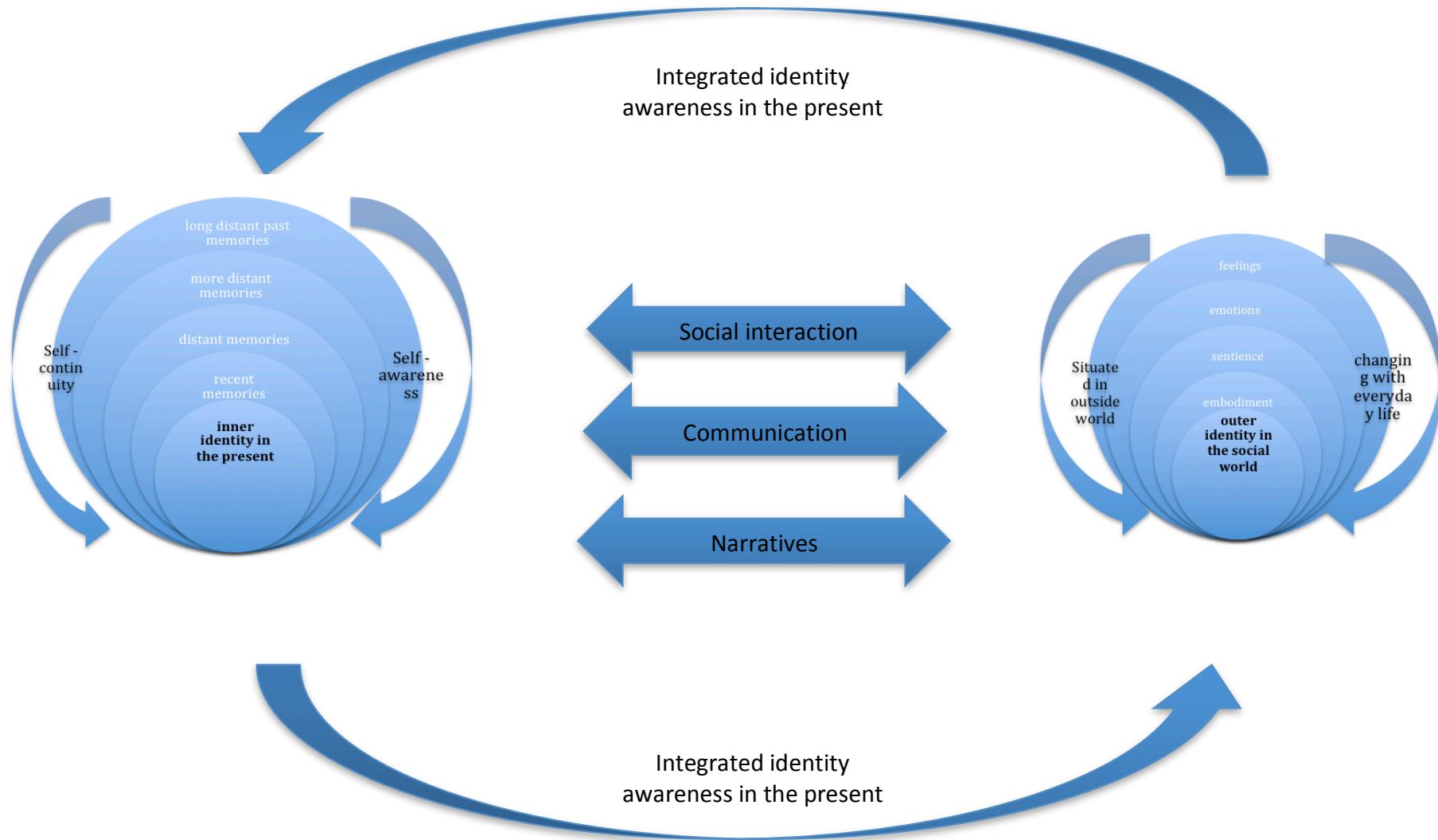
In summary, the review of selected philosophical perspectives on inner and outer identity informed an understanding of identity loss and maintenance in dementia. The inner view of identity highlights the importance of memories formed throughout one's lifespan to one's continuity in the present. A person can only achieve self-continuity and self-awareness based on the memories that are available to them. The outer view of identity situated inner identity within the external world, by emphasising feelings and embodiment. Both perspectives are complementary to each other based on their assumptions that identity is constructed within the inner mind and situated within the outer social world. Furthermore, it is through the complex and multi-layered processes of social interaction, communication and narrative formation that people make meaning of their inner and outer identities and experience an awareness of a sense of integrated identity in the present. This integrated approach to understanding identity is represented in Figure 3.4. This visual attempts to depict how a person's awareness of their sense of identity in the present fluctuates constantly, depending on the resources available within their inner and outer identities, as well as due to the processes taking place among them including social interactions and communication.

“One of the factors at work here is the extent to which our minds can no longer be regarded as entirely inner. The boundaries between inner and outer are decidedly porous. It is not that there is no such thing as the inner experience – the subjective world is not an illusion – it is just that the real world of the mental is not neat and tidy. In a messy way, it involves the outer world”. (Hughes, Louw and Sabat 2006, p. 15).

Thus, for the purpose of this thesis, identity is understood as a dynamic concept that changes as influenced by inner processes including memories as well as by outer processes involved in being situated in the world. Hence, in any given moment, our identity is evolving and in a constant state of flux. This understanding is also in line with the philosophy of social constructionism in that there is not one true version of identity; it is constantly changing and being re-constructed as it is influenced by social interactions. Thus, identity can be understood as a momentary awareness in the present moment, an awareness that does not remain true but constantly evolves with the person as they are situated in the world. Thus, this

research does not reject the idea that memory or continuity are important to identity. Instead, for the purpose of this thesis, a view is adopted that accepts the continuity of identity evolving through people's lives and the social worlds they live in. This allows for many different ways to intervene when identity diminishes. This can be seen as an opportunity for proactive engagement with people with dementia.

Figure 3.4 Integrated identity awareness in the present.



Dementia poses a risk to identity at a global level, meaning that both inner and outer processes involved in identity construction can be affected. Memory impairments are often a hallmark symptom of dementia. Short-term memory, including memories of recent events, is usually affected first, which can be challenging to a person's evolving inner identity. These changes within the inner processes of memory can be damaging to the person's identity and they may be happening in hindsight, without the person with dementia being aware of them.

In addition, receiving a dementia diagnosis or having an awareness of the symptoms associated with dementia may have a conscious impact on the person's identity as situated in the outer world, in a similar way that knowledge about other illnesses impact on a person (Gillies and Johnston 2004). The person might deny or accept their new condition. They may also change perceptions of their identity and classify themselves into a new social group i.e. as ill or demented, or refuse to see themselves as ill. Societal perceptions of dementia vary and can have either positive or negative effects on a person's evolving sense of identity (Kitwood 1997). Stigma can be very damaging to a person's sense of identity, whereas social support in coping with the new condition can have a positive impact. The way people respond to their illness may also vary according to their past experiences, abilities and environment (Pearce, Clare and Pistrang 2002).

As discussed in the previous chapter, research suggests that often people with dementia struggle with their sense of identity and in coping with their new condition (Pearce, Clare and Pistrang 2002, Clare 2003, Rankin et al. 2005). They often go through a conflicting endeavour of self-maintaining and self-adjusting influenced by various ways of coping as well as by societal stigma. It is possible that these self-maintaining and self-adjusting models of coping with dementia are also influenced by the memory impairments associated with early stage dementia. As discussed in Chapter One and depicted in Figure 1.3 (pg.14) and Figure 3.2 below, distant memories are more resilient in the initial stages of dementia and therefore may act as a force to maintain a prior sense of identity. In contrast, recent memories are those most affected and they may be too weakened to stimulate the person to self-adjust in light of their dementia.

A common theme noted in these studies is a tension or conflict within a person's sense of identity in the present due to the simultaneous endeavour of self-maintaining and self-adjusting in light of their dementia (Pearce, Clare and Pistrang

2002, Clare 2003). Some of these processes are happening in hindsight or unconsciously. People may not know how to deal with the conflicts happening to them and rarely ask for help. As a result, people with dementia are rarely supported in retaining their sense of identity during this unsettled period. Combined with progressive attacks on the inner processes of memory necessary to identity, people tend to accept a downgraded and less preferable sense of identity (Pearce, Clare and Pistrang 2002).

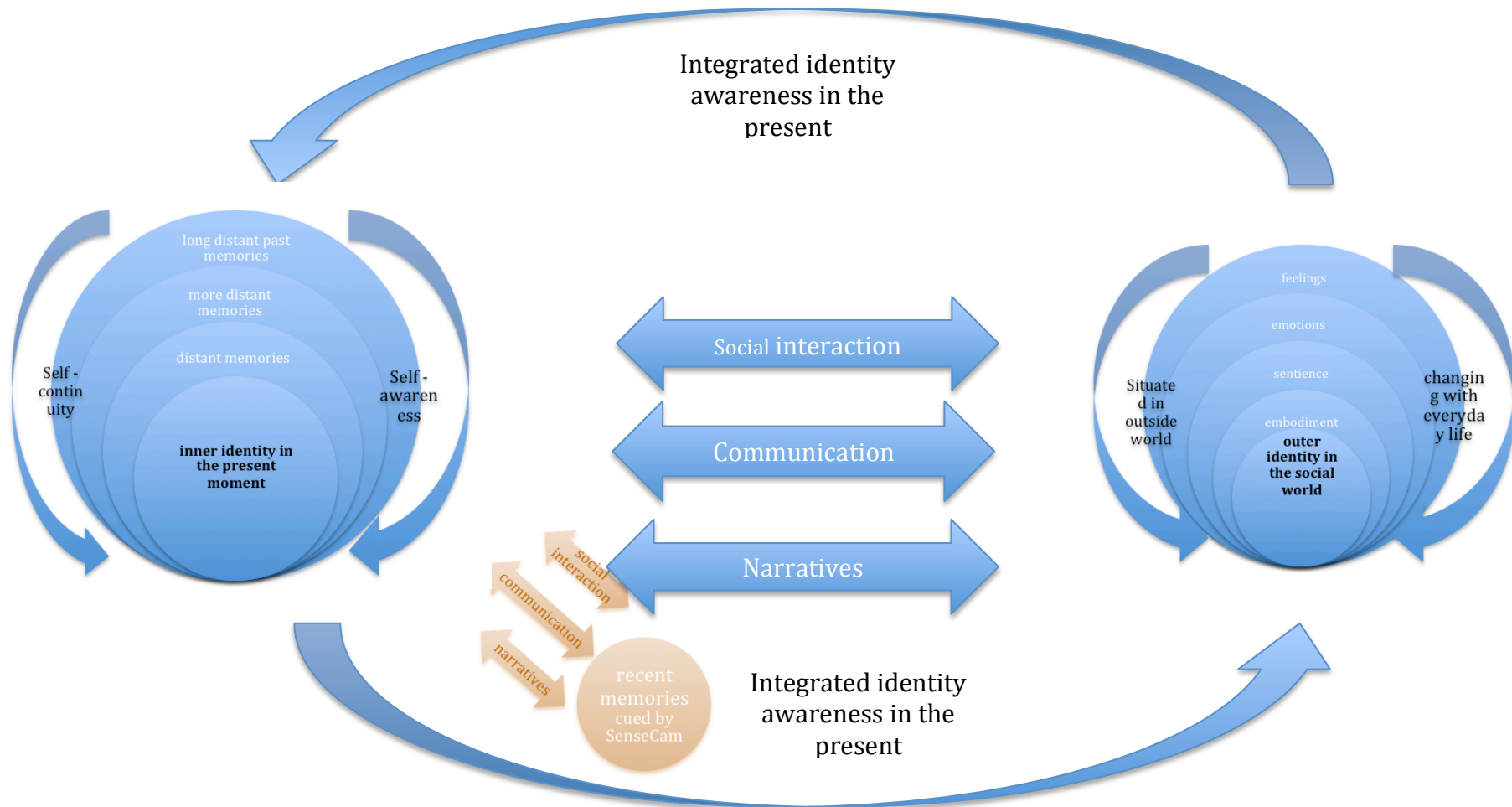
Previous research suggests that people with dementia should be supported in the process of balancing these tensions between wanting to maintain an existing or prior sense of identity, and in needing to adjust their sense of identity in light of cognitive and societal changes (Pearce, Clare and Pistrang 2002). In line with these findings, this thesis explores how using SenseCam with people with dementia can assist and support people in the delicate balancing act of maintaining and reconstructing a sense of identity. Furthermore, it is accepted that identity is constantly fluctuating and that a true version of identity does not exist; it may not be possible to maintain a true or prior sense of identity. Instead, for the purposes of this thesis, the view that one can merely feel or sense a momentary perception of dynamic identity is adopted, which a person makes meaning of through social interactions. Hence, this study is neither aiming to help people maintain a prior sense of identity or to re-construct a new identity. Instead, this study aims to support people with dementia in retaining an awareness of having an identity in the present moment, even if that identity is in constant flux between self-maintenance and self-adjustment. It is this awareness of a sense of identity, whatever it may be, that is important to retain for people with dementia. They should be supported in maintaining an awareness of being individuals, living and being involved in this world. If we accept that people with dementia are entitled to hold a sense of identity, we will support the notion that they have a personal existence in the present moment.

This research explores how, by reviewing cues to recent events in the form of SenseCam images, discussion can be stimulated to connect the present with the recent and distant pasts. This study aims to explore whether presenting people with dementia with evidence of their recent existence in the form of SenseCam images can encourage communication about themselves in the present moment. Thus, SenseCam therapy aims to support people in maintaining their sense of identity by helping them to make meaning from their fluctuating perceptions of identity in the present moment.

The integrated view of identity applied to SenseCam use in early stage dementia is presented in Figure 3.5. This visual attempts to depict how SenseCam therapy acts as a replica or prosthesis for the resources responsible for diminishing identity in people with dementia. The therapy will be delivered by replicating the usual processes taking place when establishing an awareness of a sense of identity in the present. SenseCam images of the recent past will be used as cues for recent memories impaired by dementia. The images will be reviewed within social interactions and communications between the therapist and the person with dementia, in order to support them in making meaning of their sense of identity by encouraging the creation of a narrative in the present. The goal is to extend a person's continuity from the present to recent memories (impaired by dementia) and to distant past memories. The overall processes of SenseCam therapy are situated within a bigger context of an integrated awareness of the sense of identity in the present.

In conclusion, this chapter on the impact of dementia on identity has informed the way in which SenseCam will be used in this research. Explicitly, SenseCam images are seen as cues to access recent memories that are no longer available to people in early stage dementia. However, value is not necessarily gained from the SenseCam images per se, as they merely provide access to unavailable recent memories which are formative for inner identity. The therapist should be seen as a person who enables the construction of meaning about these images, which in turn should support the person to continue to evolve a strong sense of identity. The therapist thus plays a significant role in supporting people with dementia evolving their identity as part of this SenseCam therapy. The question is whether this will be sufficient to extend the links of self-continuity of participants from their present lived identity to memories of their recent past and to those of the distant past, and whether that is beneficial to the overall wellbeing of people with dementia.

Figure 3.5 Integrated identity awareness in the present applied to SenseCam use in early stage dementia.



Chapter 4

Psychosocial and Technological Dementia Interventions

This chapter provides an empirical review of the existing early psychosocial and technological interventions in dementia. The previous chapter discussed identity in dementia by focusing on both the inner and outer processes. Thus, the focus of the review in this chapter is on interventions aimed at stimulating both the inner processes of cognition as well as the outer processes including interaction and communication in dementia. I outline a rationale for SenseCam therapy design by merging together the theoretical review of identity in dementia and the empirical evidence of existing psychosocial interventions. The rationale illustrates how SenseCam therapy was designed as an intervention to support people with early stage dementia in continuing to have a sense of identity in the present.

4.1 Psychosocial approaches supporting cognition and social interaction

Psychosocial interventions originate from the psychosocial understanding of dementia and focus on psychological and social therapies rather than pharmacological treatments (Moniz-Cook and Manthorpe 2009). They aim to improve cognitive abilities (cognitive stimulation, cognitive rehabilitation), review past memories (reminiscence, life review), enhance emotional well-being (validation), stimulate senses (aromatherapy, music therapy) and promote everyday functioning (occupational therapy). The focus of this review will be on interventions aiming to stimulate cognition especially accessing

recent memory via social interaction, as the theoretical bases previously discussed suggest this may support the sense of identity in dementia. The majority of psychosocial interventions include an element of social interaction in their approach to delivery (Kitwood 1997). Even though their main aim may be on specific cognitive functions, social interaction commonly underpins most interventions. The interaction is manifested through the person administering the intervention or through involvement of family as well as formal and informal carers.

There are three main types of psychosocial interventions directly aimed to support cognitive functioning in people with dementia (Oyeboode and Clare 2008). These include cognitive training, cognitive rehabilitation and cognitive stimulation therapy. This review does not address these in depth but discusses the empirical evidence for general cognitive benefits and their limitations.

Cognitive training focuses on the exercise of tasks, which focus on specific domains of cognition such as memory, language or executive functions. The anticipated effect is delayed deterioration in the selected domain functioning or even an improvement. The modalities through which the training may be offered range from pen and paper to more advanced IT systems discussed in more details later. The typical training activities may include crosswords, sentence completion and memorising names of objects. The variety of cognitive training available to people with dementia makes its effectiveness hard to review in terms of empirical evidence (Oyeboode and Clare 2008, Spector et al. 2000).

Cognitive rehabilitation aims to enable people with cognitive impairments to achieve their optimum level of functioning and well-being through limiting their disabilities. Central to this process is the collaborative identification of personal outcomes and the development of interventions to address them (Clare 2005). Cognitive rehabilitation interventions draw upon a mixture of approaches aimed at restoration of function, implementation of compensatory strategies and environmental modification. While initially developed primarily for people with non-progressive brain injury, this approach is equally applicable to people with progressive conditions such as dementia (Clare 2008).

The aim of Cognitive rehabilitation for people with dementia is to deal with a variety of problems arising from cognitive impairment rather than aiming to cure or reduce cognitive impairment at the neurological level. The goal of cognitive rehabilitation is to enable the person with dementia to participate in their desired activities by focusing on their strengths within their own social contexts (Clare 2005).

The rehabilitation works to identify specific strategies for dealing with difficulties resulting from changes in memory or other cognitive domains. According to Clare (2005), the psychosocial understanding of dementia also influences cognitive rehabilitation and an important aim is to empower individuals by strengthening the sense of self and of being in control. She further argues that in order to achieve that it is important to take into consideration personal coping strategies for dementia. Thus, all cognitive rehabilitation interventions should be individually tailored and should focus on real everyday situations and difficulties. The starting point should always involve identification of desired outcomes by the person with dementia or their family, followed by the design of a specific intervention based on cognitive abilities and taking into account the coping strategies. Cognitive rehabilitation interventions draw on a range of principles and methodologies, all with demonstrated usefulness for people with dementia. These can include space rehearsal, cueing or prompting. As cognitive rehabilitation is a relatively new approach to improving well-being in dementia there is only preliminary empirical evidence suggesting that cognitive rehabilitation interventions can produce significant improvement in targeted areas, at least for a proportion of participants (Clare 2008). The most recent Cochrane review of the effect of cognitive training and rehabilitation on cognitive and non-cognitive outcomes focused specifically on mild to moderate Alzheimer's disease and vascular dementia (Bahar-Fuchs, Clare and Woods 2013). The review included 11 RCTs of cognitive training and a single trial of cognitive rehabilitation. The authors concluded there was no evidence for the efficacy of cognitive training in improving cognitive functioning, mood or activities of daily living in people with mild to moderate Alzheimer's disease or vascular dementia. The single trial of cognitive rehabilitation provided preliminary indications of the potential benefits of individual cognitive rehabilitation in improving activities of daily living in people with mild Alzheimer's disease (Bahar-Fuchs, Clare and Woods 2013).

Cognitive Stimulation Therapy (CST) evolved from Reality Orientation (RO), and can be tracked back to 1958. Its rationale is to try and re-provide information that people have lost through neurological impairment (Holden and Woods 1995). The varieties of RO include: *informal RO* where the person is continuously reminded of place, time and person at the point of every interaction with staff; *formal RO* which consists of sessions or classes where the person is presented with information on current affairs that encourage discussing them in the past-present format; and *attitude RO* where the staff are encouraged to use attitudes such as kind firmness and friendliness towards

the people (Holden and Woods 1995). RO has usually been conducted in residential or care settings and was one of the first structured psychosocial interventions for people with dementia (Clare 2008). However, the highly structured method was abused and in some cases became mechanistic and confrontational. Therefore, RO has become unpopular in the recent years and alternative approaches such as validation therapy (Feil 1996) have been developed. Nevertheless validation therapy also failed to provide a strong evidence base for its effectiveness. Subsequently, a Cochrane review on RO also recognized the need for large and well-designed multi-centre trials on therapy for dementia (Spector et al. 2000). This steered the development of CST from RO, aiming to improve and develop the programme to evidence-based therapy focused on cognitive stimulation (Spector, et al. 2003). The development of the programme also involved a general review of psychosocial therapies, especially reminiscence therapy (Woods et al. 2005). CST was evaluated in a RCT, which included 201 participants. Participants were randomised to treatment or activities as usual and the CST group improved on measures of cognition and quality of life (Spector et al. 2003). The trial also showed positive trends in communication. Further studies identified that certain areas of cognition display greater improvement than others after the therapy (Spector, Orrell and Woods 2010, Woods et al. 2012). The cognitive domain displaying significant difference between the treatment and control group was that of language. These results provide empirical evidence suggesting CST does appear to have a particular benefit in prompting language function, which is likely to lead to more global cognitive benefits (Spector, Orrell and Woods 2010).

CST aims to optimise cognitive function using a range of mental activities including reminiscence, sensory stimulation, recognising people and objects, word and number games, physical games and singing and orientation. CST treatment involves 14 sessions of themed activities, which run over a seven-week period. Sessions aim to actively stimulate and engage people with dementia, whilst providing an optimal learning environment. CST focuses on strengths and abilities and is careful to avoid situations which erode self-esteem (Spector et al. 2003). The empirical evidence suggests that providing cognitive stimulation therapy alongside the usual care for people with mild to moderate dementia in both day-care centres and care homes is likely to be more cost-effective than the usual care alone (Knapp et al. 2006). As mentioned in Chapter One The National Institute for Clinical Health and Excellence (NICE) guidelines on dementia encourage administration of CST stating that all people with dementia should be given the opportunity to participate in a structured group of

cognitive stimulation programme (National Institute for Clinical Health and Excellence 2006).

Since the growing body of empirical evidence supporting CST, a new development of Individual Cognitive Stimulation Therapy (iCST) has commenced (Orrell et al. 2012). The concept is that family carers can deliver the therapy in their own homes. The principles and frameworks of delivering themed activities within a therapeutic, opinion based discussions remain the same however, the number of sessions increases to two to three weekly over twenty-five weeks instead of seven weeks as practiced in group CST. The study protocol for an RCT has been developed and a trial is currently in progress. The potential benefits include improved well-being of people with dementia and family members as well as social and economic benefits (Orrell et al. 2012).

The other most empirically researched interventions aimed to stimulate cognition of people with dementia include reminiscence therapy and life story work. Reminiscence therapy involves the sharing of memories often induced by prompts like old photographs or postcards, songs or newspapers (Woods et al. 2005). Reminiscence is one of the most popular psychosocial interventions in dementia care. Reminiscence can be practiced either as a group therapy or individualised therapy and is suitable for most stages of dementia (Adams and Manthorpe 2003). Individualised family-based reminiscence may even strengthen family relationships. People with early stage dementia may experience word-finding problems, social withdrawal and reduced communication, which in turn can be the cause of weakened family relationships (Carr, Jarvis and Moniz-Cook 2009). Reminiscence activities can be used in the early stages as a tool to stimulate communication, reinforce and demonstrate retained skills, and to authenticate personal achievements. Reminiscence therapy allows an individual with dementia to share their own unique stories and to reflect on their past, present and future lives. The person's sense of identity may be strengthened through reminiscence creative activities (Carr, Jarvis and Moniz-Cook 2009). People with mild to moderate dementia may find learning new information difficult but well-rehearsed memories are an enjoyment to share and a way of increasing confidence (Brooker 2001). Many people find reminiscence to be an enjoyable experience, including both people with dementia and their carers (Brooker 2001). Enjoyment, increased contribution and engagement are the main positive outcomes from reminiscence therapy (Brooker 2001).

The empirical studies suggest many benefits for individuals with all stages of dementia from engaging in reminiscence therapy. The Cochrane review of reminiscence

therapy for dementia did report improvements in cognition, mood and general behavioural function. The caregiver strain was also reduced in cases of a carer participating with a relative with dementia. However, the authors concluded that there is inconclusive evidence of the efficacy of reminiscence therapy for dementia due to the variety in reminiscence work examined as well as the small size or low quality of some of the studies. The review highlighted a need for more and better designed trials in order for more conclusive results on effectiveness of reminiscence therapy for dementia (Woods et al. 2005).

Life story is a similar approach to reminiscence also aiming to support the cognition and communication of people with dementia. Life story work refers to a range of ways of engaging and interacting with people to assist them to recall and to record their personal histories in a tangible format, usually a book or a folder with clear pockets filled out as the work progresses (Gibson 2005). Life story was originally practiced with children whose sense of identity, family relationships and emotional well-being were impaired due to problematic life events. Now the approach is used with people of all ages and including people with dementia. People are encouraged to look back into their past and reminisce about their lives and memories and to preserve these recollections as words or images so they can be used as a cue in future recall and reflection (Gibson 2005). Showing personal photographs and memorabilia usually prompts and accelerates the recall process, however if none are available then a generic set of images or memorabilia related to a specific time period is also used. The story is then reproduced in the words of the person accompanied by photographs, documents and letters. The story is usually collected in a number of weekly sessions and needs to include information about childhood, parents and siblings, adolescence, adulthood, relationships, family life and children, middle age, later years and any other interests or achievements. It is important to note that the process should always be more important than the end product (Gibson 2005). Life story work aims to build appreciation, acknowledge unique individuality and to assist failing memory by providing a tangible record of the past and the present. This is predominantly achieved by utilizing long-term memory to communicate in the present. The person with dementia is always at the centre of the story told (Gibson 2005).

4.1.1 Summary of empirical evidence from psychosocial approaches.

The existing psychosocial approaches to support cognition via social interaction in dementia were reviewed. Some of them displayed empirical evidence for their

proposed benefits by undergoing RCTs as per the criteria of Cochrane Collaboration. The Cochrane review of group CST reported a positive impact on cognition and quality of life comparable to published pharmacological studies of anti-dementia drugs (Moniz-Cook 2011). The Cochrane review of cognitive training showed no evidence in improving cognitive functioning, mood or activities of daily living in people with mild to moderate Alzheimer's disease or vascular dementia. The single trial of cognitive rehabilitation provided preliminary indications of the potential benefits of individual cognitive rehabilitation in improving activities of daily living in people with mild Alzheimer's disease (Bahar-Fuchs, Clare and Woods 2013). The Cochrane review of reminiscence therapy for dementia did report improvements in cognition, mood and general behavioural function. However, the authors concluded that there is inconclusive evidence of the efficacy of reminiscence therapy for dementia.

The Cochrane reviews focus on systematic reviews of care and health policy and RCTs, with international recognition of the highest standard in primary research in human health. However, the use of RCTs in psychosocial interventions is at early stages of development due to number of challenges. Firstly the original biomedical understanding of dementia and the search for medical treatment resulted in most of the investment being allocated to the pharmaceutical industry. The lack of investment in psychosocial research resulted in an underdeveloped evidence-base for such interventions in dementia. Secondly the diversity of languages among European countries also challenges the replication of interventions across different countries. This is mainly due to cultural differences and difficulties of translating protocols and manuals. Thus, wide-scale applicability across Europe is negligible (Moniz-Cook et al. 2011). Lastly as mentioned in the introductory chapter, the psychosocial interventions are usually designed with person-centred ethos. Thus, their aims commonly include the effectiveness of the intervention to the specific rather than an average person (Moniz-Cook et al. 2011). Translating this individual effectiveness to group designs is often problematic (Moniz-Cook et al. 2011). While it has been acknowledged that creating *“Evidence-base practice in dementia care entails establishing ‘what works for whom’ rather than a standard approach...”* (Woods 2004, pg. 179) there are continuous efforts being made to develop a wider-evidence base for psychosocial therapies and to demonstrate they are as effective as the pharmacological treatments (Moniz-Cook et al. 2011). These efforts include reaching consensus about the outcome measures to use so as to evaluate effectiveness of the therapies to allow comparison among different therapies (Moniz-Cook et al. 2008). Furthermore, an effort is being made to better

design psychosocial interventions with the development of concise protocols to allow for carrying out and replication of RCTs (Moniz-Cook et al. 2008).

The reviewed psychosocial interventions present empirical evidence in terms of their benefits to supporting cognition despite the aforementioned challenges and the rather early developments of an evidence base for psychosocial interventions in dementia. Thus, the reviewed approaches present exemplary practice and aspects from the above interventions will guide the design of the SenseCam therapy, which I describe later.

4.2. Technology approaches supporting cognition and social interaction.

It is important to reflect on the above psychosocial interventions in light of the advances in technology in the present day. Innovative technologies can assist, change or provide original psychosocial interventions. The main focus of this study is to support one's sense of identity in light of the potential risk of it diminishing due to dementia affecting the inner and outer processes. Thus, the emphasis of this review is placed on the technologies assisting psychosocial interventions aiming to stimulate the inner processes like cognition and especially memory as well as social processes of interaction and communication.

There are many technologies designed to support memory interventions, like reminiscence or life story work. One example includes the CIRCA technology which is a system consisting of touch screen computer with a variety of media like generic photographs, music and video. It aims at increasing communication and relationships between the person with dementia and the caregiver through technologically innovative reminiscence. The main positive effects from using CIRCA compared to traditional reminiscence therapy include reduced effort on the carers' part to initiate conversation, as well as a larger variety of topics during conversations (Astell et al. 2010). CIRCA, similar to other technologies aiming to support reminiscence uses generic photographs instead of personal images. Until recently this may have been due to limited access to personal images and the difficulty of changing the format from hard copies to soft copies, however recent advancements in technology have resolved this issue by the development of lifelogging technologies that can provide large amounts of personal images with ease. As introduced in Chapter One, the device of particular interest is the automatic, wearable camera - SenseCam.

SenseCam is fitted with a wide-angle (fish-eye) lens that maximizes its field-of-view. This ensures that the camera nearly captures almost everything in the wearer's view. SenseCam also contains a number of other sensors, including light-intensity, a passive infrared (body heat) detector, timer (set every 30 seconds) and a temperature sensor, which can be used to automatically trigger a photograph to be taken (Microsoft Corporation 2011). This technical development provides the possibility to passively capture and store a large amount of images representing memories of users' personal experiences. Combined with the evidence from existing psychosocial approaches (including reminiscence and life story reviewed earlier) that recall of memories may be prompted by using photographs to stimulate those memories, this in turn stirred great interest in researching the benefits of this technology to people with memory impairments.

The pioneering research on SenseCam use as a memory aid was carried out with a person with limbic encephalitis with symptoms of severe memory impairment (Berry et al. 2007). The subject of the study, Mrs. B, was given a SenseCam and asked to wear it during significant events rather than daily routines. She then reviewed the images on a PC. In the control condition, a written diary was used to record and remind her of autobiographical events. The findings showed that after reviewing SenseCam images Mrs B was able to recall 80 per cent of recent events as compared to recalling only 49 per cent with the use of a written diary. The retention of events was also measured showing that after SenseCam review she was able to retain them for up to 11 months, after three months without reviewing SenseCam images as compared to having no recall of events after one month without the written diary (Berry et al. 2007).

Following the success of this first trial, a number of researchers initiated similar trials on SenseCam's use as memory aid (Berry et al. 2007, Doherty et al. 2012). While, these trials are usually small scale and subject to potential bias they included various populations including people with Alzheimer's disease and showed successful results. As these studies primarily used SenseCam technology to test the accuracy of recall of past events, they mainly use an experimental design. The focus is placed on the outcomes rather than on the processes of reviewing the images itself and so there seems to be a gap in using this innovative technology to support the person with dementia in sharing their life stories. Such use may provide benefits beyond the support for memory, such as supporting one's identity and strengthening interpersonal relationships with carers or other family members.

Technological interventions designed specifically to help maintain the identity of people with dementia are a rare occurrence. One intervention adapted an exploratory case study approach with one participant who had Alzheimer's disease. The intervention offered the person with dementia and their families a "*Biography Theatre*" – an always-on computer situated in the home, designated solely to displaying the multimedia biography (Massimi et al. 2008). The biography was constructed by collecting personal photographs, videos, music, and narratives about the distant and recent past. The person with dementia as well as their family was involved in the collection process. This involved reviewing mainly physical artefacts like photographs and CD's, followed by digitising them by scanning and copying onto a computer. The artefacts were combined together to form biographies of chapters from the person's life including childhood or adulthood (Massimi et al. 2008). Once completed the computer was deployed in the home for ease of independent viewing. The hypothesis was a better performance on tests of autobiographical memory and an improved sense of identity as a result of participation in the collection and display processes. The person demonstrated improvements in positive self-identity, but did not improve on tests of memory or general cognition. Overall the researchers concluded that using technology to support the person's identity might be a fruitful way to provide rehabilitative benefits. Similar to reminiscence approach not assisted by technology this study was dominated by artefacts from distant past, which generated chapters on life periods of childhood or adulthood. The authors claimed they also included recent memories, however it wasn't clear how were they were included in the display process. Additionally once the biography chapters were included in the *Biography Theatre* even if they contained recent past, they would quickly outdate as time passed. There was no system in place to update these chapters to current life – something that could be achieved by the use of SenseCam. The authors of the study also suggested the use of a wearable camera such as SenseCam in response to reports of fatigue during the collection phase, particularly the processes of reminiscing over physical artefacts to be included in the chapters (Massimi et al. 2008). This further highlights the gap in using this innovative technology to support the person with dementia beyond the task of memory recall. The photographs used in reminiscence are usually from the distant past, which can result in stimulating memories from earlier life stages and only focus on discussing a sense of identity of the past. SenseCam can provide more recent cues to personal memories. Moreover, it has been argued SenseCam images mimic the systems and processes of human memory (Loveday and

Conway 2011). This is further evidence of using SenseCam images as means to provide resources in memory.

4.2.1 SenseCam images as means to support memory

Episodic memory is memory for personally experienced events and it plays an important role in developing and maintaining identity. Unfortunately impairments in episodic memory are one of the hallmark symptoms of dementia, but recent research suggests that SenseCam images mimic episodic memory (Berry et al. 2007). Therefore the similarities between SenseCam images and episodic memory are the focus of this discourse. Previous research has demonstrated an improved accuracy of recalling past events after reviewing SenseCam images (Berry et al. 2007). However, it is important to try to understand why these images may act as memory cues.

Episodic memory occurs when the person remembering consciously re-experiences personal events as an observer or an actor. The person who remembers is not only aware that he/she experienced the events but also has a conscious feeling the events are being remembered (Tulving 1983). The experience of remembering may just involve the feeling of personally having experienced the event even without any further memory of it. Thus, it may be the case that looking at a SenseCam image can evoke this feeling of re-living an event, even without a recall of anything else about the event. On the opposite end of this re-living memories spectrum it has been argued that SenseCam images present cues leading to “Proustian moments” (Loveday and Conway 2011). This type of re-living of memories is an intense moment when images of the past enter the consciousness and the person has a powerful experience of recollection. During such moments the person can often feature recall of memories from other senses such as smell or sounds specific to the event presented by, but not available from the image cue.

All memory systems involve three major processes: encoding, storage and retrieval. The theories on these processes are discussed below in light of episodic memory and SenseCam images (Mayes and Roberts 2002). The encoding of episodes usually involves representations of events, which have occurred over a short period of recent time. The representations are always from the observer’s or the experiencing perspective. SenseCam images mirror this as they are captured from the wearer’s perspective, they are taken from a first-person viewpoint. The wearer is rarely present in the images; instead the fish eye lens captures everyone and everything that was in the wearer’s field of view at the moment of capture. These representations combine perceptual and semantic information of objects and environments and how these are

located in space and in time, and how they relate to identity. The encoding of episodes much depends on the person who is experiencing them. The amount of attention deployed to an aspect of episode determines whether or not it is represented in consciousness (Tulving 1983). Only a small fraction of experienced episodes are represented in long-term memory and an even smaller fraction of those is then available for retrieval later. Similarly with SenseCam it is the participant who decides when to wear SenseCam and how long to wear it for though usually only a proportion of the day gets captured and is available for review.

Episodic memory must involve re-experiencing or reliving the original episode. One usually associates certain feelings and emotions with reliving an episode, however it remains uncertain how much this derives from being able to retrieve the information and how much it derives on personal semantic knowledge (Mayes and Roberts 2002). The retrieval of episodes from our memory typically involves a directed search for a target memory. The process may take several stages in which the person retrieves cues which then reactivate further memories until eventually it is judged that the memory corresponds to the correct episode. Reviewing SenseCam images also involves searching for cues to an event. A particular event may be remembered after identifying certain people in the SenseCam images. At times the participant may have to go through a number of images before the full memory of an episode is remembered. Usually the recall of an experienced episode is associated with the feeling of *déjà vu* (Mayes and Roberts 2002).

Human memory continuously segments our perceived experiences into a series of discrete events (Conway et al. 2002). Thus it has been argued that SenseCam images should also be divided into events (Doherty et al. 2012). A strategy has been developed to manage SenseCam images by merging similar images into semantic events and consequently to mirror human memory. The aim of this strategy was to determine the boundaries that signify a transition between different activities of the wearer based on recognising changes in movement or visual changes. This was possible due to number of built-in sensors that the SenseCam uses (Doherty et al. 2012). The finished product was a SenseCam browser, a software tool developed by the CLARITY² research centre that automatically segments thousands of SenseCam images captured from a single day into semantic “events”. This allows huge amounts of SenseCam data to be navigated

² CLARITY: The Centre for Sensor Web Technologies is an SFI-funded CSET and a partnership between University College Dublin, Dublin City University and Tyndall National Institute.

more easily by browsing through events rather than through individual images. In order to facilitate older people, who may have never used a computer, to easily review their SenseCam images, a simplified touch screen browser interface to SenseCam events was designed (Caprani et al. 2010). This version is also used for the purpose of this study.

4.2.2 SenseCam images as means to support communication

There is a developing case for SenseCam images mimicking episodic memories. Moreover, SenseCam technology can also act, as means to stimulate communication as reviewing these images is similar to reminiscence, which cues conversation. Hence, reminiscence using SenseCam images may encourage communication about recent memories.

Similar to the processes of inner identity highlighting the importance of continuity with personal memories, it was established that communication and one's narrative connect that inner identity with the outer world. Thus, it is important SenseCam therapy aims to encourage communication with people with dementia. The psychosocial interventions reviewed earlier focus on encouraging communication. Communication is usually encouraged by the use of different artefacts including photographs, videos or other memorabilia. This in turn enables eliciting life stories or sharing of narratives from particular life periods (i.e. childhood, adolescence, first child) – mostly from the distant past. Again this has a similar disadvantage as cueing memories by photographs from the distant past, meaning that mostly distant past will be re-remembered and narrated. In order to support people with dementia in having an identity awareness in the present the life stories should be cued to include recent as well as distant past events from participants' lives.

SenseCam images can also be used to support communication through photo elicitation technique. Photo elicitation involves using a photograph in the interview in order to obtain information, and trigger story-telling specific to the research topic (e.g. identity), which often differs from information elicited only verbally (Harper 2002). This method is often used in research to interview people about difficult topics (i.e. nationality, migrant identity, or bio history), however it is not heavily practiced in dementia research. Given that the focus of our intervention is on supporting the person with dementia in having a sense of their identity, photo elicitation can be a very effective method to examine this phenomenon. Combined with reminiscence, which taps into participants' past memories, photo elicitation can be used to encourage participants to provide narratives about their personal past and present.

There are two main approaches to using photographs for elicitation of narratives (Clark-Ibáñez 2004). The first approach is simply using photographs to encourage people to discuss certain topics during an interview. In this way the photographs act as a medium of communication between researcher and participant (Clark-Ibáñez 2004). They can be used to expand on questions and elicit information that may not have been discussed in text or verbal interviews (Clark-Ibáñez 2004). Harper (2002) argues that using photographs during interviews not only produces more information but also a different type of information. He further argues that humans respond differently to images and text, where images stimulate deeper parts of human consciousness compared to text or words. The other approach in research is to allow the photographs to tell the story. Some studies collect photographs and examine them without interviews, as they argue it is the photos themselves that tell the story. This research will follow the first approach where the photographs are used as a medium of communication between the person with dementia, the carer and the researcher. This approach also considers the processes of social interaction.

Furthermore, using SenseCam provides a novel way of capturing the photographs to be used for elicitation, as compared to conventional approaches. Some researchers like to capture the photographs, which are used for discussion themselves whereas others allow the participants to capture them. In comparison SenseCam images are all captured automatically while the person with dementia wears the camera and they are captured in an ambient way, without any action required so the responsibility of capturing the images is removed from all stakeholders. This automatic capture in the moment also ensures the images provide meaningful content for discussions about the wearer's identity. These discussions surrounded in the context of the images allow for construction and reconstruction of biographical narratives. Photographs are meaningless in themselves; it is the narratives surrounding them that give them meaning (Harrison 2002). In this research the SenseCam images are the basis for dialogue, or for the story to be elicited, but the identity is also represented through the discussion.

The review discussed the technological advances supportive of psychosocial interventions in dementia. The focus is on interventions aiming to support cognition by stimulating memory and communication in dementia. The possibility of SenseCam lifelogging technology use as a means to stimulate and cue both memory and communication was presented. Taken as a whole the discourse demonstrates the potential for incorporating SenseCam technology into a therapeutic intervention aimed

to stimulate cognition and social interaction. This in turn may support the sense of identity of people with dementia.

4.3 The design of SenseCam therapy

The theoretical and empirical underpinnings of supporting identity in dementia were combined together with innovative computing technologies to yield a novel but potentially useful therapeutic intervention for early stage dementia. The approach aims at supporting identity by encouraging communication about memories as cued by SenseCam images, all explored within social interaction between people with early stage dementia, their carers and the researcher. Specific components of existing psychosocial interventions, as well as lifelogging technology were encompassed into the design of SenseCam therapy.

Predominantly, SenseCam therapy adopted components from CST as it has the most evidence base among the psychosocial interventions with results comparable with currently licensed dementia medication (Salmon 2006). However, aspects from other interventions including reminiscence and life story were also incorporated into the design of the therapy. The general frameworks and rules of the SenseCam therapy echoed those set out by CST. The adopted frameworks of CST included the delivery of 14 sessions of themed activities over a period of seven weeks. For the period of these seven weeks the researcher visited at pre-arranged appointments twice a week, for 45 minutes each time. During this time the researcher viewed the SenseCam images and engaged the participant in discussions about them. The adopted ground rules of CST (Appendix A) included stimulating people in an implicit, passive way rather than via explicit learning, thus reducing the anxiety that accompany the feeling of being 'put on the spot'. Focussing on a pleasurable therapeutic process, stimulating rich opinion based discussion and interaction rather than fact-based discussion, remembering specific facts, events, personal difficulties or traumatic incidents. Accepting all opinions people with dementia may have even if they are amusing, sad, and unusual (Spector et al. 2003). These rules act as a safeguard without compromising the aim of SenseCam therapy to provide cognitive and social resources. CST aims to optimise cognitive function using a range of mental activities. They include sensory stimulation, recognising people and objects, word and number games, physical games and singing and orientation. These activities rely heavily on reminiscence. Likewise, SenseCam therapy also shadows reminiscence, which, aims to stimulate communication about memories by using a range of artefacts from the past. SenseCam therapy implements a similar approach by

using SenseCam images as the cues to discussions about the person's with dementia recent past. It is anticipated that this in turn will encourage narrative story telling comparable to the model used in the life story approach.

SenseCam therapy was delivered by the researcher trained in delivering CST, ensuring it followed the person-centred approach to developing a trusting therapeutic relationship in dementia. This careful adaptation of CST frameworks was an important factor in the design of the therapy as SenseCam images are used as cues to memory and communication from participants' everyday lives. Using past memories is usually an enjoyable experience like tapping into the strength that many people with dementia have. Nevertheless, some participants may have unhappy (even traumatic) memories, which could be triggered by viewing some of the photographs. The participants may find it challenging viewing photographs of their life that they may not remember. Also they may draw on their life memories or may view their photographs negatively, regretfully, as an embarrassment, or for some unanticipated reasons may become distressed during the therapy. Therefore, the rules of CST are crucial to this study and act as a safeguard without compromising the liberty to share the life narratives.

The therapy design also incorporated the use of innovative SenseCam technology as the main source for production of the artefacts – SenseCam images – used to cue the person's memories. In order for SenseCam technology to generate the personal images participants were asked to wear SenseCam every day while they went about their everyday life, for the duration of the therapy. Participants decided with the help of their carers when they wished to wear SenseCam and under what social conditions (e.g. alone at home, leisure time activities, socializing with others, etc.). Participants were also made aware of a privacy button on the camera allowing them to switch the SenseCam off at any time they wished. SenseCam images, which are taken from the first-person perspective of the wearer, are used for the provision of resources supporting the cognitive processes of personal memories, as well as cues to encouraging narratives supporting the cognitive processes of language.

SenseCam images were reviewed using the above-mentioned software, which automatically structures the thousands of SenseCam images captured each day, into "events". The participant, the carer and the researcher kept a diary, each reflecting on observations throughout all sessions during the seven-week period.

SenseCam therapy was designed based on careful adaptation of components from existing psychosocial interventions and the use of SenseCam technology. The incorporation of SenseCam images into reminiscence and life story supports the

theoretical underpinnings of supporting identity by encouraging communication about memories, within social interaction safeguarded by the rules of CST. The ideology is that a sensitively designed intervention may support identity by providing resources in memory, encouraging communication and ensuring social interaction.

4.4 Summary

This chapter presented a review of the existing psychosocial and technological interventions aimed at stimulating cognition via social interaction in dementia. Firstly, I outlined the empirical evidence for cognitive benefits of psychosocial interventions in dementia. Secondly, the advancements in technology that support dementia interventions were described. Lastly, I gave a rationale, by synthesising the theoretical assumptions of identity and the empirical evidence of existing interventions to illustrate how SenseCam therapy was designed as an intervention to support the sense of identity in early stage dementia.

Chapter 5

Methodology

The purpose of this chapter is to contextualise and describe the research methodology, including the philosophical assumptions that allow me to present my position. The rationale for uniting a case study method with constructivism is presented. The chapter is divided into two sections. The first section discusses the philosophical assumptions underlying this research. They come from the constructivist tradition implying subjective epistemology, and the ontological belief that reality is socially constructed. This means that the world is constantly evolving and being rebuilt in each era by an active population who have no choice but to reconstruct reality through their language, structures and disciplines. This is consistent with the assertion that language does not hold that actors can only appreciate its meaning and custom locally in the current epoch. The current reality will have continuities and discontinuities with previous and future ideas. The implications of constructivism on the selection and suitability of the case study as a research strategy are also discussed. The second half of this chapter deals with the research design in a practical sense, explaining the reasons behind the sampling, data sources, data collection and analysis undertaken. Finally, ethical considerations are explored.

5.1 The philosophical assumptions

The perceived importance of philosophical assumptions in research design can be varied, depending on the discipline and research topic. Blaikie (2009) stresses that social researchers too often “just muddle through” the design of their study. In particular, he states that their research fails to clarify certain ontological and

epistemological assumptions. This may be due to various perspectives on the necessity of taking a philosophical stance in social science research. Crotty (1998) claims it is unnecessary to distinguish ontology from epistemology when discussing research issues, as the two are mutually dependent, and that “to talk of the construction of meaning [epistemology] is to talk of the construction of meaningful reality [ontology]” (Crotty, 1998). Foss and Ellefson (2002) suggest that there are no obvious connections between actual findings and the rather abstract philosophical assumptions of research. Despite this, social science researchers seek to be explicit about philosophical assumptions in relation to their study as this ontological stance can impact on the methodology and interpretation of results. Adopting a philosophical stance can provide coherence to the research design, and assist the varied audiences of the research to understand and interpret the findings accordingly (Blaikie 2009). This is the reasoning behind embracing the philosophical influence of constructivism in this research design as outlined below.

5.1.1 The constructivism research paradigm

Based on the philosophical assumptions adopted, research follows a specific research paradigm. Crotty (1998) defined a research paradigm as “a particular way in which scientists make sense of the world” (p.35). The research paradigm is driven by theories about the perceptions of reality and knowledge, ways of discovering information, and establishing the validity and authenticity of findings (Crotty 1998). These theoretical influences to research are varied but are usually grouped into the following research paradigms: positivism and post-positivism; constructivism and interpretivism; criticism; and post-structuralism. The research in this thesis is influenced by the research paradigm of constructivism, implying a subjective epistemology and the ontological belief that reality is socially constructed. However, it is important to examine other paradigms used to study dementia interventions in order to understand the rationale behind the suitability of constructivist influences on the research presented here.

In comparison to the positivist approach, the research in this thesis is not in keeping with the idea that reality is “out there” independent of people and their contexts. Similarly, the idea that knowledge can be generated objectively is not one underpinning this work. There is previous research examining dementia interventions from the positivist philosophy. The majority of such research tested medical interventions for dementia, such as anti-cholinesterase drugs, frequently using

randomised controlled protocols (Jones et al. 2009). Such designs commonly involve a large population sample divided into experimental and control groups. Furthermore, they assume that elimination of (or control for) potentially influencing factors, such as social interaction, is sufficient to test for direct causation of applied interventions. Hence, they follow the positivist underpinnings that reality can be generated independently of interpersonal factors. In order to carry out an RCT, interventions need to undergo preliminary testing, producing substantial quantifiable evidence of their benefits. While there is a growing body of experimental evidence suggesting SenseCam can alleviate memory problems, there is not enough evidence to contemplate a large-scale RCT. Moreover, experimental testing designs lead to poor awareness about the use of this technology in a therapeutic context. SenseCam as a form of therapy aimed at maintaining identity is not independent of people or their environment and needs to be explored within the context in which it takes place, taking into consideration all factors that may influence its success or failure.

The constructivist ethos of socially constructed reality and subjective epistemology enables this research to consider all of these influencing factors and present a more holistic understanding of using SenseCam in a therapeutic manner. In addition, the theoretical foundations of the psychosocial understanding of dementia and the integrated view of identity followed in this research are in line with constructivist underpinnings, as they suggest that the disease progression in a person with dementia depends on the type of social interactions he / she encounters in daily life. Similarly, theories of identity suggest that both social interactions and communication are the foundations of developing and maintaining people's identities. Thus, the underpinnings of understanding dementia and identity are harmonised with the philosophical assumptions in this thesis. Furthermore, SenseCam intervention cannot follow an objective epistemology, as this would imply that SenseCam therapy should be designed and evaluated independently of the interactions taking place as part of the therapy. The ideology behind SenseCam therapy is quite the opposite, in that the interaction and relationship developed with the researcher delivering the therapy are one of the key resources provided by the therapy. Accordingly, applying constructivist assumptions is useful for this study and will best address the research questions.

Dementia research may also be underpinned by critical approaches to generating knowledge about reality, which argues that reality construction is strongly related to issues of equity and power among all involved in the research process (Blaikie 2009). Hence, the epistemology of the critical approach is comparable to the constructivism

epistemology, as both contend that knowledge is formed subjectively. However, the constructivist perspective differs in that the importance of knowledge construction lies in the interactions that participants may have with the researcher, regardless of their power status. There have been previous studies on dementia underpinned by the critical paradigm, typically examining the effects of communication and interaction patterns on empowering or disempowering the person with dementia (Proctor 2001, Surr 2006, Martin and Younger 2000). The subject of how positive interactions and communication patterns enable the person with dementia to articulate their needs and wishes, making their status more equal to that of their carers, is of particular interest to such studies (Proctor 2001). While SenseCam therapy may have the indirect benefit of empowering the person with dementia through improved communication, this is not the focus of this study. The emphasis is on the processes of the therapy and its direct effects on identity and quality of life, rather than its influences on equality and the power status of the person with dementia.

While constructivism may not be the ultimate way to perceive the construction of reality, having outlined how dementia interventions may be explored following positivist or critical philosophical assumptions, the underpinnings of constructivism seem most useful for this study and its research questions. SenseCam therapy is designed with the anticipated effect of helping to maintain identity by providing cognitive resources to the person with dementia, through social interaction with the researcher. This ideology that identity is co-constructed during communication about past memories with the researcher is in line with the constructivist point of view that knowledge is contingent on human perceptions of reality and social experience. This follows the constructivist ontology that reality is socially constructed and that its meanings may vary depending on the people who experience it. Therefore, this co-constructed reality arises from the interaction process between the researcher and the participant (Charmaz 2004). Following the constructivist paradigm has several implications in choosing the research method. Firstly, the method strategy needs to recognise that any of its consequent theories apply specifically to particular cases rather than representing broad generalisations. This is in keeping with the fact that data interpretations and developed theories underpinned by constructivism are specific to the context and the researcher (Lincoln 1985, Charmaz 2004). As the research reported here seeks to investigate the distinct phenomenon of SenseCam use within a specific context of people with early stage dementia alongside their carers, the case study method was chosen as it enables the investigation of an issue in a real-life context, and such

investigations produce case-specific theories of the processes involved. A case study methodology can be underpinned by diverse philosophies. Yin's (2003) interpretation of a case study is not in keeping with constructivism, as it follows logic and positivistic philosophical assumptions. Yin suggests a number of useful techniques to be followed in a logical process, aiming to explain causal relationships within cases. Stake (1995), on the other hand, emphasises the importance of interactions and interpretations to shaping the case in line with constructivist philosophy. While the use of the case study as a method for this enquiry follows a similar ethos to that proposed by Stake (1995), it also adapts the useful, practical techniques for carrying out case study as described by Yin (2003), without adopting its philosophies. This allows for a flexible structure for the study's research design, yet leaves the design open to adaptation as influenced by contextual factors including interactions or environments.

This is in line with subsequent implications of the constructivist paradigm, which entails that the research method has an emergent research design in order to capture developing and fluctuating relations over time between the researcher and the participant, resulting in emerging co-constructions of meaning. Furthermore, the case study is a research method in which detailed investigation is given to the development of a particular matter over a period of time. The case is often a single individual but can also be a group or an issue. Characteristically, case study research examines extensive and varied data sources within a continued time frame in order to bring an in-depth understanding about a case (Stake 1995). Consequently, therapeutic SenseCam use is explored in the context of people with dementia. The case study methodology also relies on the use of any combination of methods and data sources including those of qualitative and quantitative origin (Stake 1995). It is explorative in nature and closer to its data than other methodologies. Because of this, it often points to factors that would have been neglected in a larger group study. The aim of case study research is to demonstrate the existence of a particular phenomenon rather than to generalise its findings. This allows for multiple facets of the phenomenon to be revealed and may help to gain an in-depth understanding of the research question. The aim of case study research is to understand and interpret individual cases in their own special contexts and to find information concerning the dynamics and processes involved. A case study often produces new research questions and ideas for further studies (Mills, Durepos and Wiebe 2010).

Finally, the research strategy should acknowledge the complex interactions that have taken place between research participants and the researcher, and appreciate that

the findings are based on an epistemological position which recognises the need for various types of knowledge, as well as the temporal nature of any findings. The case study adopts the belief that reality is conditional to human experiences and interpretations. The case study method does not attempt to rank findings in hierarchical order or place different values on them; rather, it focuses on the interrelationships that constitute the contextual circumstances specific to a case, in this research a person with dementia, with the explicit purpose of using those insights to gain understanding of the case. The researcher and the participant interact constantly in a case study; therefore, mutual trust needs to be maintained throughout the case. Consequently, the principal researcher in this work realises that its findings are influenced by both the interactions with participants during the therapy, as well as by the interpretations of these interactions. In keeping with the constructivist paradigm, the epistemological stance of this research is subjective, meaning that its reality is constructed through the interactions between the researcher and study participants. Thus, it is believed that the researcher plays a key role in shaping the direction and outcome of the inquiry. For that reason, the researcher is engaged in the process of reflexivity, where I reflected on my influence and critically analysed it through diary-keeping and supervisory meetings. These meetings took place every two weeks during the therapy process and entailed reporting on the progress of the therapy, as well as observed challenges and preliminary findings. These allowed me to maintain a self-reflective stance throughout the delivery of the therapy and during the report write-up. This said, I acknowledge that both my presence, and my approach to delivery and observation during the therapy, was part of the complex process of investigating the effects of the therapy.

Discourse on the philosophical assumptions of constructivism underpinning the ethos of this research as well as the rationale for selecting a case study methodology, have been presented. Examples of the types of dementia intervention studies influenced by positivist and critical research paradigms reinforce further the suitability of constructivism to this study. The selection of a case study methodology has been influenced and justified by constructivism. Case study methodologies, as influenced by constructivism, enable the examination of several factors within the context of the process being examined. Case studies aim to understand complex social phenomena by retaining the holistic and meaningful characteristics of real life events. They are designed to bring out details from the viewpoints of all relevant participants and from interactions between these participants (Mills, Durepos and Wiebe 2010). The case study research methodology best fits the goals of this research. Adopting the

philosophical stance of constructivism provides coherence between the literature review and the case study as a research strategy for this investigation. Constructivist assumptions are in line with the reviewed literature, as they acknowledge the importance of psychosocial factors in constructing reality, which for some are the experience of dementia and the process of supporting their identity. Furthermore, constructivist assumptions accord with the case study as a useful strategy for this research, as they enable exploration of SenseCam therapy as influenced by these contextual factors of social interaction and the broader environment. Taking a constructivist stance to research should also assist the varied audiences of dementia research to understand and interpret the findings accordingly. This is predominantly to facilitate the reader in understanding that the knowledge generated in this research is deeply dependent on the context in which it is acquired, as the case studies are situated in individual environments, confined to a specific time frame and presented as based on the subjective but reflective interpretations of the researcher.

5.2 The case study design

The two most influential writers on case study methodologies are Robert Yin and Robert Stake. Yin (2003) defines a case study as: “*An empirical inquiry that investigates a contemporary phenomenon within its real life context, especially when the boundaries between phenomenon and context are not clearly evident*” (pg. 13). Stake (1995) defines the case study as a specific, complex, functioning thing rather than a generality. The case, in some ways, has a unique life. It is something that we do not sufficiently understand and want to; therefore, we do a case study. The case study should encompass specific techniques for collecting and analysing data. Furthermore, data should be collected from different sources and its truthfulness should be ensured. Both Yin and Stake distinguish different types of case studies.

Stake (1995) differentiates between *intrinsic*, *instrumental* and *collective* case studies. An *intrinsic* case study is where the case is of primary importance to the exploration. The exploration is driven by a desire to know more about the uniqueness of the case and not because of an assumption that by studying it, one learns about other cases or some general problem. An *instrumental* case study is where there is a need for a general understanding to a problem or a question and one gains insight into it by studying a particular case. The case is therefore secondary to the exploration of a specific issue. The case becomes a tool to better understand something else. A *collective* case study simply involves using more than one instrumental case study to explore a

particular issue. In instrumental and collective case studies, the cases are carefully selected through formal sampling to ensure they provide insight into the research issue. The instrumental case study differs from the intrinsic type in that the focus of the study is established in advance and designed around the theory from which the research questions have evolved.

Yin (2003) also distinguishes three types of case studies: *explanatory*, *exploratory* and *descriptive*. An *explanatory* case study often explains causal relationships and develops an explanatory theory of the phenomenon. An *exploratory* case study investigates a specific phenomenon that is characterised by a lack of preliminary research. This form of case study is often conducted in advance of an explanatory case study, where the focus is on identifying the issues or questions guiding the research. An exploratory case study is not limited in terms of its qualitative or quantitative specificity. A *descriptive* case study has well-established questions about the phenomenon. The descriptive case study distinguishes itself from other cases by the use of a descriptive theory at the outset. The theory is a review of what is already known about the phenomenon and thus helps to specify the boundaries of what the case study will investigate. Descriptive case studies seek to reveal patterns and connections to this theoretical construct. Studies are considered descriptive cases if there are no analytical comparisons between groups and there is no attempt to describe unexplored territory.

Yin (2003) further distinguishes between case studies based on their quantity: they can be single or multiple. They can also be embedded or holistic. An embedded case study may have many separate sub-units under investigation, whilst a holistic case study investigates an underlying phenomenon more globally.

5.2.1 Study design

The aim of this research is to gain understanding on “*Why and how to use SenseCam as an intervention aimed at identity maintenance in early stage dementia*”. Studying particular cases of people with early stage dementia participating in the therapy enables the generation of such understandings. Thus, I am using case studies to understand the phenomenon of SenseCam therapy. Each case study is instrumental in learning about the issue questions that emerged from the literature review. According to Stake (1995), this is a collective case study design.

Following Yin’s (2003) case study classification criteria, this study is predisposed by some theoretical foundations from previous research regarding

SenseCam use and the supporting of identity maintenance for people with dementia; however, there is not enough for the case to be entirely theory-bound. There has been no previous research that uses SenseCam within a therapeutic approach based on CST and reminiscence frameworks so this is a new phenomenon. The theory has mainly emerged from the data collected during these case studies. Thus, according to Yin (2003), this is an exploratory case study design. It is also a multiple-case design, as we are studying three cases, which Yin (2003) argues is a much stronger design than a single-case design.

The case study design plan (Figure 5.1) is based on Yin's (2003) multiple-case study replication design. Although the design plan may be interpreted as a straightforward, logical process, it was a more cyclical process, as represented by the red broken line in the diagram. This line symbolises the review of the initial case design each time an individual case study was completed. Each review brought some major and minimal adaptations to the design of the subsequent case, following the findings of the preceding case. These are discussed in detail in the next chapter in the introductory sections of both the second and third case study. The design plan involved a number of steps.

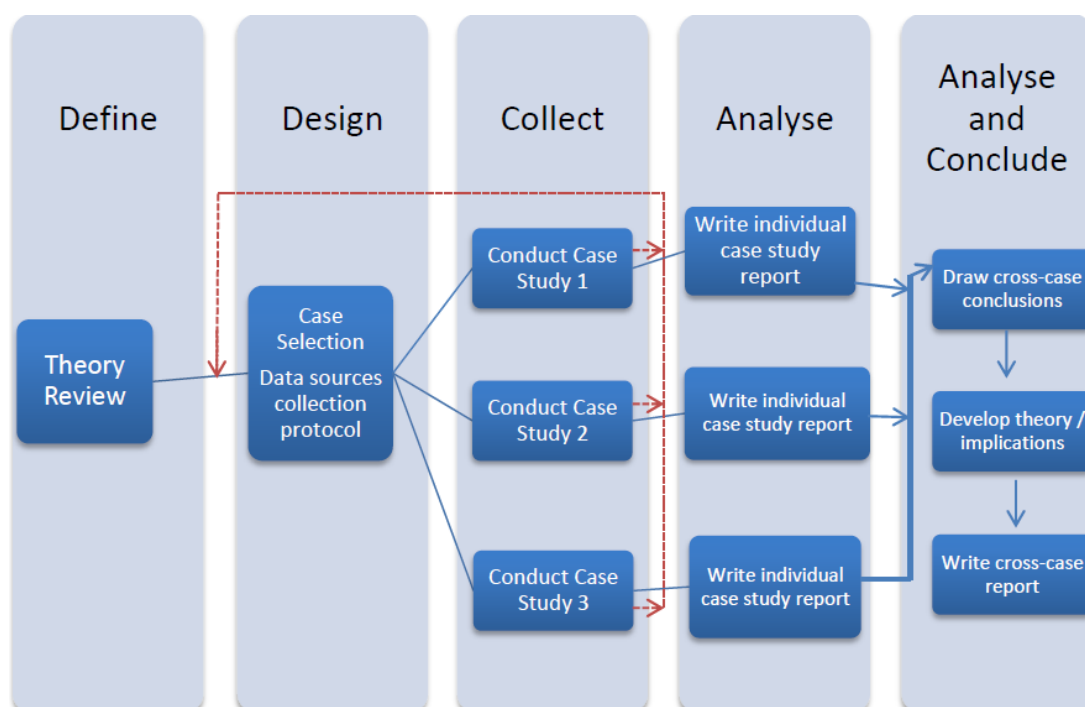


Figure 5.1 Case study design plan (Based on Yin, 2003)

The initial step was the review of any theory relevant to the case study. This included a review of perspectives and their influences on understanding dementia, and the theoretical as well as empirical bases of maintaining identity in dementia. Based on

this theory, specific cases were selected and data sources chosen. Each case study was then conducted individually and independently; however, based on intermediate findings, the overall design was changed or adjusted. This iterative process allowed flexibility in conducting the case studies, assuring a discovery wasn't ignored because of a straight-jacketed original design. After each case was completed, an individual case report was written up. These reports were then cross-case analysed and overall findings emerged from the cross-case report.

5.2.2 Case selection

Case selection is the suitable selection of one or more instances of the phenomenon under investigation by the case study. Because of the intensive use of data sources, the number of cases can be limited. According to Stake (1995), case study research is not a sampling research and thus, a case is not studied primarily to understand other cases. The initial focus should be on understanding that one case, individually. The relevance of the cases to the research question is the most important criterion for selection (Mills, Durepos and Wiebe 2010). The chosen cases should lead to understandings, assertions and even modifications of generalisations (Stake 1995). Cases providing the maximum amount of information about the specific features and characteristics of the phenomenon under question were selected. The main objective of the work in this thesis is to explore how to use SenseCam to provide the maximum number of benefits to people with early stage dementia. Thus, the obvious criterion to participate in the study was that the potential participants were in the early stages of dementia. Furthermore, as part of the case study, I also wanted to explore the role of the carer in the therapy. Thus, having a carer involved was also an important criterion. As the frameworks of CST guided the therapy, additional criteria such as the person's physical abilities to participate in the therapy were adopted from the CST criteria for inclusion.

Purposive sampling was used to recruit three participants who have been diagnosed with early stage dementia, of whom two were living with a carer. The carer is the person chosen to work in partnership with the person with dementia and views care from the position of consideration, protection, serious attention, and commitment (West 2003). Screening for inclusion criteria was done by the manager of the relevant facility referring the participant.

In summary, the inclusion criteria were:

- Diagnosis of dementia (Diagnostic and Statistical Manual of Mental Disorders – fourth edition (DSM IV) with Clinical Dementia Rating (CDR) Scale score of between 0.5 and 1.
- Can hear well enough to participate in a discussion
- Can have a meaningful conversation
- Vision is good enough to see a computer screen
- Is likely to be able to remain seated for 45 minutes
- Wants to participate

5.2.3 Data Sources

An important aspect of data collection, which improves the quality of the data gathered and enhances the study's construct validity and data reliability, is having multiple sources of evidence (Yin 2009). Conducting a case study involves gathering an extensive array of data resources related to the phenomenon under investigation. These multiple sources of evidence are used to establish construct validity and are essential in establishing the legitimacy of findings. The various data sources are plaited together into a coherent description of the case. This technique is also called triangulation of data.

The multiple sources of evidence are essential because of the need for extended descriptions to understand a given case. One single source of evidence is considered insufficient to sustain a case study. Multiple sources allow for the providing of a description of the case from different angles and perspectives while also addressing any discrepancies that may arise from a single data source (Mills, Durepos and Wiebe 2010). It is difficult to predict in advance what data resources will be most useful or informative for a particular case study. However, this study is designed based on Yin's (2003) replication design, which allows for a change to existing sources or inclusion of additional sources if such a necessity is discovered (Mills, Durepos and Wiebe 2010). In the work reported here, sources from both qualitative and quantitative data were drawn upon. They included audio-recorded interviews with the person with dementia and the carer, diaries kept by the person with dementia, the carer and the researcher, and observation field notes collected by the researcher.

5.2.4 Data collection

Data collection followed a pre-planned but flexible data-sources collection protocol. The protocol was planned based on the frameworks of CST as well as the inclusion criteria as earlier described. The case protocol was flexible to changes as guided by the specific context of each case and by findings of the preceding case. The pre-planned process included the recruitment of three individuals with early stage dementia who live with a carer. However, this criterion was changed in the final case, where the participant lived independently due to her partner being deceased.

- The initial phase of data collection involved the person with dementia and their carer or next of kin taking part in a **semi-structured audio-recorded interview** before the commencement of therapy. The constructivism ethos understands the process of conducting interviews as a dynamic, meaning-making process that results in a collaborative production of knowledge. The audio-recorded interviews used in this study were semi-structured, permitting inquiry of some additional or clarifying questions based on participants' responses. The goal was to compare participant responses while simultaneously seeking to fully understand their unique experiences. As part of the interview with the person with dementia, a single question aimed at inducing a narrative was used, based on the Biographic-Narrative-Interpretive method (Wengraf 2001). This question remained consistent across the three cases; however, in the first two cases, it was necessary to break it down into a partial biographical narrative, focusing on, for example, a phase of life i.e. youth/adulthood or professional career. In some instances, the participants were encouraged to answer this question with prompts regarding specific aspects or life stages including:

“Can you tell me about stages in your life? You could start in childhood and continue through youth and adulthood up to now?” “Can you tell me about your relationships/friendships? Did they change over the course of your life?”

The narratives produced by participants were used as a baseline to understanding their identity as well as a guide to subsequent therapy sessions. The content mentioned during the narratives was used as a cue

when selecting SenseCam images for discussion and the elicitation of more stories.

- The interview before the therapy also involved the administration of psychometric tests (Appendix B). The results from these tests were used mainly for descriptive purposes. In a relatively short period of time, they offered a snapshot of the participant, revealing many aspects of the person's medical and social history. Psychometric tests were also an effective and scientifically validated means to characterise the person's cognitive status and level of memory impairment, thus assuring that the researcher obtained an accurate perception of the participant before and after the therapy. Both the audio recorded interview and psychometric tests were administered before and after the therapy following the same process. Depending on the tiredness level of the participant, the interviews took place over one session or two sessions of one hour each.
- The data collection techniques used during the therapy sessions involved the filling out of **diaries by the person with dementia, the carer and the therapist**, reflecting on any observations made throughout the sessions from the perspective of the diary author. The diaries had a template consisting of six questions to be followed loosely after each therapy session. The amount to which the diaries were filled out varied across cases from occasional to regular inscriptions. The use of diaries provided rich data that facilitated greater understanding of the phenomenon under investigation.
- Another technique used to collect data during the therapy was the collection of **observation field notes at each session**. These were collected via participant observation techniques, which allow for observing and interacting with the participant while actively participating in the setting, as well as forming trusting relationships with all research participants and gaining in-depth knowledge of their practices through intensive immersion in their context (Mills, Durepos and Wiebe 2010). Participant observation originated in ethnographic research, which seeks to describe human behaviour and interaction patterns through fieldwork. It suited the case study method as the case study approves the use of a variety of methods including observation, interviews, conversation and personal stories. It is ideal for this research as it takes place over an

extended time period. The observations are documented in the so-called observation field notes journal. These were dated and written up after each therapy session.

5.2.5 Data Analysis

As mentioned above in this case study research, data was collected using a variety of sources including observational field notes, interview transcripts and diaries. In order to address the research questions, this data was systematically rearranged, organised and interpreted. As the case study produced large amounts of data, the analysis was a complex process requiring flexibility and skill. This was the most difficult aspect of the case study methodology, primarily because case study analysis is an activity that requires thorough human interpretation. Stake (1995) argues that no particular moment marks the beginning of analysis; rather, it simply occurs once we give meanings to observations. Unlike statistical analysis, there is no specific recipe to follow to arrive at findings (Yin 2009).

Two techniques proposed by Stake guided the case study analysis: direct interpretation and categorical aggregation. These two methods include aspects of both quantitative and qualitative analysis, as they look for the emergence of meaning from both repetition and /or single instances of the phenomenon. To make sense of certain observations, the phenomenon needs to be studied as closely as possible and thought about as deeply as possible. Stake (1995) stresses that it is through experience and reflection that the most suitable forms of analysis are identified. This echoes the subjective epistemology of constructivism, as it is the individual experience that influence the analysis process. Thus, the data analysis and resultant findings are not impartial but rather dependant on the researcher's subjective experience.

Interpretation is a major part in not only case study research, but in all research. On the basis of the interpretations made on observations and other data, this research drew its conclusions and assertions. As mentioned earlier, these interpretations were influenced by the subjective experience of the researcher. Stake further argues that interpretations should be drawn from inside a person and may be based on some personal experience. The descriptions of observations may not always be closely linked to the interpretations that one makes. *"By custom, researchers are privileged to assert what they find meaningful as a result of their inquiries"* (Stake 1995 pg.12). Thus, the interpretations described in this research present my version of reality. Furthermore, as this research is true to the philosophy of constructivism, this version of reality is

strongly dependent on both my interactions with participants and reflections during supervisory meetings.

Categorical aggregation was used to guide the collection of instances or occurrences within the data that represented a specific category, theme, or idea that was meaningful to the researcher as it emerged from the data. Both categorical aggregation and direct interpretation depend highly on the search for meaning often represented through the search for patterns or consistency within certain conditions. Patterns identified during the analysis often derive from research questions known in advance, which serve as a template for the analysis (Stake 1995). The analysis also followed case study analysis techniques proposed by Yin (2003), where only data related to the theoretical proposition questions that prompted the study are considered for analysis. This strategy implies that greater attention be placed exclusively on data relevant to the research questions, with less attention paid to other data. The use of propositions in analysis also helped to organise the case study, defined alternative explanations, and provided a path to follow where relations were expected (Yin 2009). However, in line with Stake (1995), there were instances during the analysis when novel patterns emerged from the data and formed the basis of new research questions, also known as emic questions because they arise from within the data.

While the two methods of categorical aggregation and direct interpretation guided the analysis process of this research, my interpretation of the findings remains true to the constructivist philosophy of socially constructed reality. Although categorical aggregation led to the identification of patterns, I acknowledge that these were highly dependent on the interactions that took place between the participants and myself as a researcher. In combination with direct interpretation and reflexivity during supervision meetings, this allowed the research to achieve new meaning. Stake (1995) argues that in instrumental case studies, the cases help to understand a phenomenon defined by research questions. Thus, the need for categorical data is greater and the process of analysis should focus on relationships with the research questions. As this research is instrumental with multiple cases, or alternatively is a collective case study, it was analysed in order to find linkages with the research questions.

Initially, all data was directly interpreted by searching for patterns emerging from the issue questions. Categorical aggregation also allowed for the grouping of instances and occurrences representing specific categories guided by the issue questions. Stake (1995) suggests that an additional or formal analysis in the form of thematic or chronological analysis should then be carried out on selected portions of the

observations most worthy of inclusion in the report. In the formal analysis, it was decided to firstly thematically analyse the data, followed by chronological analysis and report write up.

Thematic analysis is a systematic approach to the analysis of qualitative data that involves identifying themes or patterns and classifying all data according to these themes. A wide range of data sources may be used in thematic analysis. In this case, the data included interview transcripts, observational field notes and diaries. Initially, the research questions were used to start a list of a priori themes and the data are classified according to these. This was followed by a more inductive approach to thematic analysis. The data was analysed through a process of detecting new patterns, attending to how participants label events, and recording insights through the use of memos and patches.

Stake (2010) refers to patches as the recording of ideas or patterns throughout the analysis process. They may include the most interesting observations representing a pattern, or direct quotes from participants. Patches were collected and arranged in multiple ways including according to each case, each issue or in relation to each other. Some patches developed to generate ideas about the relations between themes or to identify new issues. I then developed these patches into memos, while maintaining the original patches in the form of “Data source extracts” used for illustrative purposes throughout the individual case reports in Chapter Six. I adopted Glaser’s (1978, 1998) understanding of memoing for the purpose of this thesis. Glaser describes memoing as the write-up of ideas relating to theoretical themes and their relationships. He suggests that they should be written freely as the ideas strike during the process of analysis. In instances where a number of patches developed into a new theme or set of patterns, I immediately wrote a memo. In the light of this memoing, I went back to the analysis of previous cases and often returned to data that was already analysed to search for evidence of new themes. I was also spontaneously struck by ideas about various observations and their interpretations, inspiring me to write a memo or at least a patch outlining the ideas. The theoretical memoing was a continuous process throughout the analysis of the three cases, where I developed further understanding of the ideas of whether they captured genuine patterns and how these patterns varied between cases.

Depending on the circumstances and availability of resources, the memos and patches were recorded in either paper or electronic format including notes on a laptop or mobile phone. They were all transcribed into a Word document and developed into comprehensive memos. Some of these more ‘mature’ memos are incorporated into the

individual case study reports as well as the findings from the cross-case analysis in Chapters Six and Seven.

New themes emerged from the data and, as is often the circumstance in case studies, the new themes became new issue questions or emic questions (Stake 1995). Following Stake's multiple case design, the analysis of this case study was also an iterative process. Continuous analysis allowed for the refining questions, adding new emic questions and pursuing new areas of inquiry in further depth in subsequent cases (Appendix C Appendix D).

All data was analysed, and results were placed in arrays using both paper formats and Microsoft Excel spreadsheets. Arrays were grouped and re-grouped by issue question and data source, thematically and chronologically. The case study report was written up in chronological order. Events were sequenced as they had occurred in the progression of the therapy. Chronological order is known as a natural order and is considered a familiar device for the form of organisation that can be found in stories that have a beginning, middle and end (Mills, Durepos and Wiebe 2010). An example of the analytical process used is attached as Appendix E.

5.2.6 Data Triangulation

Detailed exploration of all data gathered by means of direct interpretation and categorical aggregation (Stake, 1995) as well as through thematic and chronological analysis produced three individual case reports. Each of these offered rich descriptions of the process, effects, issues and benefits of SenseCam use within the context of the person with dementia. These case reports provided vicarious experiences that offered insight into the guiding research question, "How valuable is SenseCam use as a therapeutic intervention aimed at identity maintenance for people with early stage dementia".

Description reports of these three individual cases were formulated and analysed in relation to each other. Data from all case studies was further combined and recombined in several different ways using Excel spreadsheets in order to get a thorough understanding of the nuances and different points of view in each case. The patterns emerging from each case, or alternative patterns, were searched for in the remaining cases. This allowed for the identification of similarities and differences among the three cases and highlighted common themes. This process is also known as triangulation through cross-case analysis. While single case study analysis resulted in

in-depth scrutiny and description, the cross-case analysis reinforced validity, generalisability and promoted theoretical elaboration (Mills, Durepos and Wiebe 2010). Each case was examined with a case matrix using Excel software, and developed concepts according to major issue questions across different data sources. Summary tables were developed identifying the data sources that provided evidence for each issue question (Appendix F, G, H). Following the development of the individual matrices, these were reviewed in conjunction with the individual case reports in order to analyse findings across cases. A cross-case matrix display was developed for each of the eight critical issue questions underlying this study. In this way, it was possible to compare data from the three cases and to discern patterns or themes. Careful re-examination and rechecking of concepts from varied data sources and case reports led to verification, revision, and the discarding of impressions. According to Yin, the findings should be triangulated by ensuring that they are found across different data sources. Therefore, the matrices were also modified according to data sources to ensure that the reported findings were triangulated. A summary table was developed identifying the data sources, providing evidence for each issue question across all three case studies (Appendix I).

5.3 Ethical Considerations

The research proposal for the work reported in this thesis was first submitted to The School of Nursing Ethics Advisory Committee (SON EAC) in Dublin City University (DCU) to obtain recommendations prior to final submission to the DCU Research Ethics Committee (DCU REC). The only concerns raised by SON EAC were regarding the small sample size and the possibility of lost data in cases of participant withdrawal. A copy of the feedback letter from the committee is included as Appendix J. These concerns were discussed during supervision meetings. It was decided to retain the sample size of three case studies, but in a case of withdrawal, to recruit more participants respective to the number of withdrawals.

Formal ethical approval for the work was then obtained from the DCU REC. A copy of the letter from the university is included as Appendix K. The first two case studies were conducted according to the approved ethical proposal. However, based on the analysis of the first two cases, it was necessary to request an amendment to the approved research proposal. The amendment regarded the section entitled “participant profile” of the ethics research proposal. The original proposal had specified recruitment of people with early stage dementia. However, as this is a broad category, it became

clear after analysis of the first two cases that it is the “earliest” part of the early stage dementia that SenseCam therapy is most suitable for. In the initial phase of early dementia, many people often still live alone and independently. This level of competence also indicated that they would be capable of remembering to use the camera with some cues. The original proposal stated that the person with dementia would live with a carer so that they could assist and remind them to wear SenseCam. The requested amendment changed this participant criterion. Following the amendment, participants who were in early stage dementia and lived without a carer were also eligible to participate. A copy of the correspondence with DCU REC resulting in approval of the amendment is included as Appendix L.

The participants of the three case studies were recruited from clients who had attended the memory screening clinic Memory Works in the Healthy Living Centre (HLC) in Dublin City University, and through liaising with a manager of a dementia day centre directed by The Alzheimer Society of Ireland. The clinician or manager approached a person with dementia and their carer matching the participant profile criteria, and passed on information about the study. If the person with dementia expressed an interest in participating in the study, the manager or clinician passed on their contact details (with the permission of the individual) to the researcher. The researcher then sent out a plain-language statement and letter inviting participation in the research. Issues regarding confidentiality, anonymity and the right to withdraw were clearly communicated in the letter. The researcher contacted the interested participants in order to schedule a convenient time and location for an initial meeting and pre-therapy interview. During the first meeting, the study was explained in detail and opportunities to ask questions were provided. Once it was established that the participants had a clear understanding of the study and were willing to take part, all participants signed written consent forms. Copies of this documentation are included as Appendices M-O.

It was ensured that data collected was confidential and anonymous. Access to data stored on computers was protected by password and data access was restricted to the research team. Participants were referred to by pseudonyms in any publications arising from the research. All participants were assured of strict confidentiality outside of the research training within the limitations of the law during all stages of the research. Signed consent forms were instantly detached from any other captured information. Participants were asked if they would voluntarily give a selection of photographs for the research teaching and for illustrative purposes. All such

photographs were altered to protect the identity of any person or place contained within them. For example, faces or names on signage were blanked out and photographs were shown to individuals after this has taken place to ensure that they were happy with the photographs.

Given the novelty of using SenseCam - a lifelogging device - with people with dementia, the ethical conduct of this research project went beyond the attainment of formal ethical approval. Firstly, this research considered any additional risks of carrying out research with a potentially vulnerable population – people with early stage dementia. Secondly, the potential ethical issues of using wearable automatic cameras generating large volumes of images were considered.

5.3.1 Research with people with dementia

The participants I proposed to study may be considered vulnerable for a number of reasons, including impaired cognitive capacity and, for some of them, being part of a potentially stigmatised group, the elderly. Knowing that dementia is a progressive condition where the person's capacity to consent may fluctuate, the research was conducted in accordance with a series of broader frameworks for research ethics and integrity with people with dementia. These included reading broadly on the subject of conducting research with people with dementia; as a result, the implementation of an on-going consent process as part of each therapy session was included. As the therapy consisted of fourteen sessions, it was possible for the person with dementia or carer to change their mind about taking part in the study at any time. It was also acknowledged that the person with dementia might deteriorate throughout the duration of the therapy and become no longer capable of expressing their wish to withdraw from the research. Nevertheless, progressive decreases in cognitive ability associated with dementia should not be seen as a criterion for exclusion from research studies. The nature of qualitative research means that consent is not a single occurrence but a continual, on-going process between the researcher and the participant. This should be practiced especially when the person may forget that he/she has consented to participate.

The research team acknowledged these issues and decided to adopt an on-going consent strategy for the benefit of participants in this study. The on-going consent strategy has been used in several studies involving people with dementia and was also endorsed by The Alzheimer's Society of Ireland (Hubbard and Downs 2002, Dewing 2002). The process worked by first obtaining a written informed consent form; then, at every further point of contact, repeating an explanation of the research and obtaining

verbal consent from the participant. Furthermore, the participant's non-verbal as well as verbal behaviours were observed in order to determine whether the participant wished to participate in the study at any particular point in time. The participant was given opportunities to ask questions about the research and make sense of it. This strategy enabled the participant to change their mind about participation and gave them some control over the research process. A copy of the adopted on-going consent form filled out as part of each therapy session is included as Appendix P.

5.3.2 Potential risks

It was of great importance to consider participant safety and ensure ethical boundaries were not crossed during the research processes. Potential risks to participants and risk management procedures were identified prior to commencing the research. Given that this study proposed to use photographs from participants' everyday lives for the purpose of the therapy, it was acknowledged that this might generate some distress in the person with dementia or the carer. While using past memories is usually an enjoyable experience, like tapping into a strength many people with dementia have, it is acknowledged that some participants might have unhappy (even traumatic) memories, which could be triggered by viewing some of the photographs. Furthermore, participants may find it challenging to view photographs of their life that they may not remember. In addition, they may draw on their life memories or may view their photographs negatively, regretfully, or as an embarrassment.

In order to avoid any unnecessary distress caused by the process of reviewing the images rather than images themselves, the study adopted the frameworks of CST. CST sets clear ground rules about where not to place the focus, for example remembering specific facts, events or people, personal difficulties, or traumatic incidents. The focus is on a pleasurable therapeutic process, stimulating rich opinions rather than fact-based discussions. The opinions may be amusing, sad, and unusual but they cannot be perceived as incorrect or wrong. Nevertheless, despite adopting the CST frameworks, the research team acknowledged that participants, for unanticipated reasons, might still become distressed during the therapy. For that reason, safeguards to deal with such situations and to minimise the risk to participants were set up in advance. In the event that a situation where the person with dementia or carer might become distressed, participants were never pushed into exposing painful memories against their will. If, however, participants initiated conversation further discussing these, the

researcher enabled them to discuss their distress and helped reflect on the best course of immediate action, including taking a break or discontinuing the therapy.

It is also important that I reflect here on my adoption of a twofold-role, playing both the researcher and the therapist for the purposes of this thesis. Guided by both of my supervisors, I was the sole person to conduct this research. Thus, I needed to endeavour to both collect data and deliver the therapy. Firstly, as a researcher I attended a number of workshops in the area of interviewing and also had previous experience of participant data collection. Secondly, I took a number of steps to ensure SenseCam would be used in a therapeutic manner. I engaged in various online and face-to-face training opportunities in the area of therapeutic practice in dementia. These included training in the delivery and evaluation of CST and the administration of the Clinical Dementia Rating (CDR) psychometric measure. I have also had previous therapeutic experience dealing with personal or sensitive issues, gained from volunteering at a therapeutic service for people experiencing distress. Engaging in both researcher and therapist-type training prepared me for collecting data while administering the therapy. It has been suggested that the amount and type of information disclosed by participants may depend on the skills of the researcher. If a more or less skilled researcher / therapist carried out the same research, the amount and type of information disclosed may have differed. Moreover, as the therapy was delivered over an extended period of time, therapeutic relationships of trust formed between the participants and the therapist. My role, therefore, may have been interpreted as that of a trusted companion. Consequently, I may have started with an outsider perspective but as the therapy evolved, I became an insider.

Furthermore, I engaged in regular supervisory meetings with my principal supervisor who has expertise in assessment and intervention in early dementia cases and is the clinical lead in an academic practice initiative for people with memory problems, Memory Works, at HLC. She has twenty years of practical and research experience working with people with dementia. Any occurrence of the participant reacting to the therapy in an unusual or unexpected way was discussed in detail during these supervision meetings. Using relevant experience, an optimal solution to minimise unlikely discomfort for participants was always the primary consideration.

In any case where the person with dementia, the carer, or the therapist felt upset by the research and required additional support during or after the study, a highly confidential counselling and psychotherapy service was provided through the HLC. Counsellors and therapists at the HLC are fully accredited practitioners who adhere

strictly to the ethical frameworks of their professional bodies, in order to ensure high standards of safe and ethical practice.

On the other hand, it was also important to consider the risks associated with a very positive effect of the therapy on participants. Existing CST and SenseCam research shows evidence that it is often difficult for the researcher to close the study. Microsoft Research suggest many people enjoy using SenseCam and that reviewing images of their experiences makes them feel more confident and relaxed. Carers also reported that they find SenseCam very beneficial (Microsoft Corporation 2011). Some users even reported that “looking at the images is definitely helpful...”. A particular person felt less anxious about remembering key events, as she knew she would be able to view SenseCam images at a later date (Berry et al. 2007). This was one of the largest randomised control trials on CST, and the withdrawal rate was very low, $n=18$, compared to people assigned to treatment, $n=115$. It is important to note that the reasons for withdrawal included death, $n=3$, illness, $n=8$, relocation, $n=3$, and refusal of assessment, $n=4$. This shows that all participants commencing the CST had also successfully completed it (Spector et al. 2003). It is possible that using SenseCam within the rules of CST may have a similar effect with highly unlikely dropouts and difficulties ending the therapy. If that was the case in this study, participants were to be referred for support or activity groups to the Alzheimer Society of Ireland or the CST group set up in DCU.

5.3.3 Additional ethical concerns when using technology, with a particular focus on lifelogging

While the use of technology has the capacity to benefit people with dementia and their carers, it also has the capacity to act in ways which go against their interests. The main concerns often raised by users of technology relate to privacy, stigma, and a reduction of human interaction. Furthermore, some argue that this could lead to the person with dementia feeling controlled or under surveillance or feeling devalued (Nuffield Council on Bioethics 2009). Nevertheless, others argue that it is not so much the technologies themselves that have the potential to either promote or harm people's interests, as the manner in which they are used (Welsh et al. 2003, Wey 2005). Wey (2005) suggests that using technology should not be mystified by being overly concerned with technical sophistication; rather, efforts should be made to understand the processes of its use within the context of people with dementia. Furthermore, he suggests that alongside holistic assessments that take into account the person's needs,

goals and their relationship with the social environment, technology can enable rather than disable the person with dementia.

Given that this research used an automatic photographic camera, some additional ethical concerns were explored. While image-based research studies have been around for decades, wearable automatic cameras are still a rather novel approach (Kelly et al. 2013). There are three distinct features that differentiate using wearable cameras in research compared to using traditional photography. Firstly, automatic wearable cameras including SenseCam generate unprecedented levels of images compared to traditional photography. Secondly, the images are captured in a passive way, independent of any action taken by the wearer. Thirdly, these devices are wearable. These features raised some additional ethical concerns, which are discussed below. While this study used the collected images solely for the purposes of delivering therapy, rather than as data for analysis or dissemination, it was still important to consider potential ethical issues as well as ethical guidelines relating to automated wearable cameras in research.

Unprecedented levels of images captured

The first feature, the large number of images collected by SenseCam (2000 – 3000 per day), raised some ethical considerations. Specifically, because SenseCam collects many more images than a traditional camera, it means that it can potentially be more intrusive into the privacy of the individual. This large volume of images results in a vast amount of information being collected about the person with dementia and their everyday lives. Given that these images are being reviewed with a researcher raises an ethical issue in relation to the privacy of participants. The ethical guidelines state that the functionality and visual outputs of SenseCam should be explained clearly to potential participants prior to commencing the research (Kelly et al. 2013). The participants of this study were clearly informed of SenseCam's functionality and potential risks to their privacy prior to obtaining informed consent forms and to commencing the research.

The second way by which participant privacy was at risk was if the large amount of images collected became public. This larger volume of images means that potential harm from the data becoming public is also greater. Undoubtedly, it would be less harmful if traditional photography was used and if only 30 photographs selected by the participant became public rather than 60,000 images captured passively. As this research did not use the images as data, it never intended to publish them in any way

except for a small number of images to be used for illustrative purposes, which were selected by participants themselves. Nevertheless, during the times that the images were being used for the delivery of the therapy, the research team ensured that they were collected and stored in accordance with the protection of privacy, confidentiality and anonymity. For that reason, collected images were stored securely on password-protected laptops accessible only by the researcher and deleted shortly after cessation of the therapy.

Passive capture

The second feature where SenseCam use raises additional ethical concerns is its passive image capture. In traditional photography, the image capture is staged or selected by the participant. In contrast, when using SenseCam, the image is captured automatically, independent of any action taken by the wearer. This minimises participants' control over the timing at which the image is captured as well as the content in the image. The images may capture some unwanted details including visiting the toilet or reflections in mirrors. This loss of control can be interpreted as a loss of autonomy and therefore raises ethical concerns. In order to assure as much ethical safety as possible for participants, we took a number of steps to help participants regain some of the autonomy related to using SenseCam.

Firstly, I explained clearly to participants that they should decide, with the help of their carers, when they wish to wear the SenseCam and under what social conditions (e.g. alone at home, leisure time activities, socialising with others, etc.). Participants were also made aware of some settings in which photography may be prohibited, such as swimming pools and public toilets. Participants were advised to remove the device before entering such settings to avoid any challenges.

SenseCam is also fitted with a privacy button that prevents image capture for a 7-minute period and is designed especially for activities such as visiting the bathroom. The participants were made aware of the privacy button on the camera, allowing them to switch the SenseCam off at any time they wished. To make the button easily accessible, it was painted a bright red colour.

Wearable camera

As SenseCam is a wearable camera, the places and times in which recordings take place will be much broader than with traditional photography. There is a strong likelihood that images will be captured in public places at any time and in almost any situation. In combination with passive image capture, this raises concerns for the

possibility of external people being recorded on SenseCam. Over the course of a typical day, the person with dementia may encounter many people. These may include family members, other cohabitants, friends and even strangers met outside the home. These people may be captured knowingly or unknowingly, and will not have the opportunity to provide informed consent. This means that one could compare such research to covert research, which may pose some serious ethical issues. However, the distinction is that this study is not about third parties. Nevertheless, out of respect for the autonomy of external people, this research aimed to protect the privacy of third parties.

According to Kelly et al. (2013), existing guidelines state that when taking images of people external to the study in public spaces, it is not practical or necessary to obtain informed consent unless images are published or disseminated in such a way that these people can be recognised. As mentioned earlier, this research did not use the images as data, and it was never intended to publish them in any way with the exception of a small number of images to be used for illustrative purposes, selected by participants themselves. These images excluded anything that could identify any one person. Furthermore, the data was securely stored and deleted once the therapy was completed.

Nevertheless, there was still a possibility that third parties may question the person with dementia about SenseCam and its recordings. King et al (2013) investigated the perceived visibility and obtrusiveness of SenseCam by using an eye-tracking device to measure the extent to which the camera was the focus of visual attention of participants. The results suggest that participants spent a very small amount of time fixating on SenseCam in comparison to the time they spent fixating on the researcher's face or other areas. The authors concluded by suggesting that SenseCam does not appear to constitute a particularly visible or obtrusive item (King et al. 2013). However, in case the person with dementia was to be questioned, I advised the participants to simply answer that they are wearing the camera for research purposes. In addition, I prepared participants with the researcher's contact details and advised them that if anyone had further questions about the device, they could contact the researcher directly. In the duration of the study, no unpleasant questioning about SenseCam by external people took place. There were some occasions where participants reported people asking questions driven by curiosity rather than because of privacy concerns related to being photographed.

While capturing external people through SenseCam was an infrequent occurrence, capturing cohabitants in the same home as the participant was rather unavoidable. As the carers of people with dementia were considered participants in this

study, they were informed about the likelihood of them being captured by SenseCam. Additionally, they were requested to sign the informed consent forms prior to commencing the study.

5.4 Summary

In this chapter, the philosophical underpinnings of constructivism, as well as the methods of the case study approach to conducting research have been described as a methodology for gaining a contextual understanding of SenseCam use as a therapy aimed at identity maintenance for people with early stage dementia. The first part of the chapter dealt with the implications of constructivism as a research paradigm for this study, and the rationale for uniting it with a case study in the search for contextual understanding. The second half of the chapter dealt with the methods employed in gathering data for this thesis, and how that data has been analysed. Finally, ethical considerations and the approaches by which these were addressed were presented.

Chapter 6

Case Studies

This Chapter presents reports on three individual case studies, John, David and Dolores³. The aim of reporting on each is to provide a clear but in-depth description of the person, their context and the processes and their responses to SenseCam therapy. I attempt to portray what took place in each case including descriptions of episodes leading to a participant sharing narratives about their identity, as well as negative responses or challenges during the therapy. These case study reports do not aim to convey a faultless dementia intervention, rather an exploration of the SenseCam therapy as designed based on theoretical and empirical foundations presented in Chapters Two to Four. The case studies are important because they were used to guide the research to achieve an understanding of whether and how SenseCam should be used with people in early stage dementia in an effort to support their sense of identity. The descriptions generated in the reports draw on evidence from interviews, observations and journals as collected throughout the therapy.

The three cases followed the therapy design as described in chapter Four. The Participants were asked to wear SenseCam every day while they went about their life, over a period of seven weeks. Participants decided, with the help of their carers when they wished to wear SenseCam and under what social conditions (e.g. alone at home, leisure time activities, socializing with others, etc.). For the period of these seven weeks

³ Throughout the thesis pseudonyms are in use for the participants, their carers and any others mentioned in the case studies in order to assure anonymity.

the researcher visited at pre-arranged appointments twice a week, for approximately 45 minutes each time. During this time the researcher viewed the images and engaged the participant in discussions about them using specially designed software which automatically structured the thousands of SenseCam images captured each day, into “events”. The participant, the carer and the researcher kept a diary, each reflecting on observations throughout all sessions during the seven-week period. The researcher engaged in participant observation during each session describing the happenings at each session, noting reflections in their journal regarding the process of administration, participant response and any other contextual observations. Each case was completed and analysed before commencing the subsequent study. The cases are presented in chronological order in an attempt to convey how the therapy evolved over time and to demonstrate the learning and amendments in the design and delivery of the therapy, building on results from the analysis of the previous case. I start with a case study of John.

6.1 The case of John

The case of John is the first out of three case studies undertaken to explore the SenseCam therapy. In many ways this was the most difficult case to complete for number of reasons. Despite my competence in SenseCam use and provision of CST, the only pragmatic guidance available to me as a researcher in delivering the newly designed SenseCam therapy was in the reviewed theoretical and empirical literature. The empirical studies of SenseCam use were presented as flawless, positive and promising in benefiting the recall, communication and interactions in memory-impaired participants (Berry et al. 2007, Massimi et al. 2008). Theoretically, SenseCam therapy seemed to be an ideal passageway to support the person with dementia’s identity. The first case alone was very insightful and in exploration with a further two cases a vast amount of information about using SenseCam with people with dementia was created that seems to go unreported by experimental designs, which often focus solely on memory alleviation results.

The overarching research questions and topical information questions were used as point of direction throughout the case studies. The reports provide some insight into these questions as well as result in new emerging issue questions. The case of John is presented chronologically describing the emerging patterns of SenseCam use as they evolved throughout the therapy. The case study offers extracts of the different types of data drawn on in order to make the interpretations. These extracts include data from the

interviews before and after the therapy, observational field notes and journal entries. They are colour coded to identify the different types of data sources drawn upon as well as labelled numerically as Data source Extract X (DSE X) for ease of reference throughout the report. The emerging issue questions follow the same format.

Background

John was an eighty-seven year old man with a diagnosis of early stage Alzheimer's disease. He was a light-hearted man always joking and giving compliments. He lived with his wife Mary in a small village. His wife was his sole informal carer. John presented with very good social and communication skills but with a very poor episodic memory. His memory span would range from 30 minutes to the day before. He would rarely have memory of events that took place over a day earlier, apart from some minor details he may have rehearsed with Mary. Despite such episodic impairment John presented excellent semantic memory skills and no basic functional difficulties with self-care. His communication skills were also outstanding and he was always eager to chat. However, despite him frequently initiating the conversations he often seemed unsure of his answers. During these moments he relied on Mary – his wife. Early on in the therapy it became obvious she was his coping mechanism to the memory impairment. This seemed to work for John to the point that his impairment could even go unnoticed when met for the first time. On occasions he couldn't come up with an answer, he would casually reply "*hold on till I check this with Mary*". Unfortunately this had a draining effect on his wife.

John's responsibilities
"...he doesn't understand what he is leaving I remember we went in somewhere and we paid something like eight euro and he gave a fiver tip then I realised I have to take hold of this money so I do all the money now " **Mary**
Before therapy interview - 21/10/2011
Data Source Extract 1 – (DSE 1)

Disappointment in friends
"... I'd love them to say I'll come and visit him for an hour and let you get out. One friend said I'll come and visit you for an hour and that was a year ago he never did..." **Mary**
Before therapy interview - 21/10/2011
Data Source Extract 2 – (DSE 2)

Mary was in her late sixties, but moved around quickly without any difficulty, with her rather imposing posture. The age difference between her and John was noticeable and her silhouette seemed stronger than John's. She appeared very energetic. In her interview before the therapy she revealed how over time she needed to take over most of the everyday responsibilities including financial transactions, driving and household chores (DSE 1). Despite Mary being very understanding of her husband's condition and accepting her role as a carer she did express that at times it can be "*draining*" or "*taking a lot out of*

her". Mary scoring 5 out of 13 in the psychometric measure of carer strain reflected this. Even though she described her and her husband's social life as very active and them having quite a big circle of friends, she felt the friends don't offer to help her with caring for her husband too often (DSE 2). She did have some support from John's son, who invited him for an overnight stay on regular basis.

First Impressions

I arrived at the participants' address and rang the doorbell located at the side of a frosted glass entry door. Mary and John lived in a two-story house situated at the top of a hill of a small fishing village. The house was located in the middle of a secluded cul-de-sac crowded with similar detached houses. Most of these houses displayed a traditional exterior look but they were all very well maintained. Despite the lane appearing densely populated the neighbourhood was very quiet and tidy, except for some renovation works being carried out in one of the houses at the end of the road. The door opened and a cheerful woman welcomed me in. She appeared as a strong elderly lady with short tousled hair and glasses on top of her nose. We briefly greeted each other and she led the way into the sitting room. The inside of the house was old fashioned but decorated in a tasteful way - matching the exterior look. The walls in the hall displayed some photo-collages of children and other family members. The windows facing the back of the house overlooked the village and exposed some far-reaching sea views. Mary introduced us to John her husband and walked out to the kitchen to make coffee.

John was a frail older man of eighty-seven. He had a wrinkled face and grey hair always elegantly parted. His walking pattern was very much as in a slow motion film with his feet barely lifting off the ground. He was a true gentleman always rising up off his chair to greet me, he also made sure there was somewhere for me to sit. He would excuse any little cough or stomach rumble when in my company.

When Mary returned with the coffee we had some general chat since it was the first visit. It quickly became noticeable that Mary spoke at a very fast pace when responding to myself, perhaps too fast for John to follow. I described this moment in my field notes in the following passage.

I began by explaining the therapy and SenseCam, John was sitting at the edge of the chair smiling and turning his head to make sure he could hear me. I asked if they had any questions and Mary responded by asking about charging the camera. She spoke at a very fast pace facing me directly with her back turned to John. He slowly sat back into

the chair and placed his hands on the armrests. As Mary continued to converse John turned his head towards the window – the opposite direction to Mary and me.

In an attempt to get John's attention back I directed some questions at him. Despite him having some difficulty answering them Mary didn't jump to fill in information he might not remember, but rather allowed him to express himself. She asked John if he remembered what they had done the day before; it seemed like an attempt to show off his memory skills to me (DSE 3). John awkwardly answered that he wasn't too sure but Mary insisted and said that he should try harder without giving him any hints. John eventually said what they got up to, showing a great sense of satisfaction. At that moment I believed I could see a great sense of pride in Mary.

Who wants to be a "memory-aire"?
...It reminded me somehow of one of the games on the television like 'who wants to be a millionaire'. The only thing missing was the applause.
Observation field notes - 28/10/11 Data source Extract 3 – (DSE 3)

Furthermore, during this general chat I noticed that whatever direction Mary led the conversation John was happy to follow. Whenever he was asked a question and unsure of it he would quickly ask for his wife's help. John seemed happy to allow his wife to be in charge. For instance, I was admiring the sea views and after noticing a landmark of some sort, thinking out loud I asked, *"I wonder what's that it looks like a wave"*. It was a completely opinion-based question similar to asking one about a shape of a cloud. John quickly responded, *"I must ask Mary"*. It seemed like he didn't have enough confidence to state his own opinion so he quickly reverted back to his wife (DSE 4). The way John coped with his memory impairment became even more obvious during the interview before the therapy when John suggested on a few occasions that Mary should

Mary as coping mechanism
"it might be interesting to have Mary here she might give you few things"
"I think Mary might know better answer to these questions" **John**
Before Therapy Interview – 21/10/11 Data source Extract 4 – (DSE 4)

John's Psychometric tests results
MMSE score = 24, with 23 accepted as a cut off point for cognitive disorders.
CDR score = 1, mild dementia.
Before therapy 21/10/11 Data source Extract 5 – (DSE 5)

also be present. It appeared that this was John's only way of coping with a question or conversation he was unsure about.

Medical history

This section summarises John's medical details as collected from John himself, his wife, and psychometric tests. John was diagnosed with Alzheimer's disease around three years ago. Despite Alzheimer's being a progressive disease, Mary informed us he remained in

its early stages even when reassessed at his most recent visit to the clinic. The psychometric measures used in this study including the CDR, ADAS-cog and MMSE also displayed some evidence to his early dementia stage (DSE 5). John presented severely impaired episodic memory for recent events but excellent semantic memory skills and no basic functional difficulties. John's communication skills were excellent as he would often initiate the conversation and not only respond to questions but also ask them.

Perceived Identity before the therapy.

As part of the interview before the therapy John was asked about his life story to induce a narrative about his identity. This narrative served two purposes. Firstly, to guide the themes that John may be interested in discussing during the therapy if identifiable in the images. Secondly, the content of this narrative was compared to the content of narratives induced by SenseCam images. This should demonstrate the differences or benefits of using SenseCam as opposed to the typical interview methods.

John was asked a single question aimed to induce a narrative about his life. This question was based on the biographic interpretive method approach. Within this approach my contribution was limited to this single question initially and followed only by non content-specific questions. The narratives produced therefore contained only the information John wanted to include in them without much interference from me.

Memory of John's late wife
 "I married Mary My memory is bad I think I have been married to somebody else before. I'd have to ask Mary ehm yes that's my wife Cathy (pointing at a picture)... and that was my first wife and then unfortunately she died." **John**
Before Therapy Interview – 21/10/11
Data source Extract 6 – (DSE 6)

During his narrative John expressed his lifelong passion for sports and travel around the world. He described how good a tennis player he was but mentioned that now he is only able to play golf. John was born near the city centre, and then lived abroad for a while until deciding to come back to Ireland. He was an accountant all his life and gave the impression that he enjoyed his work right up until retirement. He also revealed he had been married before Mary; however the memory of his past wife seemed somehow avoided and was never explored further (DSE 6). He talked about his

Satisfaction with life
 "...I have had a happy life I have been lucky... I had a pretty good time" **John**
Before Therapy Interview – 21/10/11
Data source Extract 7 – (DSE 7)

children and mentioned they are all settled with their own families. He mentioned he has grandchildren but commented further that he doesn't remember their names. He was a very

positive person and expressed satisfaction with his life on number of occasions during the interview (DSE 7). The details included in John's narrative were mostly from distant past with barely any information on his current life. John was very repetitive in his narrative often asking "*Have I mentioned that already?*" At times when he was unsure of something he would suggest Mary should join him. John's narrative presented him as very happy and satisfied with his life. However, he did seem unsure about his recent memories a lot of the time and appeared to have a very low self-confidence.

Beginning of the therapy.

The beginning of the therapy revealed some characteristics of both John and Mary. It highlighted how using lifelogging may not always suit the existing relationship dynamics. Using SenseCam with a couple and their personalities presented many challenges and even more attempts to adjust and fit the therapy so that it was beneficial to John and to his identity. It was undoubtedly a phase of trial and error, which was testing the SenseCam therapy design.

On the first therapy session Mary welcomed me into the sitting room and John joined us a moment later wearing the camera. Mary told him to pass me the camera but it took John few moments to figure out what she meant (DSE 8). I plugged SenseCam into the laptop and started to download the images he collected during the past few days. This turned out to be quite a long process extending the time of each session by about 45 minutes. Mary was sitting with anticipation and excitement; John was rather less eager, seemingly half-aware of what was going on. I played the pictures and looked through them. John was sitting in silence and Mary kept commenting "*hold on now what is that, what were we at?*"

I'm not sure if John was able to figure out what was on the images or associate them with himself. I tried to engage John by saying it looked like they had a lovely

breakfast together and further asking him if he enjoys having breakfast. He responded, "*oh I think I do, I must have had. I must wait to ask Mary.*" The images didn't evoke flooding of memories like described in previous research. There didn't seem to be any Proustian moments or breakthroughs in communication about his recent past. SenseCam images differ greatly from generic photographs, as they might seem distorted and out of

Prompts about SenseCam

Mary said with a strong tone "You have to give it to Paulina now" John looked at the camera hanging down his chest, unsure he looked at Mary and back at the camera slowly gripping it. Holding it he gave Mary a questioning look again. She said "yes give it to Paulina"

Observation field notes 28/10/11

Data source Extract 8 – (DSE 8)

focus when seen for the first time. Initially I thought John's ability to recognise his past in SenseCam images might improve, however a different pattern emerged as the therapy progressed.

John's well-maintained semantic memory and overall good cognitive skills somehow concealed his severe impairment of episodic memory for recent events. John's ability to communicate at ease and identifying or naming rather than describing what he had done the day before was misleading me to believe that he also had the ability to remember some details about the event. This didn't seem the case. Typically

Disassociation with images
"That's a great collection you have there"
"Did you stop by and took the photos" John
Observation field notes 10/11/11
Data source Extract 9 – (DSE 9)

he could not remember any greater detail of what he had done the day before or even a few hours ago. It was during the first few sessions that this impairment became more and more noticeable. John couldn't retain memory of what SenseCam is and what it does. Possibly he was simply reminded

to wear it by Mary and he had done so every day. On occasions when John was reminded that he was the one wearing the camera he often commented "*oh I didn't realise I took all the photos*". This also indicated he didn't retain the memory that SenseCam captured images autonomously. It also appeared John didn't associate the images with himself, rather he associated them with myself the researcher (DSE 9,10). He thought they were my photographs, which I captured. The temporary solution we used was a text display area on top of the photographs to remind John he was the one wearing the camera and that the camera took the photos. At the bottom of every picture there was a text stating, "*John wears the camera which automatically takes photographs*".

Disassociation with images
John asked me if I had far to travel I said I came from Z - small town nearby. Mary asked him about the first image "do you recognise where this place is or what it is?" He responded "is it somewhere in Z?"
Observation field notes – 01/11/11
Data source Extract 10 – (DSE 10)

Emerging issue question 1 – (EIQ 1)
Is the SenseCam technology too confusing for someone with severe episodic memory impairment?

However, this had no lasting effect apart from the moment John read it. A few minutes afterwards he questioned the images again (EIQ 1).

It seemed that the novelty of SenseCam being an automated camera, the digital images being reviewed on my laptop, in addition to John having no memory of wearing it confused him about the source of the photographs. Furthermore, on most occasions this prevented John from recognising the SenseCam images as cues to his recent past. Thus, initially the images didn't act as cues to identity narratives about his recent past. While John didn't show any signs of unwillingness to continue taking part in the therapy I was concerned about how ethical it was for him to use SenseCam given his inability to maintain a general understanding about it and about SenseCam. This also raised the second emerging issue question (EIQ 2).

Nevertheless, in the instances when I explained SenseCam, John did seem to grasp the concept in a momentarily awareness and was happy to use SenseCam. Apart from some confusion

about the images during the review, the camera didn't seem to have a negative impact on John. It seemed unfair to discontinue using SenseCam merely due to his inability to retain the understanding about SenseCam. It was decided to continue using SenseCam with John but to pay particular attention to John's continuous willingness to take part. I remained vigilant to any signs of John being uncomfortable or unwilling to take part. As part of the on-going consent process at the start of each visit I explained SenseCam and the rationale for John using it and made sure John was happy to continue taking part in the therapy.

Emerging issue question 2 – (EIQ 2)

Is the criterion of early dementia stage enough to determine the suitability of the person to participate in the therapy?

Throughout the beginning of the therapy, before the start of each session during the time SenseCam images were uploading to the laptop, we had general discussions. These discussions were considered as outside of the therapy time. During these periods a number of interactions between Mary and John were observed including Mary using factual prompting, correcting John and unintentionally excluding him from discussions. With each session it became more obvious that Mary mirrored these interactions with John from outside of the therapy time into the sessions. This happened despite the clear

Belief in memory prompting
“...he can bring them all up only when I push him... not even a cue he just needs to be pushed” **Mary**
Before Therapy Interview 21/10/11
Data source Extract 11 – (DSE 11)

guidelines of CST being explained, prior to and throughout the therapy. The everyday interactions between Mary and John weren't guided by these safeguards and bringing them into the therapy sometimes made it difficult to administer it according to the CST guidelines.

Mary often asked John about factual details from the day before and she seemed confident this was in his best interest. Some of the questions she would ask included the name of the place they visited; the name of the person they had met or where were they heading tomorrow. She also believed in

Memory prompting

Mary asked John about the name of the performer at the recent concert they attended. Mary prompted, "It begins with a B", and John answered with hesitation "Billy". It seemed the name was rehearsed in advance and that was the only detail John remembered.

Observation field notes – 01/11/11
Data source Extract 12 – (DSE 12)

pushing or prompting John if he struggled with his answers (DSE 11). If John couldn't remember something, Mary would prompt him further by saying the first letter of the name of the place or a person (DSE 12). John would usually guess the name and Mary would praise him for remembering it. However, it appeared to me that John didn't actually remember the event rather that he only remembered the well rehearsed scarce details about it. Whenever John was prompted further about such events he was unable to describe or comment on them, apart from the excessively repeated names etc.

During the sessions when presented with thousands of images from their everyday life it appeared challenging for Mary not to use them as props to factual discussions and corrections. This included asking John about people, places or objects captured in the images. During the therapy John was asked by his wife about the name of the person in the image they met a few days before. If John didn't recall the name of that person or got the name wrong this would usually result in

Image recognition corrections

"This isn't a boy, its Patricia as I remember that she was wearing a blue top" Mary

Observation field notes - 14/11/11
Data source Extract 13 – (DSE 13)

correction by Mary (DSE 13). These interaction patterns often led to fact-based discussions often putting John on the spot rather than allowing him to experience a pleasurable therapeutic process. Thus, factual prompting resulted in a cycle of negative interactions between Mary and John. These factual questions were very paternalistic and rarely led to John remembering things. It seemed Mary engaged in this "*pushing*" or prompting as well as correcting John in a belief that this would indeed help him. This can be common practice among carers as they aim to help their relative retain the correct memory of recent events. However, during the therapy the focus was to be on opinion-based discussion and not on facts as per the CST's rules everyone can have opinions and these can never be wrong.

Additionally, Mary often unintentionally excluded John from discussions about SenseCam images. She enjoyed reviewing the images and frequently would describe

aspects presented in them that were of particular interest to her. During these instances she would direct all her attention at me and speak at a rather faster pace. It seemed she was caught in the moment and wasn't aware the discussions are not inclusive of John. In consequence he would quickly become disinterested but being the gentleman that he is, he usually just waited for Mary to finish without interrupting. These outbursts of discussion would only last 5 minutes but happened quite regularly.

As mentioned earlier, John's coping mechanism with his memory impairment was relying on his wife's help. This was noticeable from the first visit and became a regular incidence during general discussions, which occurred in the time I was preparing to commence the sessions. Similarly to Mary replicating the way she interacted with John on a daily basis, John began using his coping mechanism during the therapy sessions. If he was unsure of the SenseCam images, or when asked his opinion about anything presented in the images, he quickly turned to Mary for help. This happened in many situations that were not intended to be challenging.

John's low self-confidence, in addition to Mary's presence during the sessions had consequence in his coping mechanism being very accessible. This resulted in him valuing the judgement of his wife to converse about the images instead of expressing his own opinions. The attempts to encourage John to use SenseCam images as cues to recent memory and thus introduce a new coping mechanism were very challenging. This was especially due to Mary's presence during the sessions. This situation provoked new issue question (EIQ 3) and was very testing to the overall design of SenseCam therapy.

Emerging issue question 3 – (EIQ 3)

Is the carer's presence beneficial to the therapy sessions? Should the carer be present during the therapy?

As this was consistent behaviour during the first few therapy sessions it was decided through supervision meetings to use space rehearsal techniques in order to overcome John's need for reassurance from his wife. The technique worked by measuring the time space it took John to ask for reassurance or just to mention his wife during discussions. The first measurement was the time from John's first asking or mentioning of his wife to the second, usually 2-3 minutes. From then on I endeavoured to build up John's confidence in his ability to discuss the images before the measured time was up. I integrated into the conversation that he was doing well or that his ability to describe a particular event being discussed was also great. I repeated that every 2-3 minutes before he asked his wife, and after that I expanded the period by adding an extra minute or two before attempting to build up his confidence. The space rehearsal technique worked very successfully in the sessions when only John

and I were present with the time periods without mentioning Mary by John increased to even 25 minutes. However, it did not work as well when Mary was present. Mary was also adjusting to the therapy and figuring out her role as part of it. She always had John's best interest at heart but with her best intentions to allow John to benefit from the therapy, at times during the sessions she would simply not respond to John's requests for help with remembering or identifying things in the images. However, other times in moments of excitement when reviewing images from some pleasant event, Mary would happily answer John's questions. This inconsistency confused John, as he didn't understand why sometimes he was denied his usual coping strategy when within reach.

Midway through

The initial sessions seemed challenging and slightly disappointing. The original therapy design anticipated SenseCam would benefit the interactions between the person with dementia and their carer. However, thus far this wasn't the case. Nevertheless, once the ice was broken and the therapy became part of John's routine, SenseCam images did cue some memories and encouraged discussions about them. The discussions were about John's life and considered as identity narratives. It was hoped, as suggested by the theory that this re-living of memories would happen regularly during the therapy. Unfortunately, it was a rare occurrence as during most of the sessions John's memory was not cued by the images and it didn't lead to many discussions about them. Despite this, I felt I was getting to know a great amount of detail about John and his daily life. Even if the sessions didn't spark up many discussions, we were still reviewing hundreds of images from John's daily life. Initially unaware of it, I was being insidiously exposed to John's identity through the SenseCam therapy sessions. Given my initial unawareness of this exposure I wondered about John's awareness and consent to this exposure of his everyday life. While, I provided John and Mary with plain language statements and obtained informed consent forms I'm not sure one can have an understanding of the level of exposure prior to actually using SenseCam. Perhaps John and other participants could be made more aware of the level of exposure related to using lifelogging cameras even for therapeutic purposes unrelated to personal lives. I checked back with John and Mary regularly about their willingness to participate and they said they wanted to continue but this issue was explored as an important question arising from the first case.

On a subsequent session, we began viewing the photographs and as usual I explained to John that he was wearing the camera and it took photos. John looked a

little bit astonished and asked if he was really wearing the camera. I reassured him and checked his willingness to continue and I played the images and asked John to comment on any one that evoked any memories. There were photos showing a car park outside of a building. The photographs showed John's view from the car, step by step while he was approaching the building. John looked rather confused and didn't really recognise anything at first. The images progressed to the inside of the building and John appeared to be concentrating. The next few images showed the back of a man. John asked if that was him, so I explained again that it could not have been him as he was the one wearing the camera so it must have been someone he was following.

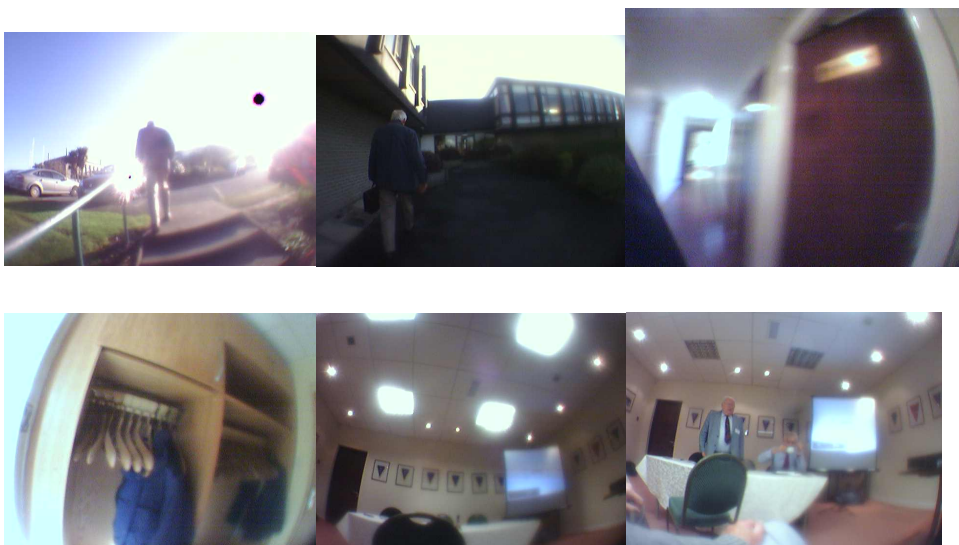


Fig. 6.1 Sample images cueing John's narrative.

The moment the browser showed images from the inside of the building John became more attentive, there were some images of what looked like a cloakroom and I prompted John by saying this must be where everyone leaves their coats. He agreed, however noticed that there is only one coat there and normally there would be more than that. I wasn't sure whether John was just commenting on the photos or had he recognised the location and was re-living his memories of seeing a larger number coats there before. The images (Fig. 6.1) then showed what looked like a meeting room, which John recognised on the first instance without any prompting. He confidently said that this is from his MAN meeting, which is linked to his life-long profession in accountancy, a name, which he previously couldn't remember. He also explained what it stands for. Even though the images only showed the room from one viewpoint facing the 'stage' the speaker spot, John went on to describe the rest of the room pointing to the left of the picture he said this is where the coffee and tea table is and that normally they would help themselves to it.

He got a little confused as quite a number of photos showed the meeting room to be empty. He commented that he didn't understand why he was there on his own, as normally there are rows of chairs with many people sitting there and listening to the speaker. John was probably there earlier than anyone else. Additionally, John was sitting in the first row of chairs thus no other rows of chairs or people in front of him were captured. SenseCam can capture many images in a short time period if the wearer is moving around, this being a design feature of the device to capture as much about the wearer's environment and activities as possible. Thus, the large number of images could have been representative of short time period i.e. 5 minutes, which in turn made John think he was on his own over a much longer time span. He also commented that the room seems off balance as if on a boat. I explained that this is because SenseCam captures images at strange angles and makes them look unfamiliar. Once I explained the reasons for each of the above confusions he seemed to understand and was happy to move on with his story.

Soon after the photos showed the room filling up and John proudly recognised many faces without seeking reassurance from Mary. The photos also showed someone giving a presentation and John was also able to identify him and then went on to the different topics the speakers might be discussing. He mentioned holidays and other hobbies. He then described how the members could invite someone to give a talk and he said that both of his sons gave a talk but he's unsure what topics they were on. The photos then showed all the men at the bar and John described how they often go for few drinks after and have more chats.

The session was hugely successful. This was the first real breakthrough in communication and first definite recognition of the images that sparked up more memories than those captured by the camera. John mentioned the stories discussed by the speakers, the layout of the room some of the attendees absent from the meeting – these were all memories, as they were cued by but not visible in the images. John communicated very confidently about these memories. It is unclear why this set of SenseCam images enabled John to provide such detail narrative and other images reviewed until now didn't have similar effects. It's possible attending the MAN meeting represents a more distant memory pattern and thus taps into John's strength.

As the therapy progressed it became apparent how much John's and Mary's ways of discussing SenseCam images differed from one another. Mary's way was to use her own memories for the time and date displayed by the calendar on the software, regardless of what the image conveyed. Because of the clear visibility of the calendar

while viewing the images it seemed impossible for her to use only the image as basis for discussion or memory cue. She attempted to provide the description in such circumstance purely from her own memory of what she was doing at the time and not from the image displayed (DSE 14). Unfortunately, SenseCam is not always completely precise and does not

Image review

Mary tried her best to make out her bedroom in an image that was in fact taken in the kitchen. After about five minutes, she slowly started to recognise the microwave, which previously was her laptop screen, the fridge, which was her wardrobe, and the kitchen table, which was her bed.

Observation Field notes – 28/10/11
Data source Extract 14 – (DSE 14)

capture everything we might remember, nor does the exact time in memory always match the timing presented on the software and it is only a perspective of our memories. Thus, sometimes her description from memory would describe a completely different scene than the one shown by the image. She struggled to forcefully fit the image representing the time and date into her version of the memory description. On the contrary John's descriptions were mainly based on the image alone. They were usually lacking any insight from memory or even recognition. If we were viewing an image of his sitting room, John would describe that sitting room including objects like television or sofas but would rarely recognise it as his own sitting room. Mary focused on very factual descriptions based on memory and seemed to forget that the therapy was meant to be about opinions not right or wrong facts. John's impairment in memory seemed too severe for him to recognise the cues in the images and describe them with an insight to his memory.

Feedback Requests

"well how do you think he's doing?"
"Do you think it's doing anything for him?" **Mary**

Observation field – notes 17/11/11
Data source Extract 15 – (DSE 15)

Around the sixth session Mary started showing some interest in John's progress and in benefits of the therapy. Mary would often try to whisper and ask about John's progress before he joined us for the session (DSE 15). This questioning in secrecy was rather uncomfortable as John could walk in any minute and I felt like giving any feedback in this way was unethical and could potentially harm John and discourage him from participating in the therapy. Through supervision meetings it was decided to arrange a session designated to give feedback to both Mary and John. This also raised

Emerging issue question 4 – (EIQ 4)

Should feedback at midpoint of the therapy be part of the frameworks of the therapy?

the issue of whether the feedback should be incorporated in the therapy frameworks (EIQ 4).

During the eighth session, exactly at the midpoint of the therapy I gave feedback to both

John and Mary. Through supervision meetings it was decided to provide the feedback to John and Mary separately in order to satisfy the different queries they may have. My supervisor accompanied me to these sessions and while I administered the therapy to John incorporating some feedback into it, she gave feedback to Mary. Some of the points mentioned during the feedback were about John's cognitive skills used during the sessions, his coping strategies, and the therapeutic potential for both Mary and John. It was fed back to John how SenseCam therapy can be used in building his confidence by independently using the images as cues to his recent memories. An opportunity was also given not to take part any longer, which he declined. It was then suggested that review of standard photographs from their life in addition to SenseCam images might be beneficial. John's recent memory was severely impaired but as is often the case in dementia progression he seemed to have retained his distant past memories. Therefore, it was anticipated that using standard photographs from a more distant past might tap into his strength and encourage narratives about them. Furthermore, as John couldn't retain the memory of wearing SenseCam, the images may not have any surplus effect as compared to traditional generic photographs. It was however, clarified to John that the process of viewing images could still be useful as it encourages general discussions and stimulates John cognitively.

Some of the interaction patterns between Mary and John were discussed and it was explained that it is challenging to adapt their daily interaction patterns to the CST guidelines. It was agreed that it was natural to interact in the same way during the therapy as on a daily basis. However, it was also explained how sometimes that goes against the guidelines of CST. Mary often expressed her lack of free time and her presence varied in the therapy sessions up until now. Furthermore, the sessions with just John and myself present seemed to result in most discussions cued by the images. By mutual agreement it was decided Mary would not participate in the remaining sessions. The real need for Mary as a carer was to have some free time. Thus, the benefit SenseCam therapy offered lay in her gaining this opportunity to get out of the house or just to give her a "*head-break*" when I delivered the therapy twice a week.

Ending of therapy

The feedback seemed to ease Mary's questioning about John's progress. However, it also emerged that she no longer encouraged

Lack of encouragement

"We don't have many photos as we haven't been up to much so I didn't see the point in wearing it"

"He didn't wear it to that" **Mary**

Observation field notes – 08/12/11
Data source Extract 16 – (DSE 16)

John to wear SenseCam. Despite John consenting to the therapy it appeared it was Mary who provided the motivation to either encourage or discourage him from participation. After all she was John's coping mechanism and he was strongly influenced by her decisions and advice. During the remaining sessions it was a regular occurrence for Mary to inform me that John didn't wear the camera on most days in between my visits (DSE 16).

A combination of factors may have led to this development including what seemed like Mary's loss of faith in SenseCam therapy. Despite providing a clear explanation from the outset of the therapy that it may not result in any direct benefits for John, it seemed like Mary had hoped it would fix John in some way. However, as the therapy progressed and it didn't result in a miraculous recovery of John's memories, Mary seemed to lose hope and interest in the SenseCam therapy. It appeared that this led to a lack of encouragement to wear the SenseCam more often. I believe that John lost some opportunities due to this development, as SenseCam use was not self-motivated and required encouragement from Mary.

Despite John not wearing SenseCam as often as at the beginning of the therapy there was still a large number of new images available for review from John and Mary's recent holiday trip. The first time the images were discussed during the session directly after their holiday, John was well able to describe some of them. Some of the images were from a walk they took at a big lake. I placed the focus on how this walk made John feel and I explored general feelings associated with walking and outdoors. I didn't pay particular attention to the date when the images were collected. During the next session (about a week following their holiday) we viewed the images again and John recognised the place but commented that the photographs must be very old (DSE 17). He then quickly looked at the calendar and noticed the date when the images were captured. Despite his trouble with time relations he knew that the date displayed was quite recent. I noticed that this caused him some confusion, but he continued to participate in the sessions. He described the location as a beautiful seaside area and then referred to his world atlas to pinpoint it on the map. Once he had the atlas in front of him, he was no longer interested in reviewing the SenseCam images. Instead he showed me different places he

Inaccessible memories

"we haven't been there in about 10 years"

"it's funny cuz I don't remember being there" John

**Observation Field notes – 06/12/11
Data source Extract 17 – (DSE 17)**

had visited throughout his life. Any attempt to review the images resulted in him quickly discussing yet another place he visited, which was always accommodated.

I believed John wanted to protect himself from the feeling of confusion and awkwardness, as he had no memory of the recent holiday. Mary confirmed that he certainly doesn't remember the trip, and that she is unsure why that might be. John avoided discussing the images from their holiday on every occasion an attempt was made to view them. He developed a very clever technique, where he would lead the conversation towards one of his travel books. John showed learning skills by developing this new coping strategy of using books to avoid discussing images that clearly caused him some confusion and potentially put him at risk of embarrassment. This new coping strategy was separate from relying on his wife and could potentially be useful for John in the future. However, John's development of a coping strategy in order to avoid discussing images also starkly demonstrates the potential ethical risks of reviewing images of recent events with people who's memory of recent past is impaired.

Thereafter I didn't attempt to review the images from John's holiday and focused instead on images that John seemed to enjoy reviewing throughout the therapy. These included images that always made John smile or to give a remark. Among them were self-portrait images captured while he was standing in front of a mirror. He always happily commented on them and laughed when he recognised he was combing his hair or fixing his shirt. John was able to associate these images with himself and because SenseCam was also visible around his neck in the picture, he knew that's where the image came from (DSE 18). The joy John expressed in self-recognition in the images was explored further by requesting Mary to wear the camera for a few days. Surprisingly the images collected didn't show a lot of John. After reviewing them it was clear that this was mainly due to Mary usually sitting beside John rather than across from him. The images that did capture John weren't as clear and it seemed they didn't have the same effect on expressions of joy as compared to John's self-portraits captured in front of the mirror. John also showed happiness anytime he recognised his wife in the images. He also remarked on the things she was doing or the clothes she was wearing (DSE 18). If there were some unclear photos and they made his wife look a little bit blurry he would acknowledge that. Despite having trouble recognising a lot of objects in the images he always recognised wine glasses and commented on them with joy. He

Happy Images

"Oh there I am, what am I at?"

"There is Mary"

"Your red coat gave you away"

"Oh that one doesn't do you any justice" **John**

Observation field notes – varied dates
Data source Extract 18 – (DSE 18)

would use expression like “we must have been having some vino” and then he would quickly say some wine. I think the wine cued John’s feelings of enjoyment even though he mightn’t remember the event. The images of the wine were also a good discussion starter on the topic of drinks and food in general. However, John’s accurate recognition of wine glasses and poor recognition of other objects seemed to cause Mary some discomfort. It appeared Mary wanted to justify or minimise John’s excitement about alcohol. Eventually, John’s reactions to wine glasses captured in the images led Mary discussing a rather private concern related to alcohol consumption by people with dementia in general. While Mary was given the space to discuss any related issues confidentially, it also raised ethical concerns relating to SenseCam images exposing private and undesired details about the participants’ identities. Despite the function of the privacy button and the freedom to wear the camera only during suitable times, the images, which appeared mundane, have managed to unexpectedly expose private details about the participants.

The last session’s format was purposely planned to be a little different. During supervision meetings as well as the feedback session it was debated whether SenseCam images have any surplus benefit to John over generic images. John’s memory of recent episodic events seemed too impaired for the images to offer a representation of his recent past on most occasions. It was decided that the last session should be administered using normal generic photographs for comparison to the discussions evoked by SenseCam images. It was planned to do a life review work on John’s favourite discussion theme – travel. I hoped this would tap into John’s strength evoking some interesting narratives. Mary also participated in some of the session. I used a large map of the world and some photographs from John and Mary’s travels including John’s favourite places that he always mentioned. Unexpectedly, the photographs weren’t generating that much discussion and even the ones of John’s favourite places weren’t really sparking up any memories. Also a lot of the time John asked for Mary to help him identify where the photograph was taken. When Mary asked him about one particular photo and he recognised it correctly he sat back in the chair laughing in disbelief that he got it right.

The sparse discussions were surprising as previously it was assumed the lack of narratives may be due the recent capture and unusualness of SenseCam images. However, I believe the SenseCam images actually generated more discussions due to their different appearance. Often John and Mary had to guess what SenseCam image represented – resulting in many opinion-based discussions with which John seemed

more at ease. Similarly to SenseCam images, the photographs from their travels led to many factual discussions especially with Mary putting John on the spot and asking if he remembered a particular place. Additionally, it seemed when discussing standard photographs John had the same strong need for reliance on Mary's memory as with SenseCam images. In one of the previous sessions John recommended for me to visit one of his favourite cities by the bay whereas today he looked at Mary and asked her to recommend a place for me to visit.

Perceived Identity after the therapy

In the same way as during the interview before the therapy, as part of the after-therapy interview, John was asked about his life story to induce a narrative about his identity. The narrative was very similar to the one shared before the therapy and

consisted mainly of distant past memories.

Recent memories
“...I play golf now”; “...I’m married to Mary now”; “...I’m retired now” **John**
After therapy Interview -22/12/2011
Data source Extract 19 – (DSE 19)

However, it was significantly longer and contained a lot more detail. Similarly to the before-therapy interview, John mentioned his place of birth, school and employment. This time

he also elaborated on detailed stories from each time period. All of the stories were from childhood or young adulthood and none from a more recent period of his life. Another similarity to the narrative shared before the therapy was the repression or lack of access to memory of his late wife. Again, while mentioning his travels John questioned himself if he was married to someone else, prior to Mary. He got a little confused and again looked at the framed photograph of his wife. He then remembered that she died and began talking about something else. The more lengthy and detailed narrative after the therapy can be interpreted in many ways. It may be due to improved communication as a result of the discussions during the SenseCam therapy. It may also be result of building trust in me as a researcher delivering the therapy, hence feeling more comfortable sharing more details about his life. Either way it appears this longer and more detailed narrative shows some positive effects of the therapy. Corresponding to the narrative shared during the interview before the therapy, this narrative also contained very little or no detail about recent past (DSE 19).

This lack of detail about recent past was in line with the sparse narratives cued by SenseCam images during the sessions. The most insightful narrative was cued by SenseCam images from John's social group meeting. The narrative about his social group meeting was described earlier and it varied from the narratives provided before

and after the therapy. During the SenseCam review John was describing his recent past rather than distant past. He was describing events from the meeting as cued by the images yet at other times questioning the unusualness of SenseCam images and figuring out reasons behind it. He was able to include details and talk about particulars not captured in the images but related to the event. This narrative induced by SenseCam seemed somehow disjointed as compared to the seemingly rehearsed narratives from distant past. The SenseCam narrative seemed more dynamic in line with the flow of the images and discussions about them. It was noticeable that John's memories had been stimulated and he seemed to have been reliving the MAN meeting while reviewing the images and discussing them with me.

This group meeting is an activity John took up after his retirement associated with both his distant and recent past. The narrative showed how important and enjoyable the meetings were to John in the present time. Surprisingly however, this wasn't mentioned in either the before or after therapy narratives. They focused much more on the achievements and enjoyments of distant life. This revealed that SenseCam stimulates different types of discussions to general reminiscence or standard interview methods. The discussions contain details about the recent past, which shows the potential of using SenseCam to discover more current version of the identity of the person with dementia. It was also realised the narratives from before and after the therapy are very much incomparable with the narratives cued by SenseCam images leading to yet another issue question (EIQ 4). John's narrative shared before and after the therapy was induced by a single question and largely directed by John. This narrative seemed continuous with his distant past whereas in the discussions cued by SenseCam images the focus of the review was on recent events. This raises some concerns that perhaps facing people with dementia with large numbers of images of their recent past may be confronting to their identity, which seems continuous with their distant past.

Emerging issue question 4 – (EIQ 4)

Should the identity be explored differently in the "before" and "after" therapy interview in order to allow use of more recent past? By asking more recent aspects like: "what do you do regularly?" or allowing finishing of as many "I am..." statements?

Conclusions

The case of John was the first out of three case studies undertaken to explore SenseCam use as an intervention aimed at identity maintenance for early stage

dementia. To conclude, the perceived benefits of the therapy, its usefulness in helping to maintain the persons' identity and emerging issue questions are summarised below.

The perceived benefits were interpreted from variety of data sources. It appeared that Mary and John enjoyed the therapy despite some of the challenges it presented (DSE 20). John enjoyed discussing the images and since Mary stopped taking part in the sessions and other supports were put in place his narratives expanded and his confidence grew as his need to rely on Mary decreased. Mary seemed to enjoy her "head space" and even attended a yoga class on one of the twice-weekly visits.

The narrative shared by John before and after the therapy interviews revealed his life stages and past achievements. This was complemented by SenseCam image review and discussions about his current life shared by both Mary and him. As a researcher I got an overwhelming feeling I got to know John as a person and his identity from both past and present. John described himself as a strong and active man, yet I got to know him as a calm and frail gentleman. I believe that the level of my newly learned comprehension about John's life extended beyond what I ever had about any of my own grandparents.

Finally, five new issue questions or emic questions emerged from the data and these are discussed in more detail below.

Emerging issue question 1) Is the SenseCam technology too confusing for someone with severe recent memory impairment?

SenseCam itself and the images were confusing to John mainly due to him not being able to maintain the memory of wearing it and its autonomous functionality. If the feelings of confusion caused by the technology outweigh the potential benefits of its use, it implies such technology shouldn't be used in cases of severe memory impairment.

Emerging issue question 2) Is early dementia stage enough to determine the suitability of the person to participate in the therapy?

The observed processes of John using SenseCam offered some insight into the criterion of people with dementia the therapy may be suitable for. Initially it was expected that a diagnosis of early stage dementia would be enough to determine suitability. However, John's case illustrated that despite his early stage dementia his episodic memory of recent events was very severely impaired. The impairment seemed too severe for John to gain the maximum potential benefits from the therapy. In the

subsequent cases a different manner of establishing the suitability may have to be deployed. The focus may need to lie more on the memory alone rather than an overall dementia stage. The participant ideally should have some ability to recall recent events in order for them to gain any benefits from the therapy.

Emerging issue question 3) Is the carer's presence beneficial to the therapy sessions? Should the carer be present during the therapy?

Initially it was hoped that SenseCam could act as a way of encouraging discussions and interactions between the person with dementia and their carer or relative. John's case showed how different coping mechanisms involving the carer can make this a difficult process. Because of John's low self-confidence in his memory and opinions, he had a well-established coping mechanism - reliance on Mary's memory. Thus Mary's presence during the therapy made it difficult for John to rely on SenseCam instead of her. It was further hoped that SenseCam might improve relations among people with dementia and the carers but in this study this wasn't the case. As Mary mirrored many everyday interactions into the therapy sessions, difficulties emerged with administering the therapy within the CST ground rules. Excluding the carer from therapy sessions resulted in John using images as cues to memory and even encouraged the most open discussions and some narratives about the events. The carer benefited by using therapy time as "head-space" or free time. The idea of excluding the carer needs to be explored further on case-by-case bases.

Emerging issue question 4) Should feedback at midpoint of the therapy be part of the framework of the therapy?

Mary clearly expressed her need for some feedback midway through the therapy. In this case it remains a possibility that the feedback along with Mary's loss of faith in SenseCam benefits resulted in her not encouraging John to wear the camera as often. It needs to be explored further on case-by-case basis if the carer seeks feedback and how to present it in an ethical manner.

Emerging issue question 5) Should the narrative be explored differently in the "before" and "after" therapy interview in order to allow use of more recent past? By asking more recent aspects like: "what do you do regularly?" or allowing finishing as many "I am..." statements?

The narratives during the therapy were very different to the ones before and after the therapy. A possible change of methodology used to induce the narrative during the

“before” and “after therapy” interview may be considered. Instead of asking a biographical question, more current questions about the person’s life may be asked. This should allow greater comparison of the amount of detail mentioned in the narratives with or without the use of SenseCam images.

The case of John highlighted some emerging patterns with SenseCam use as well as some potential ethical issues related to the overall processes of administration of the therapy. By acknowledging these issues before the next case studies there is a potential for maximizing benefits of SenseCam use for people with dementia and their carers.

6.2 The case of David

The case of David is the second of the three case studies undertaken to explore SenseCam use as an intervention aimed at identity maintenance for early stage dementia. The study was guided by issue questions and topical information questions as well as questions emerging from the first case study. This case is presented in the same format as the first in chronological order to describe patterns as they evolved within therapy and offering colour-coded examples of the different types of data drawn on to make the observations. These include before and *after-therapy interviews*, observation field notes and journal entries.

The major issues that emerged from the first case were addressed before commencing the second case study. The first two issues evolved around John’s severe episodic memory impairment, suggesting the therapy may be more suitable for someone with less severe memory impairment. This was addressed by reviewing the participant inclusion criteria and the recruitment process.

The inclusion criteria were satisfactory as they accommodated the earliest stage of dementia. Maintaining this criterion was important to sustain the therapy as one designed for people with dementia. Changing this criterion to inclusion of people with memory problems was considered, as it would probably increase the likelihood of less severe memory impairment in participants. However, inclusion of participants without diagnosis would result in the therapy changing its focus to people with memory problems rather than specific to dementia. Thus, while we felt it was important to keep the early stage dementia diagnosis as a criterion for inclusion, because otherwise it was a different target, it was necessary to review the recruitment process in order to locate participants with some memory for recent events, intact. John the first participant was recruited by approaching the Alzheimer’s Society of Ireland day centres with our

inclusion criteria. While usually it is people in the early stages who attend the day centres, often they have received their dementia diagnosis quite some time ago and their cognitive decline is progressing. For that reason, it was decided to approach a memory clinic, which specialises in assessing subjective memory complaints. This led to the recruitment of David. The other issue questions were explored as the therapy evolved.

Background

David was a fifty-seven year old man aware of his memory problems yet unconvinced of his early stage dementia. The diagnosis wasn't clearly disclosed to him by the medical professionals at the time it was identified. Instead, his wife Patricia was informed of his dementia diagnosis, which left her burdened and unsure how to disclose it to David. They lived together with David's elderly mother. Yet, due to the complexity of the situation they decided not to disclose David's memory problems to their family. Patricia was very troubled about maintaining this secret (DSE 1).

Burden of diagnosis
"...I mean I feel terror most of the time...yeah terrified of not knowing what's going to happen where are we going to end up..." **Patricia**
Before Therapy Interview – 17/05/12
Data Source Extract 1 – (DSE 1)

David's dementia was at a very early stage to the extent it was probably unrecognisable to most people. He was still able to carry out most tasks independently both at his house as well as outside it. His communication skills and episodic memory for recent events were still well preserved. However, he did show some signs of cognitive impairment. He showed some confusion with time relations, often getting the events from different weekends or days of the week mixed up. David also often had a very vacant look and occasionally it seemed he was disconnected with the world for a couple of seconds at a time. His answers and speech were also rather slow and characterised by using collective instead of specific nouns.

Patricia too, noticed some cognitive changes in David like choosing simpler woodwork projects or having to explain to him about paying bills in a bit more detail than

previously. However, the most noticeable changes noted by Patricia were his lower confidence, anxiety about going places by himself and decreased enjoyment and laughter (DSE 2).

Changes in David
"I think definitely I think there is a major loss of confidence..."
"I just picked up that he's not afraid to go but a little bit apprehensive because the plan was he was to go to the meeting..."**Patricia**
Before Therapy Interview – 17/05/12
Data Source Extract 2 – (DSE 2)

First Impressions

The locations for the therapy sessions were generally chosen in various cafés around Dublin instead of at David's house. This was decided by both participants as a result of their decision not to disclose David's memory problems to the extended family. Together with the second researcher we arrived at the arranged place to meet the participants in this case. We easily spotted the participants in the busy, tourist city centre location. They were standing together looking relaxed and could actually be mistaken for tourists. They were a middle-aged couple. David was of average height, with a receding hairline and glasses. He was wearing combat trousers, loose t-shirt with no hem around the neck and an unzipped rainproof jacket. He was standing with his hands clenched around the straps of his backpack. He wore a fishing hat to complete his outfit. Patricia, David's wife, was a tall lady with her hair cut into a tight bob, naturally highlighted by streaks of silver. She was always smiling. She was wearing very loose clothing, a floor length skirt, loose top and a jacket. They both looked relaxed in style even a little hippy. They both shook hands with me as I introduced myself. David had a little bit of a vacant look on his face. Together with the second researcher we asked if it was okay to separate for the interviews. Patricia looked at David and with a caring look reassured him about going with me "*you'll be okay going with Paulina*". She ran her hands along his open jacket and gave him a kiss on the cheek. David didn't mind but was rather response-less and then we went separate ways.

Medical history

This section summarises David's medical details as collected from David

Memory – problems awareness
“...and ehm I'm on memory tablet whatever that means (laughing)” **David**
Before Therapy Interview – 17/05/12
Data Source Extract 3 – (DSE 3)

himself, his wife, and the results of psychometric tests. David revealed he had had a heart attack twelve years previously and that he suffered from epileptic seizures a couple of months ago. After the seizures he

was diagnosed with epilepsy and then with early dementia, however he wasn't fully aware of his latter diagnosis. He was on medication for both conditions. When asked about his memory, he was aware he is taking tablets to help his memory but is unsure what that means (DSE 3). He scored 0.5 on the clinical dementia rating which would indicate

David's psychometric tests results
MMSE score= 28, with 23 accepted as a cut off point for cognitive disorders.
CDR score= 0.5, questionable dementia. ADAS-cog = 18 out of 70, increased scores worsening cognition
Before therapy 17/05/2012 Data source Extract 4 – (DSE 4)

very early stage dementia (DSE 4). David presented some cognitive impairments, however his memories for recent events were still largely preserved. He often had trouble with time relations, but not so much with the content of events. He had good communication skills and his abilities for daily living were excellent.

Perceived Identity before the therapy.

Consistent with the first case study as part of the *before-therapy interview* David was asked about his life story in order to induce a narrative about his identity. During his narrative David revealed his childhood memories mainly focused around being mis-

David's narrative

"I was in school it was in the sixties and they used to use the stick on you and ehm brutal, brutal treatment you got..." **David Before Therapy Interview – 17/05/12 Data Source Extract 5 – (DSE 5)**

treated in school (DSE 5). He mentioned leaving school early but quickly changed the focus onto his various employment places (DSE 6). He seemed proud to remember that he had been a working man. However, he also shared how this was cut short due to him

suffering a heart attack. It was noticeable how his life story was clearly divided as a result of this. He identified events as those that happened before the heart attack and those that happened after. David seemed to focus on the events prior to his heart attack, with one of the concluding sentences of his narrative stating "and then I had the heart attack". Thus, David's narrative was mostly about the distant past with much less information about his current life. One of the recent life's interests was a passion for wildlife. He described how he loves observing wildlife with a particular interest in birds and butterflies (DSE 7). It seemed unusual that

David's narrative

"I was in it (school) for three months and just walked out cuz they were making a mockery out of me and that was a horrible thing so it was and ehm I went to work I went to D..." **David Before Therapy Interview – 17/05/12 Data Source Extract 6 – (DSE 6)**

Passion for wildlife

"...my biggest interest in life really is wild life butterflies I record butterflies from different parts of where I live around and it all goes into a book in the end where you know new butterflies come to Ireland and its trying to find them and that and same with the birds really you know its just so relaxing to be out there " **David Before Therapy Interview – 17/05/12 Data Source Extract 7 – (DSE 7)**

David never mentioned his wife in this narrative. However, this might be explained by the emphasis placed on events prior to his heart attack and the fact that David and Patricia got married just a few months before this.

Additional to this narrative, David was also asked to complete the twenty statements test to share more current aspects

of his life. This measure was used because the narratives collected during the interviews in the first case were incomparable with the narratives induced by SenseCam images. This was addressed by exploring this alternative approach focusing on the current identity. It was hoped that by asking David to complete, as many “I am ...” statements as possible, it might reveal more recent or even current information about his life. In comparison to the narrative, in the “I am” statements David did mention his wife Patricia as well as his interest in politics (DSE 8). However, it was only through the SenseCam therapy sessions that David mentioned his literacy problems, regardless of which he had a passion for reading books. In combination the life story, TST and SenseCam therapy sessions gave a richer picture of David than any of these eliciting methods alone. In general, David appeared rather shy and cautious about revealing details about himself.

Twenty Statements Test
1. I am happy and laugh a lot
2. If I get tired sometimes I can get grumpy
3. When I'm working on a job I would give 100%
4. My best friend in the world is Patricia
5. I would do all to help any friend
6. I save wildlife and I look for ways of saving wildlife
7. I am a political activist
Before Therapy Interview – 17/05/12
Data Source Extract 8 – (DSE 8)

Beginning of the therapy.

The beginning of the therapy had a distinctive atmosphere of David becoming accustomed to SenseCam, to the sessions and to myself. David always acted in a very polite manner and rarely initiated conversations. Initially it seemed he had no trust in the SenseCam or in me. He was careful about what aspects of his life he wanted to discuss and used the images very cautiously without revealing any personal details of his life. In the early sessions it was a slow progress to build a trusting non-judgemental relationship with him. Despite this, very early on some patterns of how the SenseCam encouraged discussions with David were observed.

It was arranged to meet at a café in David’s hometown for the first session. As I was approaching the location I saw David standing at the corner and looking out for me. I approached him and even though he was looking out for me he didn’t really see me until I said hello. Maybe he just didn’t recognise me or didn’t remember me. We greeted and proceeded to the café with David leading the way. He was very quiet and unsure about what was going to happen. While the images were uploading David was telling me about the politics currently in the news. His story telling had a very poor flow, and he often had to stop to think about what he was saying. This happened regularly throughout the therapy. Once the pictures uploaded I explained how the

software works and its different components. David acknowledged everything by “*yeah*” or “*okay*” but never asked any questions. He seemed very shy and happy for me to lead the sessions. This was a distinctive behaviour of David and in general in the initial sessions David came across as a cautious and anxious man.

I proceeded with the therapy session by asking David if he has a preference as to from which day to view the images and he started to think and focus but didn’t answer. He seemed too polite or unsure to decide so I clicked into the set of images from our last meeting as David started to wear the camera towards the end of it. David recognised his wife in the images straight away and it seemed to bring him a little joy. He also explained that throughout the days Patricia and he were swapping who wore the camera. While looking at the photographs he identified something and said, “*oh that must be the café we went to*”. I paused the images to allow him to have a better look and he identified all different parts of the café as the deli and croissant sections. He then said that the café serves great vegetarian food. I explored further whether he is a vegetarian. He explained that he isn’t but that he quite likes the food and he doesn’t like having meat every day of the week. He then mentioned a few other café’s in the area and that he and his wife like to go to for this type of food. The first session was successful with many different discussions and stories evoked by the images.

During the subsequent sessions at the beginning of the therapy, certain patterns emerged of how SenseCam images encourage discussions and the type of discussions they encourage. The first very noticeable pattern was in the way David used SenseCam images to cue his memory about a captured event. David looked at the images and when he identified something that cued his episodic memory of the event he would progress narrating the story while looking away from the screen. He would rarely describe something simultaneously to looking at the images. He told the narratives at his own pace despite the images playing through on the screen. This was his particular manner in which he told the stories using the images. The images frequently worked as cues to initiate the story telling. However, as the story evolved, David’s use of the images wasn’t always simultaneous to the events he was describing. David didn’t seem to fully understand that the images are presented in chronological order. Thus the images didn’t really lead David to describe the events in sequenced detail. At times he would tell the story ahead of what was displayed in the images and then use the images to confirm the truthfulness of his story. When he was actually looking at the images he rarely commentated at the same time, rather just viewed them in silence. However, he always looked focused and stimulated when viewing them. At times it felt like David didn’t

narrate the images as they were playing through because he thought the images themselves told the story. He would sometimes refer to people in the images as if I

Recognition in SenseCam images

“Oh there is Anne. Oh and I wasn’t trying to rob her or anything”

“Oh there is Elizabeth”

“Oh there is the Italian guy”

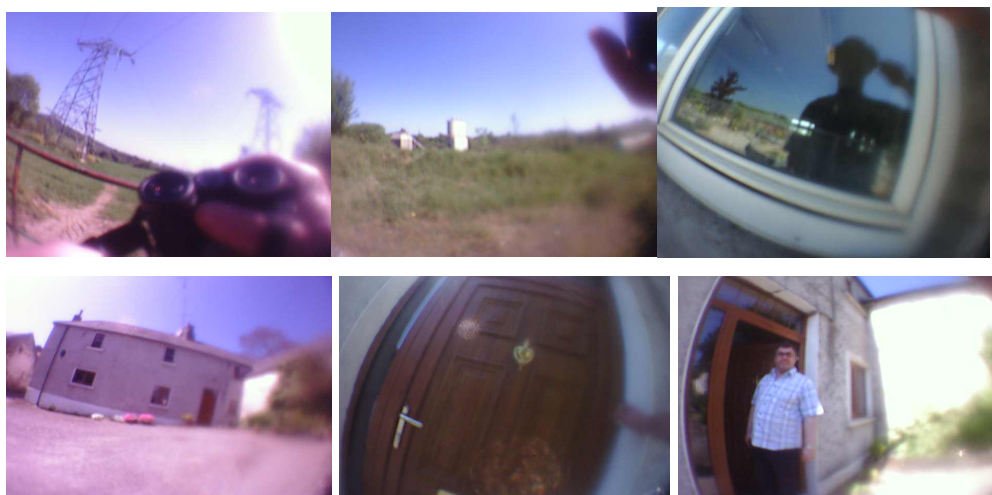
Observation field notes Varied dates

Data source Extract 9 – (DSE 9)

knew them and only when I enquired about more details would he realise that in fact I didn’t know anyone in the images except for his wife (DSE 9). This would sometimes apply to events too. It seemed like David was re-living the story in his mind while looking

at the images but he just wasn’t able to narrate them at the same time. Once some images showed him waiting on a bus and there was an elderly lady there, he joked “*oh and I wasn’t trying to rob her*”, however I didn’t get the joke as I couldn’t guess what happened during the event represented in the images by just looking at them.

Contrasting with the first case study, spontaneous recall and reliving of past events cued by the SenseCam images was a regular occurrence throughout this case. During such occurrences David shared in-depth, details about some events. They included memories from other senses like taste and smell, which were not captured by the images. In addition it was noticeable that David was reliving them with his mind and body. I believed, David often experienced Proustian moments (as explained in Chapter 4) while reviewing the SenseCam images. On one of the first occasions David seemed to experience such moment, it was while we were viewing images from what I thought was another one of David’s field trips to watch wildlife. He was talking about butterflies in his usual calm and unhurried way while looking at images of green areas. He was relaxed but then all of a sudden he focused on the screen and said, “*hold on a minute, is that?*” “*Can you go back to that for sec*”.



6.2 Sample images cueing David's narrative

He began describing the events by saying he was walking “*there*” (pointing at the image) and that he’d seen through his binoculars that three people were swimming in a water reservoir which was build up in an old sand and gravel quarry. He said he got extremely worried, he conveyed the anxiety he felt in his posture by slowly shaking his head in disapproval and by tensing up his shoulders as if reliving that moment. He described how he went looking for the owners or someone at the reception to report them in case something might happen to them. He explained how he had to go from one building to another to try and get an answer when he knocked. He said because it was the weekend and the place was closed but he managed to get a man to answer the door and he told him about what he’d seen. He said that a while after he had seen a Gardaí car coming up. While describing the events his voice was low and tremulous, as if he was once again anxious about safety of the two people. During this description he was using the images (Fig. 6.3) and commenting on them: “*oh look there I am knocking at the door*” and “*there is the man I was talking to*”.

Another great example of David reliving events as cued by SenseCam images were his descriptions of food. SenseCam would capture most of David’s meal times including the preparation and the finished dishes. When David was viewing the images during the sessions, he was reliving his memories of the delicacies and tastes but at the present moment. David was very passionate about food and any time SenseCam images showed one of his dishes he would describe them in a very detailed manner. He would first list all the foods he was having along with how ripe, sweet or sour they were (DSE 10). He would then describe how he made the dish, whether he chopped them, baked them or mixed them, finishing with describing how that particular dish tasted. David would have his eyes half-closed and roll them simultaneously to making a

“*mhhhhmmm*” noise. It’s like he was back there and was able to taste the dish again.

Thus, it was clear from the very beginning sessions that the images worked really well to evoke memories for David and enable him to relive these recent events during the sessions.

Complementary to the images cueing episodic memories for recent events, it was also apparent they stimulated some semantic memories, usually prompted by some specific details in the images. David would often describe a known fact, object or

Re-living the memories of taste
 “I chopped a banana and that other fruit what do you call it, the kind of hairy, round green one...”
 “I mixed that with a yoghurt, of my favourite flavour raspberry and you wanna taste it ohhh (rolling his eyes) it was unreal oh I loved it”
Observation field notes 24/05/12
Data source Extract 10 – (DSE 10)

wildlife species after spotting some minor detail in the image (DSE 11). For example,

SenseCam images cueing semantic stories
Some of the images showed Patricia in her study room, which led David to describe her love for art.

On another occasion an image of a café led David to describe his love of vegetarian food

Observation field notes 21/05/12

Data source Extract 11 – (DSE 11)

when reviewing images from a walk through a forest, David would just comment on different types of trees that grow there. This pattern was insightful and the ability of SenseCam use to stimulate semantic as well as episodic memory was explored further. Thus, this theme was conveyed into an

emerging issue (EIQ 1).

Overall at the beginning of the therapy David was very polite and came across as a little self-conscious. He rarely initiated any conversation without my help. It seemed he had gotten used to the images and was starting to enjoy reviewing them. He was happy for me to take the lead during the sessions despite encouragement for him to make some choices. I felt I really got to know David during the first weeks both through the images and his narration around them. This feeling of being exposed to a very detailed representation of David's life was similar to the impression of John in the previous case. This exposing nature of SenseCam image review raises some ethical concerns on whether participants should be explicitly advised about a possible exposure of their lives is potentially an unavoidable side effect when using lifelogging.

Emerging issue question 1 – (EIQ 1)

SenseCam usefulness in stimulating the semantic as well as the episodic memories?

Midway through

Around the midpoint of the therapy the dynamics of the sessions changed to more relaxed and friendly atmosphere. David became used to SenseCam; his wife informed me that he looked forward to the sessions; and had built some trust in me as the therapist. He started greeting me with a big smile and some story about the happenings since I had last seen him. It felt like we had formed a friendly connection. At the start of each session he would hand me the camera without a reminder. He seemed a lot more confident than at the beginning of the therapy. Some of these changes were accomplished due to his carer being present in some of the sessions. Her presence reassured and encouraged David to talk about personal details of his life and have a laugh about it. She showed her trust in me as the therapist and this helped David build a trusting relationship with me also.

David's wife Patricia joined us on the fourth session and we arranged to meet in a quiet pub in a lovely port town. I arrived few minutes early and I spotted David and Patricia rushing in through the door looking a little bit tired and irritated. Patricia took the central seat with a direct view of the screen and David took the seat at the other side of the table. I started uploading the images. Once they popped up on the screen Patricia immediately asked David to swap seats and he made a little joke saying, *"I better swap our bottles too"*. He seemed more relaxed with her around. We decided to view some images from last Sunday, as they would display events from a time they were together. Patricia saw the SenseCam images for the first time. She commented in an agreeing tone directed at David *"gosh they are really blurry"*, which must have been in relation to a previous conversation she and David had. Patricia was able to figure out things in the images and made a comment that the dog seems to be in more images than anyone else.

It became a common occurrence for David and Patricia to discuss their memories of recent events together without taking any notice of me. The images displayed some small town and Patricia began to wonder if the images were from their visit to her mother as that had happened the previous weekend. David recognised the town as the one in which her mother lives and further identified and described a certain

Emerging issue question 2 – (EIQ 2)
Can the carer replace the therapist and under what circumstances?

building so Patricia could recognise and confirm it was indeed the town her mother lived in. They were having a conversation on their own about their memories and I was somehow excluded, as I wasn't part of their memories. They were enjoying viewing the images and having discussions about them. It seemed reviewing SenseCam images by David and Patricia as a couple was really beneficial to both of them and led to the next issue (EIQ 2).

Patricia would often join in when David was telling a story and encourage David to give more details about a certain event or some funny story about a particular person. She would also often joke saying *"David is like a CIA agent, he'd tell you nothing, you really have to dig at him to get information out"* She was a real benefit to the therapy as whenever she felt David was capable of exploring an event or story in greater detail, she encouraged

Patricia's encouragement of discussions
"why am I saying this David you tell Paulina what happened"
"go on hun what's happening there go on tell Paulina"
"oh you little CIA agent tell you nothing"
"you have to tell Paulina she doesn't know"
"no that's finished so you need to close click touch the red button"
"go on you pick which one would you like to look at"
Observation field notes – varied dates
Data source Extract 12 – (DSE 12)

him to do so (DSE 12). I couldn't fulfil that role as I didn't have the knowledge about the particular details of the event.

Patricia often encouraged David to talk about some personal details of his life and have a laugh about them. In comparison to David she was very open when revealing aspects of their lives. She would often select details from SenseCam images illustrating some of their habits and bluntly discuss them often joking about them. She also wanted to share some private details of their life as cued indirectly by the images. While this reassured David to use SenseCam images in a similar way it also raised some concerns about the risks associated with reviewing the images with people with dementia and their carers. The images cued Patricia to discuss some private details of their lives however she didn't seek David's permission or confirmation to discuss them. It seems that the combination of the images and the carer's presence during the therapy can potentially lead to discussing aspects of life that may otherwise seem undesired by the person with dementia. This is a potential ethical risk of using SenseCam with people with dementia and their carers. Nevertheless, David and Patricia's honesty helped to build a very close and trusting relationship during the sessions. I regularly checked in as to whether they were happy to continue and if they were uncomfortable about the details of the conversation however, both David and Patricia were very keen to continue the sessions.

One of the sessions illustrated David and Patricia's openness about using the SenseCam images. While looking at a set of images from David's typical day in the house when Patricia is away at work. David was proudly narrating the images, which showed him eating his usual healthy breakfast. Patricia also joked that his breakfast preparation is like his ritual. While they continued to discuss how much of a healthy eater David is, the images showed a big plate with biscuits and David's hand reaching over and clearing a few from the plate. They could have chosen to ignore the images but instead they made a joke about it saying that those biscuits have always been David's soft spot. The images then showed David coming inside the door and then there were a number of dark images. Patricia started laughing a little bit. She then looked at David and said one of her usual sayings, used to encourage David to tell a story "*you have to tell Paulina what they are*". She said, "*I often hug David and that's where they come from.*" She said "*it's very important to have that little play in our lives.*" The sessions with Patricia really helped the discussions to be very open and relaxed. Her presence also reassured David it is okay to talk about all the little details and have a laugh about it.

On another occasion, as we were clicking through the images I noticed something going up and down in front of the camera and neither David or Patricia commented on it, they may not have recognised the object as the images were a little blurry. I asked if I was recognising the object correctly. I said, *“is that a pipe you are smoking there David?”* He just started laughing like a small child after being caught. Patricia also started laughing and commented, *“He is but it’s a secret because he’s not meant to be smoking”*. I think David’s pipe smoking would never have been revealed in a standard interview setting, however they found it hilarious when I recognised it in the SenseCam images. I also laughed about it and expressed my surprise at their intention of keeping it a secret, as I wouldn’t care or judge David for it. The pictures then showed the back lane again and David commented that he was going to get tobacco in a shop. We even had a chat about all the different tobacco available in the shops. I wondered about the type of conversation we would of had if I hadn’t asked him about the pipe. Would they have told me what the purpose of David’s trip was? It felt like the content of the images was allowing them to discuss all the details from their life and allowing me to get to know them at a more personal level. The atmosphere was very pleasant and everyone seemed to be enjoying the sessions. These were just a few from many occasions where through the SenseCam images, real life was discussed including some of the habits they may have wanted to omit or simply not thought of as worth conversing about. While this allowed me as a researcher to perceive a more holistic version of David’s identity I wondered how ethical this exposure was. Without the SenseCam images or Patricia’s presence many of the little details or personal details may not have been revealed. Thus, the identity he would have portrayed without these resources would have been fundamentally different. These resources also helped David to be more open and to discuss all aspects of his life shorn of feelings of being ashamed of it. However, these exposures to personal details raise another issue around SenseCam use (EIQ 3). Furthermore, I wondered about crossing the boundaries of Patricia’s encouragement and whether it is possible for encouragement to become factual prompting or exposing as seen in the previous case.

Emerging issue question 3 – EIQ 3

How ethical is it to discuss private details of participants as revealed by SenseCam that may not otherwise be revealed?

The sessions with the carer, Patricia also helped to identify images that may be of interest to David. We played the images from the day quite quickly and they showed David back in the house and in and around the garden. Patricia kept on commenting, *“I wonder when will we see Kevin or Tina,”* I asked who they were and when do they

normally see them, she informed me it's on a Tuesday and Wednesday respectively. I displayed images from Tuesday showing David working in the garden and then a young man or teenager appeared in them and both David and Patricia identified him as Kevin. They then shared some stories about him. Once Patricia was satisfied that she had seen Kevin in the images she asked to view images of Tina. I asked them when they see Tina, and David said it is on a Wednesday around 7.30. I clicked into these images and it showed a desk and a lot of paper and every now and then a person was visible from the left. They paused the images and both proudly identified the person as Tina the person who teaches David how to write. They described her as a really nice person who makes them feel at real ease. Patricia asked me "*is that the first time you've seen Tina in the images?*" She was shocked when I said it was. David would never request to see any particular set of images and if he did pick a set to view I think it's a rather random choice. Thus I wasn't aware that Kevin and Tina are a routine part of their lives. David had mentioned Kevin before but never really mentioned Tina. I wondered whether David had felt I would judge him if he discussed his "read and write" teacher. Discussing her would also reveal his literacy problems. Patricia helped to reveal this part of David's identity through requesting to view these particular SenseCam images. David didn't seem uncomfortable with this, quite the opposite he seemed proud to be sharing how Tina helps him with improving his reading and writing skills. He happily discussed Tina and his classes thereafter, often sharing the content of the stories he would write as part of his assignments. I wondered whether David had not discussed his literacy problems by chance of not coming across the particular images or was he purposefully avoiding it. While, there was no awkwardness in Patricia guiding David to share certain aspects of his life, I wondered how ethical was it for her to make these choices.

Patricia's role was very important to the therapy sessions as she demanded certain things or perhaps expected to see certain things in the images and asked about them. David on the other hand would never ask to look for particular sets of images. I think this was partly due to him not really comprehending that they would show all of his activities or maybe just not being able to think on the spot about what he had done on a particular day. All the sessions with the carer were really successful and consisted of much laughter and enjoyment. SenseCam images allowed them to reminisce about their recent past together and to have a laugh about it, despite David's early stage

dementia. Patricia brought humour and fulfilment to the sessions. David also enjoyed the sessions with his wife and was always very positive about them (DSE 13).

The sessions with the carer led to David becoming more open and relaxed during all subsequent sessions thereafter regardless of Patricia's presence. He had formed a trusting relationship with me, which helped him to discuss many personal details. He used the SenseCam images to share aspects of his identity irrespective of the prejudice that may be associated with them. His confidence grew enormously and he was never ashamed to share any potentially embarrassing moments.

On one occasion the images uploaded with the wrong dates as they showed as January, year 2000 so neither David nor I had any idea when exactly they were from. David had only the images as cues to his memory –

David's response to sessions with carer
"Yes I do enjoy it. I like it more when Patricia is there"
David -Journal entry -18/06/12
Data source Extract 13 – (DSE 13)

no date indication to help him. I clicked into a set and just played the images at a medium speed and asked if he recognised what was happening here or if anything sparked up a memory, to tell me. The first set started showing David's chin. The camera must have been placed flat on the table and David must have been above it. He was trying to figure it out where it was. *"oh that's us looking out our attic window "*. He started concentrating some more on the images and then said, *"these lights are throwing me off"* the images showed spotlights in the ceiling. He just said *"I don't have a clue where I am to be honest I'm lost"*. Initially David would never admit he doesn't recognise something in the images. Whereas, now in the middle of the therapy he began to be more comfortable and confident in his discussions and occasionally admitting when he didn't recognise something. The images started showing the view changing and then my face popped up in them and it was clear they were from one of our meetings in the café. David looked up to the ceiling and said *"look"* pointing at the spot lights *"that's exactly where we are at"* I replied saying that we must have placed the camera on the table after uploading the images. He started laughing.

Towards the end of the therapy

In the final sessions of the therapy both David and Patricia were at ease talking about most aspects of their lives. David went from initially trying to keep his pipe smoking a secret to describing how he used to hide it from Patricia. The therapy allowed David to discuss his life with me and with the help of SenseCam images and his wife, a certain version of his identity was portrayed. It also helped David reinforce

this by having relaxed and humorous discussions about all aspects of himself including the positive and the negative aspects. The sessions became a highlight of his day. During them he was always laughing and smiling while sharing the stories and was always very positive about them (DSE 14).

Reviewing SenseCam images enabled me as a researcher to get to know a version of the participant's identity that may differ from one presented in a standard interview. SenseCam

images revealed aspects of the real life and encouraged discussions about everyday life – it seemed different to what a standard interview, or even a therapy using generic or staged images like reminiscence or life storybook could ever evoke. SenseCam showed a wide range of aspects of the person in the present time.

During one of the last sessions we were viewing images from David's garden shed and some of them seemed to show the lower or bottom shelves. David commented that that's the shed and I asked what exactly were we looking at. David described the different tools and how he should sell them all as he doesn't use them and there are so many. One of the images showed David taking out the pipe and then smoking his pipe and Patricia and David were both laughing. They shared the story of how he hides it in the shed. Patricia said she found out he hides the pipe, tobacco and matches separately in three different places in the shed. She said she found out when David was in hospital and phoned to explain where it is. I assumed that she had no idea at all that he smoked

it, but she quickly commented that "*she wasn't that stupid*" and she only didn't know he hid it. I then asked David why would he hide it if Patricia knew about it, to which he said he just doesn't want to offend her. Another major aspect of David's identity, which he opened up about throughout the therapy, was his literacy problem. Initially, David was slow to share his literacy problems but towards the end he even described how he and Patricia often play scrabble to practice his skills (DSE 15). During the therapy he also told stories from his childhood about how his brother used to read books and laugh to

David's enjoyment

"I always feel better after the session"

"I always come out of a session feeling happy and good in myself"

David -Journal entries – varied dates

Data source Extract 14 – (DSE 14)

David's openness about personal details

"...we play scrabble and that's fun especially when Patricia is in it"

"well you know the way scrabble works it's like drafts the words come down the way and across the way and she doesn't get that you know the way you know the way if you put another word against a word and I would say what does that mean say you get the first little word in and I'll put something through it and then she puts another couple letters then and then it doesn't make any sense cuz you can't have two rows close together"

David

After therapy interview -19/07/12

Data source Extract 15 – (DSE 15)

himself but not share with David the content he was laughing at (DSE 16). This made David a little annoyed but also interested in reading and books.

In the last few sessions David often reminisced about his long distance past. On one occasion when we were reviewing images from one of his wildlife trips I explored his passion further and asked how he developed this interest in wildlife. He said that his father used to love birds, but that back in “*those days*” people used to catch wild birds and keep them. He said he didn’t really like that and ended up letting all the birds out (DSE 17).

He said, “*it might be nice to see a bird in a cage but it’s much nicer to see it flying in the wild*” He spoke about this without referring to his father as a bird catcher or without mentioning his father’s death. However both of these occurrences were obvious from the story. Perhaps his father may have died and David was left with all the

David’s openness about personal details

He said that his first book was a bird identifier and that it used to get destroyed in the rain...He said that his brother also read a lot and that he used to laugh while he was reading but never shared what he was laughing about.

Observation field notes – 09/07/12
Data source Extract 16 – (DSE 16)

captured birds. The focus was then shifted back to the SenseCam images and I asked David if he had seen much wildlife on that particular day. He said he didn’t see as much as he hoped he would. He then went into explaining how he goes about looking for wildlife. He said “*you can’t just walk into a place and walk all different ways, you need to do it in a circuit*”. The SenseCam images often made David reminiscence about how things were in the past.

Reminiscence long distance past

“My father was interested in birds but I took it to a different level”.

Observation field notes – 02/07/12
Data source Extract 17 – (DSE 17)

Nearing the end of the therapy both David and Patricia became very complimentary of the therapy. They often expressed how much it has helped David to express himself and become more confident. The SenseCam crashed when we only had few sessions left and I needed to take it home for a day to fix it. When I met David the next day he said that he missed it and felt “*lost without it*” On one occasion Patricia, asked if I would have any more participants for this study and I answered truthfully that my intentions were to conduct another case study. She then joked “*Can we do it all again, can we be your next case again*”. They often asked if there was any way they could extend the therapy. This posed yet another ethical issue around dealing with the anxieties associated with ending of the therapy (EIQ 4). Through numerous discussions with my supervisor and especially taking into consideration how successful the sessions with the carer were we

decided to offer the SenseCam to Patricia and David. This allowed them to continue the therapy on their own with some supervision. I installed the software on their home PC and left very detailed instructions on how to use it. For Patricia I prepared the rules of CST, as her role would be of a facilitator. They were delighted when I informed them they could keep SenseCam. I have kept regular contact with them and they enjoy reviewing the images from their life on a weekly basis. They had no difficulties with continuing to use SenseCam by themselves other than a few technical issues.

Emerging issue question 4 – (EIQ 4)
How to deal with an anxiety associated with the ending of the therapy?

The therapy seemed like a very positive experience for the participants with their subjective opinion of the therapy being beneficial to David in many ways. David's journal entries revealed multiple positive feelings towards the sessions (DSE 18). Patricia also revealed that the therapy had helped David to gain confidence and to be less anxious in her *after-therapy interview*. However, when asked which part of the therapy in her opinion was most beneficial, she found it hard to distinguish, leading to the final issue emerging out of this case study (EIQ 5).

David's positive feelings about therapy
"I am always enthusiastic about the camera"
"I look forward to the day she comes out its always a good day"
"I always feel better after the session"
"It was more fun lots more photos"
David -Journal entry- varied dates
Data source Extract 18 – (DSE 18)

Perceived Identity after the therapy.

In the same way as during the *before-therapy interview*, as part of the *after-therapy interview* David was asked about his life story, to induce a narrative about his identity. The narrative was very similar to the *before-therapy interview* and consisted mainly of distant past memories. However, David's life story seemed more positive this

Emerging issue question 5 – (EIQ 5)
Can the therapist relationship be separated from the therapy?

time around. He never mentioned his heart attack and didn't concentrate on his epilepsy as much. Instead he focused on strengths and positives in his life – his distant life. Similar to the *before-*

therapy interview, David talked about his employment history. However, this time he described them in a lot more detail including the varied rates of his salaries. He never mentioned his wife which again was similar the narrative shared before the therapy. The after therapy narrative seemed to contain very selective details from a rather distant past. Additionally, David seemed to become more confident about his life throughout

the therapy. Evidence of this subtle shift in emphasis can be seen in the “I am” statements (DSE 19).

The lack of detail about recent past was in contrast to the voluminous narratives cued by SenseCam images during the sessions. The stories cued by SenseCam were mostly all about the recent past revealing all aspects of David’s life, including ones he may not have shared without the use of SenseCam images. While sharing these stories David often experienced Proustian moments where he relived events captured by the images in his memory. The stories about David’s recent past revealed a version of David’s identity based on the images, his memories and stories shared with me. This perspective of David’s identity created during the sessions was also reflected in the Twenty Statements Test used in this study. It required David to finish as many sentences out of maximum possible 20 starting with “*I am...*” In the *before-therapy interview* David finished seven of these

statements and in the *after-therapy interview* he finished all twenty. This result may be a little bit biased however, as the process of administering the survey was changed from a written format in the *before-therapy interview* to oral format in the *after-therapy interview*. This was as a result of me becoming aware of David’s literacy problems throughout the therapy.

The content of the answers was similar, however the statements given in the *after-therapy interview* seemed more realistic but also more confident (DSE 19).

Twenty Statements Test	
BEFORE	AFTER
When I’m working on a job I would give 100%	Unemployed kind of unemployed person
If I get tired sometimes I can get grumpy	I am a nice guy
I would do all to help any one friend	I am very good to my friends
Before versus After Therapy Interview Data Source Extract 19 – (DSE 19)	

Conclusions

The case of David was the second out of three case studies undertaken to explore SenseCam use as an intervention aimed at identity support for people with early stage dementia. To conclude, the perceived benefits of the therapy, its usefulness in helping to support the person’s identity and emerging issue questions are summarised below.

The perceived benefits were interpreted from a variety of data sources. In comparison to the first case study the enjoyment of the therapy by David and Patricia was overwhelming. David’s recent memories were still preserved to an extent so that he was able to use SenseCam images as cues to recall them. Thus, it can be argued

narrowing down the inclusion criteria to a person with recent memories less impaired resulted in the therapy offering more benefits to the participant. This also enabled David and Patricia to enjoy reviewing the images together to such a degree that my presence wasn't always a necessity and the fact that they are continuing to do so on their own time is further evidence for. Throughout the therapy, David's confidence increased and he seemed to have become more positive about his life.

The narratives shared by David during the *before* and *after the therapy interviews* focused on distant past and included only selective details about illness or employment. This was complemented by the discussions around SenseCam image review, which were mostly about events from his recent past. Additionally, SenseCam review revealed details about his life David may not have shared in other settings. This created a more rounded outlook on David's identity. This version of David's identity created during the therapy sessions included all aspects of his life: distant and recent past, mundane and astonishing details, as well as positive and negative behaviours. Similarly to the previous case, this raises ethical concerns around the level of exposure of participants' lives to the researcher, which occurs while using lifelogging.

Finally, five new issue questions or emic questions emerged from the data discussed in more detail below.

Emerging Issue Question 1) SenseCam usefulness in stimulating the semantic as well as the episodic memories?

Initially it was expected that SenseCam would primarily cue episodic memory. However, SenseCam also encouraged discussion about semantic facts. These discussions were inseparable as often they were interchanging between episodic and semantic memories. It would be interesting to explore if cueing semantic memory also supports the identity of people with early stage dementia.

Emerging Issue Question 2) Can the carer replace the therapist?

The sessions with Patricia present seemed to work exceptionally well and to bring much joy and laughter to the sessions. At times it felt like my presence as the therapist was unnecessary. A possible issue is whether the carer could potentially replace the therapist and under what conditions - perhaps in the form of maintenance sessions.

Emerging Issue Question 3) How ethical is it to discuss private details of participants as revealed by SenseCam, that may not otherwise be revealed?

Many personal details were revealed because the *always-on* SenseCam captured them. Before any of the details were discussed a trusting relationship was formed between the therapist and the participants who were very comfortable talking about intimate aspects of their lives. However, they might never have mentioned some of them without SenseCam images revealing them and acting as cues to such discussions. Thus, it may be disputed how ethical is it to discuss such details or under what circumstances is it acceptable to do so. Participants are already made aware of the possibility of such details being revealed in the plain language statement, though therapists should be aware that such discussions should only take place after a trusting, therapeutic relationship is made between them and the participants.

Emerging Issue Question 4) How to deal with an anxiety associated with the ending of the therapy?

In this case some anxiety was associated with the ending of the therapy. The participants enjoyed the therapy very much and found it difficult to end it. In this case it was decided to support them to continue using SenseCam in a therapeutic manner with the carer acting the role of a therapist. At the moment the data is being collected to establish benefits or negative aspects of such an approach. It is important to note that anxiety associated with ending of the therapy can be reported and the therapist should deal with it in a way that helps to minimise it.

Emerging Issue Question 5) Can the therapist relationship be separated from the therapy?

When asked what was it specifically, that provided David with most benefits the participants couldn't separate the photos from the therapist or from the stories. It may be that the therapy is only beneficial when administered as a whole including the social interaction, the discussions, the therapeutic relationship with the therapist and the resources of memory provided by the SenseCam images. This issue should be explored further in the final case study.

6.3 The case of Dolores

The case of Dolores was the final of the three case studies undertaken to explore SenseCam use as an intervention aimed at identity support for people with early stage dementia. The study was guided by issue questions and topical information questions as

well as new emerging questions from the first and second case study. This case was presented in chronological order to describe patterns as they evolved during the therapy.

The previous two cases and their emerged issues informed this case. The case of John led to the amendment of the inclusion criteria by narrowing participants to those with reasonable episodic memory for recent events still intact, notwithstanding them having an early stage dementia diagnosis. The case of David was a result of this change as SenseCam images worked very well for him to cue discussions about his recent past. Thus, it was decided to maintain these adapted criteria for the final case. However, identifying participants matching these narrow criteria was difficult. Many people with dementia receive diagnosis when they are nearing the moderate stage and their memory is already becoming severely impaired. The memory clinic did suggest another participant who matched all of the criteria apart from the criterion of living with a carer. It seemed illogical to exclude this participant based on just one criterion. The previous adaptation of inclusion criteria to people with recent memories still intact increased the likelihood of people being at the very early stages of dementia, still with the capacity to live independently. It was assumed that if the person has the capacity to maintain living independently they also have the capacity to partake in the study without the help of a carer. It was decided through supervision meeting to change the criteria and invite the participant to take part in the study. However, as this was a fundamental change of inclusion criteria, permission was sought from the DCU Research Ethics Committee, which granted full approval (Appendix L). This led to the recruitment of Dolores.

Background

Dolores was an eighty-seven year old woman with a diagnosis of vascular dementia. She lived on her own in an apartment in a central city location. Dolores was very capable of living independently and her apartment was very well maintained. The psychometric measures which are used in this study as a rough guide rather than diagnostic tools also indicated early dementia stage. The signs of cognitive impairments were observable in Dolores by her weakened communication skills as well as poor or no memory of past events without referral to her main coping mechanism – the diary.

Worries associated with dementia

“my other son he would be very very very very upset all together if he thought he’s a manager he owns all nursing homes he’s a huge way into those and I think if he thought for once that I was an early Alzheimer’s that I think he would take out it would affect him very much I’d say”

Dolores

Before Therapy Interview – 03/04/13

Data source Extract 1 – (DSE 1)

When asked how she felt about her cognitive impairments, Dolores revealed that she was aware it was getting worse and she was worried about issues associated with that. One of her concerns was that the people around her would notice the changes. She wanted to keep her memory problems and diagnosis private from some family members and

friends. She was especially worried about one of her sons as he manages nursing homes and would be aware of the symptoms of the

disease or maybe the stigma associated with it (DSE 1). On the contrary she also worried that her children may never realise she has a memory problem and over-rely on her for minding her grandchildren or other home help (DSE 2). However, her main worry was about her failing communication skills. It was evident

Worries associated with dementia

“they don’t seem to think that you know that there is anything wrong because I get up and I do my work as everybody else you know they expect me to do the same thing like you know like would you in an emergency” **Dolores**

Before Therapy Interview – 03/04/13

Data source Extract 2 – (DSE 2)

Dolores had some difficulty with expressing herself due to a reduced ability to find

Dolores’s realistic perspective

“I realise that I do feel that I do feel its going to deteriorate I realise that”

Before Therapy Interview – 03/04/13

Data source Extract 3 – (DSE 3)

specific nouns, which at times removed a lot of the content from her speech. She was also very aware of her condition and realised dementia was a degenerative disease (DSE 3).

First Impressions

Dolores greeted me at the front door of the building to her apartment. She was an elderly lady; however she certainly didn’t look her age. She was always very well presented with fashionable clothing; lightly framed glasses; and some make up applied enhancing her features. She had shoulder length, highlighted, blonde hair and a petite silhouette. She opened the door to the building and welcomed me in, energetically she walked towards the elevator and I followed. She was holding two sets of keys, a mobile phone and a purse in her hands. She was jostling them around as if constantly checking if they were all there. We took the lift and she welcomed me into her apartment where she lived on her own as her husband passed away a few years ago.

I explained the purpose of the research and showed Dolores the SenseCam. In response she asked some questions. Many of them concerned the visibility of wearing SenseCam. She asked if the camera would work if worn underneath clothing and if it's meant to be worn outdoors. I explained that wearing it underneath clothing would result in dark images being taken. She was a little bit surprised or perhaps sceptical about wearing the camera on the outer layer of clothing (DSE 4). I'm not sure if this was due to the potential embarrassment about wearing it or because it jarred with her sense of fashion.

Anxiety about wearing SenseCam
 "Oh it won't capture through that? Even through something as transparent as that"
Observation field notes – recruitment session 25/03/13
Data source Extract 4 – (DSE 4)

Once I answered all questions posed by Dolores she seemed satisfied and comfortable with the information on SenseCam and we moved on to arranging the weekly visits. Dolores took out her diary and searched for the best days and times to fit the sessions in. I suggested that ideally they would be days at the start and end of the week. Monday suited both of us, and then Dolores suggested Thursday. However, once she began noting this down in the diary, she realised that she attends aqua-robics and meets with her friends every Thursday. It appeared she had no memory about what seemed like a regular weekly event. The diary seemed to serve as a reminder to events, even ones that happened on a weekly basis. We arranged to meet on Saturdays for the second weekly visit.

Medical History

When asked about her memory problems Dolores explained that she started noticing some memory and speech impairments little over a year ago. Following an MRI scan she received a diagnosis of vascular dementia. The psychometric test used in this study also suggested some cognitive impairment however these are not

Dolores' psychometric tests results
 MMSE score= 24, with 23 accepted as a cut off point for cognitive disorders.
 AD8 score= 4, questionable to mild dementia.
 ADAS-cog = 11 out of 70 increased scores worsening cognition
Before therapy 03/04/2013
Data source Extract 5 – (DSE 5)

diagnostic tools. Dolores scored 4 on the AD8, which is a version of CDR for people with dementia without a carer. The score can be translated as a score between 0.5 and 1 on the CDR test indicating mild dementia stage (DSE 5). Dolores scored low on the MMSE especially when her score was adjusted for number of years spent in education. Again this suggested some cognitive disorders (DSE 5). She also showed poor time relations, often getting the events from different weekends or days of the week mixed

up. However, the dementia was still at an early stage and Dolores's episodic memory for recent events was still somewhat preserved. The most noticeable impairment was her speech impairment, as she would often forget names of objects or places causing her speech to be very incoherent and broken. She would also often use a collective noun instead of a specific noun (DSE 6).

Dolores's use of collective noun
 "That thing oh the name escapes me now"
 "we went onto the thing you go on..."
Observation field notes – varied dates
Data source Extract 6 – (DSE 6)

Perceived Identity before the therapy

In keeping with the prior cases as part of the interview before the therapy Dolores was asked about her life story in order to induce a narrative about her identity. Dolores narrated her life story in a beautiful manner which at times kept me in suspense as well as evoked emotions of empathy as she discussed some of the less fortunate moments. She admired her mother and was thankful for the opportunities she gave her by sending her to college. She devoted a great part of her story to her youth and the years she spent in college and training, mainly focusing on the social aspects. The second part of her narrative was devoted to her children as she described what each one of them has achieved to date. There was little focus on the present except for a statement at the end saying she was happy where she was (DSE 7). This was similar to the previous cases.

Dolores's narrative
 "Great life it was in X they were all bachelors ... and they'd all go to the river and we'd do the sandwiches and the lunch and the thing for the meal and we'd take it out with us and we'd do that every week"
 "I'm very happy here and I'm going to stay and that's where I am up to this day" **Dolores**
Before Therapy Interview – 03/04/13
Data source Extract 7 – (DSE 7)

Twenty Statements Test

1. I am over 60 years of age
2. I am a happy person
3. I am happy that my children are all happy and settled
4. I am slow walking at times
5. I am slow to get angry
6. I am I'm a kind person
7. I am a healthy person
8. I am the eldest of my family
9. I am grateful that I am living here
10. I am good at making friends

Before Therapy Interview – 17/05/12
Data Source Extract 8 – (DSE 8)

Following the adaptation to measuring the identity before the therapy in the second case, the TST was also used with Dolores in hope to induce more current aspects of her life. Dolores was asked to complete as many "I am" statements as she could. Dolores completed ten statements, which complemented the narrative by describing her general traits rather than events of her past. In the process of completing these statements she seemed a little indecisive about what to say, with each statement taking

30 seconds or more to complete. In two of the statements she seemed to position herself within a group and describe herself indirectly (DSE 8). In general Dolores appeared to be an optimistic person, but at times anxious about her condition.

Beginning of the therapy

The atmosphere in the beginning sessions of the therapy was that of scepticism, trial and error, trust-building and adaptation. Dolores consented to the therapy but always expressed her uncertainty about committing to take part until the end of it (DSE 9). She would often worry about wearing the camera and expressed that she wouldn't want to wear it to dinner parties or other occasions where her friends might notice it and ask questions about it (DSE 10). She was also careful about what aspects of her life she wanted to discuss and only wore the camera when it wouldn't capture anything she may not want to disclose. Thus, initially SenseCam captured very selective sets of images that were mostly taken indoors. It was a slow process for Dolores to adapt to the unusualness of the images and to identify anything in them. It took Dolores approximately the first five sessions to get used to SenseCam, the images and to build up trust in me before she could discuss the events presented in them freely.

Uncertainty to committing
"see how I get on first there was nothing stopping me from trying"
Observation field notes –
recruitment session 25/03/13
Data Source Extract 9 – (DSE 9)

Anxiety associated with SenseCam appearance

When reviewing images from Dolores's shopping trip a number of them showed her reflection in the mirror...Dolores commented
"I was checking how visible it was against the clothing..."

Observation field notes – 17/04/13
Data Source Extract 10 – (DSE 10)

During this time some distinctive patterns of Dolores's use of SenseCam as well as the use of other memory aids were observed.

In the very beginning sessions I noticed that Dolores very often referred to her diary when speaking about any past events including events as recent as the day before. Initially it didn't seem like anything unusual, as many people would refer to a

diary either digital or written when discussing past events. Early on Dolores revealed how she keeps two types of written diaries one just a regular pocket size diary where she writes all her appointments for the day. These are very detailed and include things like phone calls and weather reports. The other diary was more free style where she writes about her day for example how she was feeling and what she had done or thought about. During the sessions we would have some general conversations while the laptop was starting up and I would often ask if Dolores had a nice weekend or if she got up to anything exciting in the past few days, to which she would respond

“Oh yes I had a lovely weekend I had things on, let me just check this (referring to her diary) oh yes I went to visit my daughter on Saturday and then on Sunday...”

Dolores never gave the impression she didn’t remember any events and checking her diary was so natural, fast and precise it seemed like she was just confirming things. However, with time it became noticeable that Dolores didn’t seem to have detailed or episodic memories of these events but rather she just acted as if she did. On occasions she would read things from her diary and then question them. This gave the impression she had no memory whether the event noted in her diary actually happened. One example was a day she was referring back to her diary, which included my visit, and after reading the schedule out she questioned it *“you were here weren’t you, were you here?”*

As the sessions progressed it became more obvious the diary was Dolores’s way of coping with the impairment of her prospective and retrospective memories. During the *before-therapy interview* Dolores discussed how she would not remember any forthcoming appointments unless they were written down in her diary (DSE 11).

However, she claimed she had a fair memory of past events. Nevertheless, it seemed

that Dolores struggled with memory of past events similarly to her prospective memory.

Unless she referred to her diary, she couldn’t recall much detail about a past event. As earlier mentioned, she even had trouble with

identifying whether a past event written in her diary actually took place. On the contrary to her admittance to her impairment of prospective memory, she never really acknowledged or discussed her retrospective memory impairment. She may not have realised this impairment yet as she coped with it very well by using her diary.

Dolores was very quick to integrate her existing coping mechanism – the diary – into the therapy sessions. When reviewing

SenseCam images we would decide on a date from which we would review the images. Dolores would notice the date and time and refer to her diary to check what she was doing. If we changed the day or finish reviewing one day and move onto the next

day on the browser, she would flick through her diary accordingly. She referred to her diary nearly every time before looking at the images. It would only be a very quick check at times it would even go unnoticed to me as she didn’t always read the contents

Dolores’s diary use

“I write everything down I wouldn’t remember unless I write everything down” Dolores

**Before Therapy Interview – 03/04/13
Data Source Extract 11 – (DSE 11)**

Scanning the diary

“On the 20th I went to the dentist I met my friend and went to the park, it was a glorious day” Dolores

**Observation field notes – 17/04/13
Data Source Extract 12 – (DSE 12)**

out loud (DSE 12). Dolores seemed to have perfected this coping mechanism over the past years and it seemed to work very well for her.

For that same reason of having a well-established coping mechanism, reviewing SenseCam images seemed a little confusing and appeared to be conflicting with it at first. This was due to SenseCam capturing a lot more images from Dolores's day than those written in her diary. Very often the images were captured during the times Dolores hadn't noted anything in the diary. This would often make Dolores question her coping mechanism "*I have nothing written for that*" Another example would include the detailed information that SenseCam images reveal as compared to the very brief schedule of the day written in the diary. For example, she had written that she went on an afternoon walk but when we went to view the images from that day she had no recollection of where she went on that walk. Only through viewing SenseCam images was she able to recognise the park and eventually remember the event. Thus, reviewing of SenseCam images often exposed she had very little or no memory about the day except for the brief details written in her diary (DSE 13). Dolores viewed SenseCam as beneficial to her memory impairment and seemed happy with the cues it provided to the details of events otherwise forgotten. However, it is concerning how other people with dementia could react to the review of SenseCam images, which could potentially make them realise the extent of their forgetfulness.

During one of the initial sessions I proposed we review some images without checking the diary and Dolores happily agreed. I explained it's not a memory test rather a stimulating exercise to see if we can discuss the event without worrying about the correctness according to the diary. She narrated through the images no problem, however checked her diary at the end as if to confirm if what she was talking about was correct. When we attempted to follow the same principle of not checking the diary in the following session Dolores agreed but then accidentally revealed that she was checking

her diary before I arrived. Therefore, it was purposeless trying to eliminate her established coping mechanism, as it would never be possible to control for it. Instead in the subsequent sessions we

Dolores's surprise by activities of her day as revealed by SenseCam

"...but I would never realise that I fit so much into my day like I considered like when something is put before you on a screen you say oh my God the day must be very long I got so much fitted into it I didn't sit down or sit in the cafes or I didn't but I had an activity every day" Dolores

**After therapy interview -12/06/13
Data Source Extract 13 – (DSE 13)**

Emerging issue question 1 – (EIQ 1)

Does using SenseCam conflict or complement any existing coping mechanisms to memory impairments?

aimed to work with the diary and SenseCam images combined. This was also reflected upon in the first emerging issue from in the third case (EIQ 1).

Another challenge at the beginning of the therapy was the unusualness of the SenseCam images, which caused Dolores great difficulty in recognising anything in the images. At first she was rather confused by the images and often sat in silence trying to figure them out (DSE 14).

Thus, at first instead of enjoying viewing the images it seemed that the sessions consisted of a lot of thinking and figuring it out. She commented on a number of occasions that she finds it really hard to find any association with the images (DSE 15). I

explained that they are different to normal images and that they may often come up

blurry or distorted. In the beginning sessions I often had to help Dolores identify objects and surroundings captured by images. She also struggled initially with the concept of her being absent in the images, as she was the wearer of the camera, however with time and explanation she

was able to comprehend the idea that she is the photographer (DSE 16).

By the fourth session she had made great progress in recognising the images and was able to recognise different rooms in her apartment as well as objects without any hesitation or help from me. She made a positive comment about the blurriness and weird angles of the images saying that they stimulate her cognitively as she needs to think about what they are of and tries to associate herself with them.

She also said she was used to them now. Once she adapted to the images she was able to start discussing their content rather than just identifying things in them. Anytime she recognised the physical things in the images, she was able to add some semantic memories to it. For example, when she recognised photo frames hanging on the walls she also talked about her children and her grandchildren (DSE 17).

Figuring out SenseCam images

Some of the images showed really clear shots of a coffee cup and bottle of water as they must have been placed in front of Dolores but she couldn't recognise them in it. I'm not sure if she expects different images for example of people or other things...?

**Observation field notes – 17/04/13
Data Source Extract 14 – (DSE 14)**

Association to SenseCam images

"It took a while for me to identify the pictures and what they represented"

"I am still getting used to what the pictures are representing"

**Dolores
Journal entries – varied dates
Data Source Extract 15 – (DSE 15)**

SenseCam an automatic camera

"Initially Dolores continuously identified herself in the images where in fact it was myself that was captured – during the sessions. She didn't seem to remember at first that the camera would rarely picture herself as she was the wearer"

**researcher -Journal entry– 17/04/13
Data Source Extract 16 – (DSE 16)**

The fifth session was a breakthrough in Dolores communicating about SenseCam images. Up to this point she would only identify things in the images and discuss some semantic memories associated with them. During the fifth session she narrated through the images, as she was re-living the

Semantic memories recall
The images showed the sitting room, which she recognised. Some close ups of her framed photos were captured. She described everyone in them, which were mostly her grandchildren, and she elaborated further saying which daughter had them who she's married to and where they are currently living.
Observation field notes – 24/04/13
Data Source Extract 17 – (DSE 17)

moments captured by them. Upon checking her diary Dolores stated she wore the camera outdoors for the first time about a week prior to this visit and that she would like to review them. The images uploaded and we clicked into the specific date and Dolores concentrated very hard when figuring out what was the exact location presented in the images. She was deciding if they were representing her way into town or back home. She figured out that they were images from her way in very quickly by identifying four tourist buses. She narrated through her journey adding descriptions of the atmosphere present during that event

“The streets were very busy and there were many tourists around and I really struggled to get by them.”

She continued to describe additional details to what was present in the images. The images induced Dolores to re-live the moment in her mind as it happened. With the flood of episodic memories she narrated through the event describing buildings she passed, people she met, and unfolding how she felt. The last image showed a handbag, which looked like it was just floating in the air. It had both Dolores and I confused and we were about to skip it and blame the unusualness of SenseCam images for this peculiar photo. However, Dolores once again had a Proustian moment where she remembered how before she walked into her building she placed her handbag on a car parked outside to find her door keys. In that moment I also remembered that I had also seen that same car parked at the door of her building every time I came to visit. The camera must not have captured the car but just the handbag making it look like it was hanging in the air. These additional details were not present in the images and without Dolores' description the images would not make sense. However, with her narration it all became clear.

Midway through the therapy

During the middle stages of the therapy the sessions became more enjoyable and less puzzling for Dolores. She was now at ease with SenseCam and looked forward to the sessions (DSE 18). She also became more open in the stories she shared. There was a feeling of mutual respect and trust between us. Dolores started wearing SenseCam more often and also outdoors. She became much more confident in recognising objects, places and people in the images which in turn cued her memory and helped her access some details otherwise inaccessible. This gave light to some emerging patterns in which SenseCam images evoked Dolores' storytelling. Through the shared stories and built-up trust I got to know Dolores as a very light hearted and positive person. During the review I also felt I was getting to know a lot of details about Dolores, her life and her daily routines.

Looking forward to therapy sessions

"I looked forward to this session"

"Felt great after this session"

"I feel relaxed after it" **Dolores**

**Journal entries – varied dates Data
Source Extract 18 – (DSE 18)**

The most noticeable pattern throughout the mid stages of the therapy was SenseCam images cueing Dolores to discuss recent events, including details of both semantic and episodic memories. Recalling episodic memories from an event also allowed her to re-live these moments. Her confidence in recognising different things in the images increased greatly and with that she started recalling additional details not present in the images. These would include her mood some of the conversations or even details of a book captured by SenseCam. She often commented that the image allowed her to be back in that event's presence. She enjoyed being able to use the images to share stories of her life. The sessions were flooded with Dolores's narratives and became much more vibrant and stimulating. She often commented on her new ability and how it made her realise things did actually happen and they weren't just written in her diary. This may be because with SenseCam, Dolores was encouraged to actually access the memories of an event where as with her diary most of the time she just read them out loud and took for granted that they did happen.

Another noticeable pattern involved SenseCam stimulating Dolores to access and discuss memories otherwise forgotten about. This included events, which weren't noted in her diary and therefore never mentioned by Dolores. Usually only the most important activities as determined by Dolores were noted in the diary. These include things like dentist or doctors' appointments and family or friends' visits. However, visiting a local café is one example of an activity, which may not be noted, as it was too common and unimportant. Thus, there often was a gap of two to four hours in her diary

for example between 12pm and 4pm. When asked about that day Dolores would just describe it omitting that time. She would then get slightly confused if SenseCam images displayed an event that hasn't been noted in her diary. Despite that, as she viewed the SenseCam images she actually remembered the event and was able to narrate through it. At times she might re confirm the date of the event *"Is this still the same day?"* Without SenseCam images these events were not normally recollected by Dolores, and usually forgotten about instantaneously. Yet, they were still accessible in her memories with cues like SenseCam images allowing her to not only remember them but also to relive these moments (DSE 19). Additionally SenseCam images also reminded Dolores of forgotten details of an otherwise remembered event. Most of the time we viewed images from events Dolores did remember or at least she claimed she did as they were written in her diary. However, frequently SenseCam images would reveal details about or within an event that would surprise Dolores.

Accessing inaccessible memories

"The images showed what looked like a park; she checked her diary to see what she had done that day. She read out. "Dental appointment at 11, not feeling well, didn't go to pool aerobics" She didn't get any information on what looked like a walk in the park she must have taken. Slowly she recognised the buildings and the fence in the park. She was still a little unsure which park it was until one of the images showed a memorial and she recognised that straight away describing in great amount of detail.

Observation field notes – 08/05/13

Data Source Extract 19 – (DSE 19)



Fig. 6.3 Sample images cueing Dolores' memories.

One example includes images from her stay at her daughter's house. She narrated through the set of images captured throughout the day without any hesitation. Then, images from the evening displayed a square screen in front of Dolores – this was a puzzle for Dolores at first. After flicking through the images and some thinking by her, she recognised the object as her iPad (Fig. 6.5). However, she said she did not remember that she had it with her at all. After another few moments she commented *"oh yes I did have it with me because the boys were on their own thing [computer] and I didn't want to disturb them so I used that [iPad] in my bedroom to*

Forgotten memories

"I found it very relaxing and helpful especially when she goes back to review a date I have forgotten about"

Dolores

Journal entries – 29/05/13

Data Source Extract 20 – (DSE 20)

look at the news” Dolores often commented how great the SenseCam images are at helping her to remember these little details she would otherwise not remember (DSE 20), which also led to the next issue (EIQ2).

Emerging issue question 2 (EIQ 2)
SenseCam images special cues to access otherwise inaccessible memories?

The next major theme observed during the therapy with Dolores included the way in which the images were narrated once they were already reviewed. When SenseCam images were reviewed for the first time, Dolores usually narrated through them along with me interacting with her story. I would ask questions, re-phrase something she had already said or at times help out in recognising things present in the images. Thus, the story of an event was co-created by the discussion between Dolores

Emerging issue question 3 - (EIQ 3)

Does reviewing and discussing events represented on SenseCam images formulate new SenseCam memories? New SenseCam memories or usual episodic memories recalled on repeated events reviews?

and myself about the images. When the same set of SenseCam images was reviewed again, it became very noticeable that the story narrated by Dolores included parts, which I may have inputted at the initial review. She would use the exact same wording as I had used, alongside her own parts.

She would also recognise objects that she could not make out at the initial review. It seemed like a learned off narrative rather than the more natural episodic memory recall that comes with the initial image review. This posed an issue about forming SenseCam image specific memories (EIQ 3).

Dolores’ excitement accompanying a review of images from a meaningful event was yet another observable pattern of the dynamics during the mid-stages of the therapy. A meaningful event would usually include meeting some family members or friends and Dolores would refer to it as one of importance to her. During the time of the therapy Dolores took part in a number of such events. In a session following such an event, she would be very excited and greet me with anticipation about reviewing the images (DSE 21). Dolores would be very eager to recognise people and places and once she did you could sense she was very proud that she was part of this event. She would narrate every single detail with her whole body. She would gesticulate to illustrate some aspects, including a lot of detail not present in the images. This energetic narration was very different from reviewing images of mundane activities (i.e. from around the house). Nonetheless, the latter also

Meaningful events

“I was looking forward to this session because I wore the camera while I was on a trip to the West of Ireland with my friend” **Dolores**
Journal entries – 15/05/13 Data
Source Extract 21 – (DSE 21)

evoked narratives, however they lacked this sense of excitement and pride that came with the descriptions of meaningful events. As SenseCam images had been used previously to discuss only meaningful events, this became a significant issue (EIQ 4).

Emerging issue question 4 (EIQ 4)
Should just meaningful events be recalled?

The more relaxed and enjoyable atmosphere associated with the middle of the therapy unveiled interesting patterns in the way SenseCam images stimulated memories and encouraged discussions about them. Dolores had grown in confidence in identifying everything in the images enabled her to use them as cues to initiate narratives of episodic memories of the events reviewed. The images also stimulated Dolores to access and discuss memories of entire events or details about events, which were otherwise forgotten about. There was also a lot of excitement and laughter mostly during sessions where the images discussed were from meaningful events. Most interesting was the issue of whether new memories were formed during these sessions and how they affect future recall of events already reviewed.

Ending of the therapy

In the final sessions of the therapy Dolores became very comfortable using SenseCam, reviewing and discussing the images. She also expressed interest in using SenseCam independently once the therapy ends. However, she also revealed the interaction with the therapist was a major factor to discussing the images suggesting independent use may not be as stimulating. A number of more philosophical discussions took place in the final sessions on the subject as to whether Dolores' identity was portrayed by SenseCam images. The relationship between the researcher and the participant changed to a trusting and friendly one. It was obvious that Dolores became very used to SenseCam and enjoyed her final therapy sessions. She commented frequently about how reviewing SenseCam images helped her remember things and especially activities otherwise forgotten by her. She often stated how initially it took her some time to identify things in the images but with time she found them a lot easier. When asked if she would use SenseCam independently she answered *"Oh I would without a doubt I think its great at helping me remember what I did during a day or I forgot where may have left something"*

However, the real benefit of the therapy identified by Dolores was the ability to share stories and communicate. She described herself as an involuntary listener throughout

SenseCam therapy enabling Dolores to express herself

“...that I was able to talk about images that I saw I was able to express what was happening because there was nobody else competing against me there was nobody making any remark about it or criticising what I said or anything from my point of view” Dolores

After therapy interview -12/06/13

Data Source Extract 22 – (DSE 22)

her life due to her husband being a talker. She felt that limited communication during her middle ages had led to her impairments in communication nowadays. She declared that the therapy allowed her to express herself and it was very beneficial from an interaction point of view (DSE 22). She also compared it to other interactions she may be exposed to and commented that it is a lot easier to share her stories and ideas during the therapy

sessions than in the company of friends. She also felt that because of this freedom to talk about herself during the sessions, her communication improved slightly. In the very last two sessions she also expressed concern about the ending of the therapy and being left without the stimulating interaction it brings her.

Overall it was very clear that the enjoyment of partaking in the therapy by Dolores built up in stages, initially presenting many obstacles, then finding ways to work them out and finally enjoying and using the therapy to her benefit. The final sessions allowed the researcher to explore the issue of identity portrayal

by SenseCam images directly with the participant.

In the *after-therapy interview* Dolores expressed how the therapy was a very positive experience for her with her subjective view of improvements in communication and recalling events otherwise forgotten by her. The journal entries revealed multiple positive feelings towards the sessions (DSE 23).

Meaningful events

“...I feel relaxed after it”

“...I found it most helpful and enjoyable”

“...I really enjoyed it” Dolores

Journal entries – varied dates Data Source Extract 23 – (DSE 23)

Perceived Identity after the therapy.

In the same way as during the *before-therapy interview*, as part of the *after-therapy interview* Dolores was asked about her life story, to induce a narrative about her identity. Similarly to the *before-therapy interview* Dolores described her life story in a beautiful manner. The story contained similar details about her childhood, young adulthood and her children and grandchildren. In addition to the same content as in the *before-therapy interview*, Dolores also described parts of her life after her retirement. She mentioned how she fulfilled her life by traveling and volunteering in third world

countries to up-skill the locals to do x-rays. Thus, the *after therapy* narrative was much longer and contained elements about an additional stage from her life. However, it still lacked details about her current life. This contrast between the identity portrayed through the narratives and the identity portrayed through SenseCam images was explored with Dolores directly. Initially, I asked if there was anything in her life that helps her or reinforces her identity. She thought for a short while and then answered saying that when she looks at photographs she had collected over the years they remind her of all different stages of her life and of who she is. This question also triggered a narrative of some of the achievements in her life (DSE 24).

Identity in images

Dolores described how she reared the children and then opened up a nursing home that she owned but appointed someone to manage it since she wanted to spend more time with her children. How she travelled the world volunteering on different missions.

Observation field notes - 22/05/13

Data Source Extract 24 – (DSE 24)

Following this I asked if she sees SenseCam images in a similar way to her personal collection of images. She revealed that the SenseCam images portray different part of her – which is only the present one. She reflected that her identity is represented more accurately by the collection of photographs from her life. She further commented that SenseCam images represent what she does now as opposed to who she is. She also revealed

Accessing inaccessible memories

“They (SenseCam images) are different it takes a while to get used to them but now

I can associate much better with them than at the start...they show more of what I do now and make me realise that I am a lot less active and I don’t do as much volunteering or walk that much anymore ... I don’t get up that early as I feel tired then whereas used to I’d be up very early

Observation field notes – 22/05/13

Data Source Extract 25 – (DSE 25)

that viewing SenseCam images alone without the interaction and discussions about her present and past could be a little negative at times (DSE 25). This was an interesting view of SenseCam images and the participant’s identity. It seemed that Dolores didn’t feel that recent events were as important to her identity as the lifelong events many of which are from distant past. This is in line with the narratives shared before and after the therapy being continuous with distant past. Thus, Dolores’ view similarly to the previous cases raises concerns and questions the value of confronting people with dementia with large amounts of images of their recent past.

Despite Dolores differentiating between her supposed identity and the identity portrayed by her descriptions of SenseCam images, she seemed to become more aware of herself. In the Twenty Statements Test she completed all twenty “I am.” statements. This shows a 100% increase in terms of quantity of knowledge about her identity.

Additionally, the character of the statements also changed to a more direct way of describing herself (DSE 26).

Conclusions

The case of Dolores was the final case study undertaken to explore SenseCam use as an intervention aimed at identity maintenance for early stage dementia. To conclude, the perceived benefits of the therapy, its usefulness in helping to maintain the

Twenty Statements Test	
BEFORE	AFTER
I am the eldest of my family	I love my family
I am grateful that I am living here	I am able to look after myself
I am good at making friends	I am a very approachable person
Before versus After Therapy Interview Data Source Extract 26 – (DSE 26)	

person's identity and emerging issue questions are summarised below.

The perceived benefits were interpreted from a variety of data sources. Similarly to the case of David, Dolores' recent memories were still preserved to such extent that she was able to use SenseCam images as cues to recall them. Thus, this final case offered further evidence to support SenseCam use within

very specific inclusion criteria in order to maximise the benefits of the therapy. The lack of a carer didn't cause any inconvenience and it appeared Dolores got the same sense of enjoyment from the therapy, as did David who had a carer. However, unlike the situation in the second case study, the presence of the therapist was a necessity for the session to take place. Throughout the therapy Dolores' communication seemed to improve with reduced use of common nouns observed. She also appeared to become more self-assured about her living situation and capabilities.

The narratives shared by Dolores during the *before* and *after therapy interviews* seemed like well-rehearsed accounts of her past. They were beautiful stories shared with ease by Dolores. They were very different from the discussions around SenseCam image review, which were mostly about events from her recent past. These discussions weren't as coherent; instead they were full of unpredictability in the cues and excitement to the different memories shared. Additionally, SenseCam review enabled Dolores to recall memories she doesn't normally recall. This helped Dolores realise the fullness of her life. This realisation was also mirrored in Dolores completing ten additional statements in the twenty statements tests. Despite this, Dolores didn't associate the SenseCam images with her identity but sees them as something more current. The narratives collected in *before* and *after-therapy interviews* along with the

discussions cued by SenseCam image review presented a very well rounded version of Dolores' identity.

Finally, the emerging issues out of the final case study are discussed in more detail below.

Emerging Issue Question 1) Does using SenseCam conflict or complement any existing coping mechanisms to memory impairments?

When designing the SenseCam therapy many aspects of dementia were taken into consideration. However, some unforeseen aspects were impossible to predict including existing coping mechanism. The case of Dolores revealed how SenseCam can conflict with such a mechanism but can also work to enhance it. Working against a coping mechanism has shown to be the least beneficial or stimulating.

Emerging Issue Question 2) SenseCam images special cues to access otherwise inaccessible memories?

The therapy sessions revealed that without SenseCam images certain events from Dolores' life were never recalled by her and often forgotten instantly. However, they were still accessible in her memories with cues like SenseCam images. The recall of such events was often very surprising to the participants and poses a question as to whether SenseCam has the potential to cue memories, which are otherwise inaccessible?

Emerging Issue Question 3) Does reviewing and discussing events represented on SenseCam images formulate new SenseCam memories? Are new SenseCam memories or usual episodic memories recalled on repeated events reviews?

The SenseCam therapy revealed a very interesting pattern where if the same set of SenseCam images were reviewed twice, the narration accompanying them included discussion parts inputted by the researcher at the initial review. The participant would use the exact same wording as the researcher alongside her own parts. She would also recognise objects, which she could not make out at the initial review. It seemed like a learned off narrative rather than the more natural episodic memories recall that comes with the initial review. This poses an issue of SenseCam images review creating new "SenseCam" memories, making it very hard to differentiate which ones are being recalled at recurring reviews of same sets of images.

Emerging Issue Question 4) should just meaningful events be recalled?

The excitement and anticipation of reviewing images from a meaningful event was a very evident pattern observed throughout the therapy. The enjoyment associated with viewing images that were significant to the participant was unlike any other excitement present when reviewing the less significant images. This meant the narratives were

much more vibrant and lively. Thus it is relevant to ask whether mainly images from meaningful events should be reviewed. This question poses more issues in itself including how to identify the meaningful events and what if they don't happen too often?

6.4 Summary

In this chapter I have presented the processes accompanying the delivery of SenseCam therapy as they occurred in three case studies. More importantly, the effects the therapy had on the participants as well as the therapist perception of the identity of the persons with dementia were discussed. The full significance of SenseCam therapy to support the identity of people with dementia will also be discussed in Chapter Seven, under the heading "SenseCam and identity of people with dementia"

There were discoveries made about the practical, ethical and contextual factors that need to be taken into consideration when delivering SenseCam therapy to people with dementia. Yet they seem to go unreported in light of the quantifiable results. These findings will be discussed under the heading "SenseCam as therapeutic intervention" in Chapter Seven. In all three cases, new issues emerged. Some of these issues were addressed through adaptations of the study design discussed throughout the reports. The remaining issues along with the initial issue questions guided the cross-case analysis process, the result of which is presented in the form of findings addressing most of these issues in Chapter Seven.

The overall purpose of the next chapter is to describe how the participants' identities were existent in discussions cued by SenseCam images and how this can contribute or challenge supporting the identity of the persons with dementia. Complementing this with the ethical issues raised around using lifelogging with people with dementia should better the understanding of how to deliver the therapy so that it maximises its benefits for the identity of people with dementia.

Chapter 7

Cross-case findings

In the previous chapter, I have presented the case studies of John, David and Dolores, and given an account of my observations and their opinion on the impacts and effects of using SenseCam technology for the duration of the therapy. The intent of the research was neither comparison nor generalisation, rather exploration and understanding of the specific cases. The main emphasis was not on knowing how each case was different from the other, but to know more in an in-depth manner about the particularity and complexity of each case within its context. Nevertheless, taken together, the cases were instrumental in helping to gain an understanding of therapeutic SenseCam use aimed at identity maintenance for people with dementia. Each of the three cases were distinct in as much as John, David and Dolores are individuals, but there were many similarities in the way that the SenseCam therapy evolved.

The cross-case analysis has led to a coherent exploration of the data from the three individual cases in order to produce aggregate impressions (Stake, 1995). These aggregate impressions are presented as findings and are representative of the patterns most commonly manifested across the three case studies. The findings were not simply discovered through the application of a scientific research method. They were constructed by my subjective interpretation of the data and furthermore by embracing the fact that the occurrences during the therapy were a product of social interactions between the researcher and participants as guided by the constructivism philosophy. They are based on cross-case analysis but also refer back to the individual case study

reports for examples to support some of their arguments. The findings are divided into two main sections. The first section, “SenseCam and the identity of people with dementia”, concerns the value of SenseCam use in supporting a sense of identity among participants. The second section, “SenseCam as therapeutic intervention for people with dementia”, presents the findings related to the delivery of the therapy. I endeavour to delineate the discernible findings of therapeutic SenseCam use and show how they are embedded in the philosophical assumptions of constructivism.

7.1 SenseCam and the identity of people with dementia.

This section presents a discussion on the subject of *SenseCam and the identity of the participant*. There are four main findings within this section, discussing:

1. “Establishing a sense of identity continuous with distant past memories”;
2. “Exposing private identity and related ethical concerns”;
3. “The participant’s response to SenseCam identity”;
4. “Increased awareness of a sense of identity in the present”

When taken together, these improve understanding of the potential benefits and risks of using SenseCam with people with dementia. We now examine each of these in turn.

7.1.1 Establishing a sense of identity continuous with distant past memories

In all three cases, participants seemed to perceive and portray their identities in the present as continuing with their distant as opposed to recent past memories. This is in line with the philosophical insights discussed in Chapter Three, namely regarding self-continuity as depending upon accessible memories. Once recent past memories become inaccessible, they do not seem to enter the sense of continuity necessary for identity awareness perceived by an individual over time (Locke 1690/2012). While the level of memory impairment varied among the participants in this study, the impairments were mostly in the memories of the recent past. Hence, it is possible that the memories of recent events did not enter their perceived sense of identity in the present.

This point became evident through comparison of participants’ life narratives, which were cued by SenseCam images, and narratives that were not cued by the images. The recent events captured by SenseCam images guided the construction of the participant’s identity to include aspects of their current life. The images reviewed presented events from the preceding days of the participant’s life, which mainly consisted of mundane details of daily routines. Thus, the narratives shared with the researcher during the therapy sessions were based on these recent memories about

everyday life as cued by the images. This was unusual when compared to the narratives produced in the interview carried out before therapy, which predominantly consisted of details from the distant past.

The narratives collected during the before-therapy interview offered each participant a freedom of choice with regard to what details about their lives and identities they wanted to share. Typically, the details they discussed concerned their distant past, where they exemplified themselves by their achievements, occupational roles, enjoyments and the fruitful stages of their lives. This continuity with distant memories was more evident in the case of John where severe impairment of memories of recent events existed, but also partially evident in the cases of David and Dolores who had some access to recent memories and an awareness of their condition.

In the case of John, during his before- and after-therapy narratives, he described his love for travelling, his life career in accountancy and his love of sports.

“...I’ve travelled and seen around the world and when I think of it and I lived in J in Cape Town in South Africa I have been working for a company and ehm I lived in New York and ehm another famous city San Francisco... and ehm played golf and tennis and some rugby and ehm been keen on sport really...”

Without the cues from SenseCam images, John described himself as a very active man with a love of international travel. The narratives cued by SenseCam images showed how this identity has continued, but has also transformed over the years. They portrayed a slightly different, more sedentary view of John. They showed John still enjoying a lot of outings; however, these were now restricted to the city in which he lived. His love of sport was also represented by John viewing it on television or by an occasional game of golf.

Similarly, in his before-therapy narrative, David focused on his love of wildlife, his various occupational roles and in general presented himself as a hardworking man.

“Then I went to work I went to X and got a job in X for a few weeks and then I got out of that and I worked for a landscape gardener we used to do the maintenance in a lot of the hotels and we used to we had a contract in the airport and an awful lot of banks in Z like used to maintain all that stuff”

Both the cues in SenseCam images and his wife’s encouragement helped David to discuss more recent details about his life, which, in turn, conveyed a more rounded picture of his identity. The narratives shared during the sessions showed that while he was no longer employed nor had the ability to work on complex projects, he maintained other important but less demanding aspects of his identity. These included his passion

for wildlife and a healthy diet as displayed by endless SenseCam images from various nature trips and wholesome food dishes.

Yet again, Dolores narrated her life story in a beautiful manner, giving the impression it was a very well rehearsed story. She concentrated on the years she spent in college and in training, which consisted of a vibrant social life. A major part of her narrative was also devoted to her occupation and her children. There was little focus on the present except for a statement at the end saying she is happy where she is.

“There was plenty of work and ehm I came back to X and worked all around the different hospitals and doing locums here and there”

“Great life it was in C they were all bachelors ... and they’d all go to the river and we’d do the sandwiches and the lunch and the thing for the meal and we’d take it out with us and we’d do that every week”

“I’m very happy here and I’m going to stay and that’s where I am up to this day”

The discussions cued by SenseCam images portrayed Dolores’ life as more relaxed, with her no longer working or having as exciting a social life. Nonetheless, the narratives shared during the sessions also revealed that she sustained some aspects of her identity including her passion for knowledge represented by the great amount of time she still devotes to reading and writing. Other aspects of her identity continued but altered over time including replacing her professional occupation with voluntary work overseas.

The narratives shared during the review of SenseCam images were predominantly steered by their content and by social interactions with the researcher. The content of the images guided these discussions into both recent timeframes and of a revealing nature about participants’ lives. In comparison, it seemed that the narratives, and essentially the identity that participants portrayed without using SenseCam, were disconnected from the lives they now lived. There seemed to be no continuity between the present and recent memories, perhaps because they were no longer accessible to the participants or perhaps because the participants chose not to include their recent events as part of their identity. As established in Chapter Three, the concern in this thesis was to explore whether SenseCam can act as an external prosthesis for recent memories and extend the continuity link between present identity in the moment to that of recent past and the more distant past. Some insights into this issue are captured under the findings relating to participants’ responses to SenseCam images.

Furthermore, the narratives cued by SenseCam enabled the researcher to perceive a more holistic version of participants’ identity. In other approaches, such as

reminiscence or life story, little attention is given to recent events, which in turn results in participants creating a particular version of their identity, very different to the one constructed within SenseCam therapy sessions. The narratives shared as cued by SenseCam images enriched the identity presented in the interviews before and after the therapy and revealed how this continued and transformed throughout participants' lives. However, this also raised ethical concerns related to the exposure of perhaps undesired details, and to whether participants were aware and consented to such exposure of their identities.

7.1.2 Exposing private identity and related ethical concerns

Prior to commencing the study, ethical concerns relating to the use of lifelogging research were acknowledged and a number of steps to help participants regain some of the autonomy when using SenseCam were put in place. These are described in detail in Chapter Five. Despite this, throughout the therapy there were a number of observations which raised ethical concerns relating to SenseCam use with people with dementia. Mainly, the concerns related to the exposure of unforeseen details from the participant's life.

Participants had full control over when they wore the device, and they were advised to wear SenseCam only at times when they were comfortable with what the camera might capture. However, even within the controlled periods of wear, at times the type of content SenseCam captured was unexpected and surprising even to the participants themselves. The controlled wearing was supposed to provide ethically-safe boundaries ensuring private or intimate moments were not captured. However, power over the content of the images was still limited, due to the passive and automatic manner in which the camera captured the images. Furthermore, by choice, participants had no access to these images prior to reviewing them with the therapist. This was mostly due to the complexity of the software and limited information technology literacy among participants. As a result, SenseCam images at times exposed uncensored contents from participants' recent pasts. It seemed that if participants had a chance to review the content captured by SenseCam, these uncensored details might have been avoided. This unexpectedness of SenseCam images differed significantly to the standard, staged or posed photographs participants might have been used to.

For John and David, these unexpected revelations included capturing and discussing certain practices that seemed to be considered undesirable by their carers.

John accurately recognised wine glasses in the images and commented on them with joy, despite having trouble recognising most other objects captured in the images. It was also observed that any time John did mention wine, his wife tried to justify why he had done so. It seemed that at first she was a little self-conscious by John's positive reaction to wine being displayed in the images.

"...we must have been having some vino"

For David, this exposure consisted of SenseCam images capturing David's previously unmentioned pipe smoking. In both cases, the exposures were handled carefully and ethically and treated in a non-judgemental manner. The participants seemed at ease and comfortable discussing these revelations, despite their disclosure being so unforeseen. In the case of David and Patricia, they were even able to find humour in it. Mary opened up about some issues related to alcohol use in dementia, which highlighted that this was a sensitive issue and might not have been discussed without this exposure from the SenseCam image reviews.

In the case of Dolores, there was not as many particulars revealed by SenseCam that she might not have chosen to discuss as one of her identity components. This was due to her being very selective about her SenseCam wear. Her selective SenseCam wear could be explained by her being in the very early stages of dementia and having high cognitive functioning. This in turn questions the use of the stage of dementia as a criterion to participate in this study. Perhaps the potential participant's ability to judge in which situation SenseCam should be worn may be a better estimate of using the technology in an ethical manner. It seems that in the cases of John and David, they were less careful about when to wear the device. Nevertheless, even in Dolores' case, a strong theme came through via reviewing the images that may not otherwise have become evident. There were many images of Dolores' reflections in the mirrors throughout the images. Initially Dolores ignored them, but as the therapy progressed and a friendly relationship was built up, she commented on them.

"oh yes that's me doing my make up, I always do my make up in the mirror in the room"

"I was probably checking how visible the thing (SenseCam) was, and it's not noticeable at all"

Without the use of SenseCam images, any of these details may never have been revealed in a standard interview or therapeutic setting. The content of the images unveiled some uncensored details that may never have been freely chosen as identity components. This further differentiates the version of identity constructed during the

therapy sessions and displays how it was dependent on the content of SenseCam images. This version of identity depicted by SenseCam seemed more holistic due to the unforeseen content of images and the freeing from limits that one may impose on aspects of identity shared with others.

These findings suggest that the images captured some potentially unwanted details. This loss of control in relation to the particulars of participants' lives can be interpreted as a loss of autonomy and therefore raises another ethical concern. Furthermore, this finding highlights the possibility that SenseCam image review may expose an undesirable version of the identities of people with dementia to the researcher. As explored in detail in Chapter Three, as individuals we constantly edit and refine the identity we portray to others. People with dementia also have the right to do this but may be more vulnerable to undesirable exposure of themselves due to their memory deficits and lack of awareness of their condition. The therapist should have no right to gain deeper access to the psychological or physiological existence of a participant than what seems contentedly and mindfully consented to by the participant. These findings suggest that there needs to be clear boundaries on when it is ethical to use SenseCam; otherwise, there might be a danger that the technology becomes a purely voyeuristic tool which endangers the privacy of an individual with dementia.

Nevertheless, using SenseCam within a therapeutic approach enabled an intimate but temporary partnership to be formed between the person with dementia and the therapist that allowed for the discussion of such private life events. It is possible that using a different approach focusing on selected past life events might not have produced these same intimate discussions about uncensored recent life events, as they might have been considered undesirable. Thus, it is assumed that the particular version of identity constructed during the sessions is distinctive and unique to SenseCam images and the trusting interactions established among participants and the therapist. It is probable that the identity constructed via a review of SenseCam images would differ from an identity depiction one might perceive during a standard interview without the use of SenseCam images.

7.1.3 The participant's response to SenseCam identity.

It seems fair to say that a particular version of participant identities was created with the use of SenseCam images through the delivery of the therapy. This version also seemed different to the identity portrayed by participants without the use of SenseCam. I called this version a "SenseCam identity", as predominantly it was dependent and

steered by the content of SenseCam images. Additionally, it was confined to the timeframe within participants' lives in which the images were captured and the narratives shared within the interactions that took place. Consequently, this SenseCam version of identity is not inevitable and could have been different depending on the means and processes used to unveil it. This perception echoes the constructivist idea of the inevitability of knowledge as determined by subjective choices made to confer it and not by an objective reality.

SenseCam identity was constructed during the therapy sessions by discussing SenseCam images within social interactions with the researcher. The content of the images guided these discussions which were both recent and revealing of participants' lives. This exposed a rather different version of participants' identity than the version that might have been revealed without the use of SenseCam. This raises some ethical concerns, especially in light of observations that, at times, participants seemed challenged and did not fully accept this more up-to-date SenseCam version of their identity. The version of identity portrayed by the participants without the use of SenseCam seemed continuous with the distant past. This was apparent through direct references to events from their distant past and indirect displeasure in certain, more recent events captured by SenseCam images.

John often seemed a little confused by the SenseCam images, perhaps due to a possible disconnection between his identity in the present, and recent events. John's episodic memory for recent events was severely impaired and he seemed to have had very little insight into his current life. However, in the perceptions of people in John's life, recent events continued to create a version of John's identity and they had little impact on John's awareness of this current version. It seemed that John's identity was mainly continuous with distant past memories. There were occasions when John recognised the images and had an understanding that they were from his recent past, but purposefully avoided discussing them by distracting the researcher with other items in his house. The images that John avoided often included sedentary behaviour like watching television. John often remarked that they were very uninteresting and used items like the world atlas as a distraction and a hint to discuss his history of travel from his distant past. His wishes were always respected and as part of the on-going consent process, John was often reminded of his right to withdraw from the therapy at any stage.

In the case of David, the idea of his identity being continuous with his distant memories was invoked by his wife more often than by David himself. This could be due to David's denial or lack of insight into the nature of his memory problems. Patricia, his

wife and carer, often referred to David in conversation as “*the way David used to be*”, “*before this all [David’s diagnosis] started*”. In addition, when asked if SenseCam portrayed a version of David’s identity to the researcher, Patricia answered that it did but only partly. When probed further she explained:

“Well I suppose she would have picked up that he’s not out he’s not in big crowds or he’s quite alone he’s quite a reserved guy compared to before but he is he’s very calm he’s very quiet and he’s a very gentle person ... I hope she picked up his whole love of nature that’s all really and lots of quietness...”

The idea of SenseCam portraying Dolores’ identity was explored directly with her. Initially she was asked if there was anything in her life that helped her or reinforced her identity. After giving it some thought, she answered saying that when she looks at photographs she has collected over the years, they remind her of all the different stages of her life and of who she became. Dolores was then asked if the SenseCam images represent her identity in a similar way to her collection of personal images. She revealed that the SenseCam images portray a different part of her – which is only the recent part. She reflected that her identity is represented more accurately by the collection of photographs from her life. She further stated that SenseCam images represent what she does now as opposed to who she is as a whole. She also revealed that viewing SenseCam images alone without the interaction and discussions about her present and past does not hold much meaning for her.

“They are different in that they show more of what I do now as opposed to what I have worked hard to achieve/become... they make me realise that I am a lot less active and I don’t do as much volunteering or walk that much anymore ... I don’t get up that early as I feel tired then whereas used to I’d be up very early”

Similar to John, it was also observed that Dolores showed reluctance reviewing images of sedentary behaviour. Frequently, she remarked about the time she wasted during any activity she thought of as insignificant. For example, if the images showing her eating her breakfast were reviewed for too long she would comment: “*Am I still at it?*”

These observations suggest that SenseCam identity seemed to challenge participants’ perceptions of their identity in the present. It may be because, by reviewing SenseCam images, participants are forced to adjust and update their identities to the recent events of their lives. However, it is hard to say whether this is challenging for participants solely due to a lack of access to recent memories. In the case of John, this may be accurate due to the severity of his memory impairment and given that there

seemed to be an evident disconnection between the recent past and his perceived identity in the present. Instead, his identity seemed to be continuous with distant past memories and this may be what causes SenseCam images to be confusing. In the case of David and Dolores, this may also be partially accurate, as they also had some impairment of recent memories, but they seemed more displeased than disconnected with the way SenseCam portrayed them. They appeared annoyed by certain aspects of their more updated versions of identity, including being classed as elderly, inactive or with memory impairments. Furthermore, regardless of the reasons for participants perceiving their identity as more established with distant as opposed to recent memories, reviewing SenseCam images and constructing a SenseCam version of identity seemed, at least to some extent, confrontational and challenging. This highlights the potential ethical risks associated with SenseCam use as a tool to support the identities of people with dementia.

7.1.4 Increased sense of identity awareness in the present.

Despite what might seem like the limited benefits of SenseCam in extending the continuity of participants' identities from present to the recent past to the distant past, the therapy did seem to increase participants' awareness of having an identity in the present moment. There were discernible differences in the way they described themselves after the therapy compared with beforehand. This suggests that, maybe at an unconscious level, the therapy did enhance their sense of identity. I problematised in Chapter Three what I mean by enhancing a sense of having an identity as opposed to maintaining or adjusting to a particular version of identity.

This finding applies to the last two cases only, as the method used to explore differences in identity awareness had been adjusted after the analysis of the first case study. Initially, the study set out to explore attitudes and awareness towards identity by collecting narratives before and after the therapy and comparing their contexts with the discussions that had taken place during the sessions. However, after the first case study, it was observed that the narratives during the therapy were very different to those before and after the therapy. The narratives collected during the before- and after-therapy interviews mainly contained references to the long distant past and were mostly incomparable to the narratives or discussions shared during the SenseCam sessions. It was even necessary to change the methodology used in order to induce a narrative in the before- and after-therapy interviews. Along with the biographical question, participants were asked to finish as many sentences as possible that began with the statement "I

am...” This thus presented more current details about the person’s life, allowing greater comparison of the interview representations of identity with SenseCam-induced self-narratives. By way of illustration, the differences in the personal statements from before and after the therapy can be examined.

In the case of David, the first noticeable difference between the before and after results of the TST is the number of statements provided. The number of statements increased by more than 100%, from 7 at the before-therapy interview, to 17 in the after-therapy interview. This suggests that David’s awareness of his identity did increase or perhaps his confidence to express it increased. The more interesting finding is, however, the change in the content of the statements. The statements given before the therapy seemed to describe David indirectly. They were placed in the context of other people or the environment e.g. friends or employment. After the therapy, some of these statements remained the same; however, there were many more direct statements about David which complemented these. They were a lot more positive in defining David’s skills and values. Some of the statements also suggested David’s more realistic view of himself e.g. before the therapy he presented himself in the context of a job in one of the statements, whereas after the therapy he gave a statement defining himself as unemployed. The statements are listed below in Table 7.1.

Table 7.1 David’s TST statements before and after the therapy.

BEFORE	AFTER
I am a political activist	I am political
I save wildlife and I look for ways of saving wildlife	I am interested in wild life
I would do all to help any one friend	I am very good to my friends
I am happy and laugh a lot	I am funny
When I’m working on a job I would give 100%	Unemployed kind of unemployed person
If I get tired sometimes I can get grumpy	I am a nice guy
My best friend in the world is Patricia	I am a 57 year old
	I am interesting in local of history
	I am good with people
	I am very kind
	I am very gentle person
	I am good in gardens
	I am good with my hands
	I am very generous

Table 1. - legend

Matching statements

Same idea statements – change in expression.

Additional statements

I am good at woodwork
I am I can dance
I am glad I have been in this research
I am I will miss it
I am I am I loved every minute I was in it

In the case of Dolores, similar to David, there is a noticeable difference in the number of statements given before and after the therapy. Dolores gave 10 statements before the therapy and 20 statements after the therapy, an increase of 100%, suggesting an increased awareness of her identity. The content of some of the statements also changed to be more realistic, personal and positive. Dolores was able to describe herself using a more direct approach, at the same time stating her values and beliefs.

Table 7.2. Dolores' TST statements before and after the therapy.

BEFORE	AFTER
I am over 60 years of age	I am middle aged woman
I am a happy person	I am happy most of the times
I am happy that my children are all happy and settled	I am happy with my lot
I am slow walking at times	I give up when I'm not able to walk
I am slow to get angry	I am resourceful and content
I am I'm a kind person	I am attending to anyone that needs my help
I am in a healthy person	I am glad I had the health and fitness
I am the eldest of my family	I love my family
I am grateful that I am living here	I am able to look after myself
I am good at making friends	I am a very approachable person
	I am easy to get on with
	I am general with what I have
	I am grateful for life that I have lived
	I am a person that lives day by day
	I am not a person that reflects and analyses things very much I just accept it as it is

Table 1. - legend
Matching statements
Same idea statements – change in expression.
Additional statements

I am not regretful of anything I have done in my life
I am supportive of anyone that needs help even financially or materially
I love my country
I am not a person that automatically agrees with what's happening in our country at the moment
I am sorry for the state of our country at the moment and how our young people are not responding to things

These differences in the TST results suggest that, after the therapy, participants seemed to become more aware of themselves in the present time frame. Despite disagreeing with SenseCam images representing their identity as discussed earlier, their self-awareness did seem to increase after the therapy. Hence, it can be argued that using SenseCam within a therapeutic approach supports people with dementia to have a sense of identity in the present moment. As questioned in the previous chapter, it is hard to separate the role of the growing trust between the participants and the therapist, and the results collected after the therapy. One can argue that participants may have been more inclined to reveal additional details to the therapist due to the development of trust between them. However, without undermining the value of the relationship between the participants and the therapist, reviewing SenseCam images specifically seemed to be of meaningful value in supporting this awareness of their sense of identity in the present. The narratives shared by participants without using SenseCam during the sessions before and after the therapy showed that the discussions were mainly distant past-oriented, with little reference to the recent past or the present. One can assume that, without incorporating SenseCam into the therapy, perhaps all discussions during these sessions would have remained focused on the distant past. In contrast, SenseCam images guided the discussions in becoming more focused on recent events. The discussions about recent events seem to be reflected in the additional statements of the TST. Thus, it seems that using SenseCam within a therapeutic relationship enabled a unique awareness of identity in the present moment, which was unlikely to happen without SenseCam images.

7.2 SenseCam as a therapeutic intervention for people with dementia.

This section presents a discussion on the subject of SenseCam use as a therapeutic intervention for people with dementia. There are two main findings within this section, discussing “Contextual factors determining suitability of SenseCam therapy” and “Evolving therapy phases”. Combined, these better our understanding of how to deliver SenseCam therapy successfully to people with early stage dementia.

7.2.1 Contextual factors determining the suitability of SenseCam therapy

Throughout the delivery of the therapy, it became apparent that its suitability and effectiveness depended on certain contextual factors. These included the level of impairment of a person’s cognitive functioning, mainly the impairment of memory for recent events, the person’s coping strategy and the presence or the nature of interactions with the carer. These factors impacted on the delivery of the therapy and in most cases, it was necessary to tailor the therapy accordingly. The impact of each of these factors on the delivery of SenseCam therapy is briefly considered below.

1. Level of impairment of cognitive functioning.

The necessity to consider the level of impairment of cognitive functioning as a factor determining the suitability of SenseCam therapy surfaced via the diverse meanings applied to the category of people in early stage dementia as discussed in Chapter Two. One of the criteria for participants to take part in the therapy was to be in the early stages of dementia. All three participants fulfilled this requirement by receiving an early diagnosis and indicative results of early dementia on psychometric tests used in this research. However, as the participants illustrated, even with a small sample size of three, the category of “early stage dementia” presented very diverse levels of cognitive impairment and the label “early” seemed very broad in determining suitability to take part in SenseCam therapy.

Although John had an early diagnosis, his episodic memory of recent events was very severely impaired. Generally, John’s memory span extended to the previous hour or two. Occasionally, this would stretch to the previous day or two. Despite these severe amnesic features for recent events, he had a very well preserved long distant memory. Furthermore, John’s other cognitive skills including communication and problem solving were so intact that his recent memory impairment was difficult to detect in the initial therapy sessions. This

particular level of impaired recent memory and otherwise intact cognition proved to be problematic in the delivery of SenseCam therapy, in most cases causing confusion for John when reviewing images from recent days. These incidents of confusion and other issues with SenseCam use are described in detail in the previous chapter. As the impairment seemed too severe for John to benefit from the therapy, a new issue emerged after the rather unsatisfactory results of the first case study: “Is early dementia too late for SenseCam therapy?” This issue mainly questioned whether early stage dementia was specific enough a stage in order to determine the suitability of a person to participate in the therapy. Therefore, in the two cases that followed, participants with early stage dementia were still recruited; however, more focus was placed on the level of their cognitive impairment, predominantly their memory impairment. Participants with some ability to recall recent events were recruited, ensuring that recent episodic memory was intact to a degree so that the images could act as cues to their recent events. This resulted in much more success observed in the cases of David and Dolores. While they still had episodic memory problems without cues, they were both able to discuss and narrate most of the events captured by the images. The sessions were much more vibrant, with many episodes of enjoyment and laughter.

These observations of SenseCam therapy being largely successful with participants with some ability to recall recent events, yet causing confusion in a participant with a severe impairment in recent memory, demonstrates the complexity of delivering this intervention with people with dementia. Yet again, I reflect on this finding in light of constructivist philosophy, in that assigning a category of early dementia does not hold a universal meaning among all people who present with it. For the purposes of this research, early stage dementia was used to ensure that participants had some capability of remembering recent events; however, as was discovered, the meaning behind the category encompassed a much broader range of cognitive impairment among participants. All three cases had a diagnosis of early stage dementia; however, the nature of the therapy and the differentiation among their profiles meant it was more suitable for two of these three cases. This suggests that refined inclusion criteria for participation in SenseCam therapy should be established in order to determine the most suitable candidates among people with early stage dementia. The focus needs to be on the level of cognitive impairment, predominantly on

the memory domain as well as the overall dementia stage. This is a crucial finding for any research being carried out using SenseCam with people with dementia, as potentially it can offset the possible harm that outweighs the benefits of the therapy.

2. Existing coping mechanisms.

The way in which participants learned to cope with their memory impairments was also one of the factors affecting the delivery of SenseCam therapy. A coping mechanism is a behavioural tool which may be used by individuals to offset or overcome difficulty, disability or impairment. In the context of people with dementia, a coping mechanism is usually developed to deal with one of the cognitive impairments caused by the disease. During the design of the SenseCam therapy, many factors that could have been affected or highlighted by the therapy were taken into consideration; as a result, the frameworks and ground rules of CST were adopted to suit this therapy. However, it was impossible to predict each participant's existing mechanisms for coping with their memory impairments.

In the case of John, his coping mechanism was a reliance on his wife's memory. Frequently, when John wanted to share something that he did not feel he remembered very well, he asked Mary to tell the story instead. John also redirected any questions to his wife. Even when John was asked opinion-based questions about the images, he would still refer to Mary for help. The recurrent use of this coping mechanism may also be linked to John's poor memory of recent events. This posed some difficulties during the sessions in which Mary was present, with detailed descriptions presented in the previous chapter. Ultimately, they resulted in a mutual decision for Mary not to take part in the therapy sessions, as well as the use of spaced rehearsal techniques with John. This allowed John to use SenseCam images mainly as discussion-starters, but also occasionally as cues for some memories.

In the case of Dolores, her well-established coping mechanism to her memory impairment was a written diary. In parallel to John, her sessions needed to be altered to suit the use of this mechanism. As Dolores was aware that the images were of the recent past, her instinct was to review her diary, as she would in any other situation discussing her recent past. Initially, the SenseCam images caused some confusion and conflicted with her use of a diary, as they captured

much more detail than Dolores had noted in her diary. Dolores did not remember anything in addition to her written notes in the diary without the use of other cues. At first, Dolores referred to her diary simultaneously to the use of the SenseCam images and was unable to use the SenseCam images on their own. As the sessions progressed and Dolores was comfortable with the images, she began to use them as cues for additional memories not noted in her diary, resulting in her recalling otherwise forgotten details of her day.

The existing coping mechanisms to memory impairments played an important role during the SenseCam therapy. In the initial phases, it seemed that SenseCam images reviewed conflicted with these, but as the sessions evolved, these were tailored to suit them and augment their use. It is common for people with dementia to have existing coping mechanisms and this needs to be considered in light of SenseCam therapy; however, it should not become a reason for exclusion. Instead, the crucial point is to be aware that the coping mechanisms exist and that SenseCam therapy should always be tailored to enhance these.

3. The carer's presence and interaction patterns.

The presence of a carer and the relationship the participants have with them were also important factors impacting on the suitability of SenseCam therapy. It was anticipated that the communication between the carer and the person with dementia may be enhanced through the therapy sessions. However, this was not always the case. Regardless of the information provided to carers on the framework and guidelines of the therapy, the interactions between them and the person with dementia taking place during the therapy were strongly influenced by, and even mirrored, their existing relational patterns outside the therapy. For John, these patterns involved factual prompting and correction of mistakes by Mary, which was done with the best of intentions but jarred with the therapeutic process of SenseCam use. Mirroring these interactions within the therapy sessions, combined with John's coping mechanism being a reliance on Mary's memory, became too problematic for the carer to remain in the sessions. Nevertheless, as Mary had a high level of carer strain and often complained about a lack of time, it was mutually decided that instead of taking part, she would benefit by having some free time and some headspace. For David, the interaction patterns mirrored during the therapy sessions included Patricia's

relaxed approach to encouraging David to discuss the images in detail. These interactions were in accordance with the therapy guidelines and frequently resulted in improved communication during the sessions. Dolores did not have a carer and still had the cognitive capacity to live independently. These factors influenced the decision to deliver the therapy to her individually. The absence of a carer did not seem to pose any challenges to delivering SenseCam therapy.

The three case studies presented diversity in terms of the social networks of participants. Overall, it is important to acknowledge that reality for people with dementia is constructed through these social interactions with a carer, if present. Furthermore, these interactions will influence the construction of reality within the therapy sessions. Once these follow the guidelines set out by the therapy, they should have a positive influence on the reality created.

Additionally, if the carer is not present and a trained therapist delivers the therapy, there is a lesser risk of violating therapy guidelines. Thus, the nature and type of interactions needs to be considered before offering the therapy to both the person with dementia and the carer.

It is necessary to consider a number of contextual factors when determining the suitability of SenseCam therapy as outlined. These include the level of cognitive impairment, existing coping mechanisms, the presence of a carer and caring style.

7.2.2 Evolving therapy phases

The therapy evolved throughout the sessions with three distinct phases. This was evident across all three cases and these are presented chronologically according to these stages. This is a crucial finding, demonstrating that SenseCam should be used continuously rather than occasionally with people with dementia, as their familiarity and attitudes towards it change over time. The therapy can be phased in order to maximise the potential benefits of SenseCam use or conversely, minimise them. The characteristics and endeavours within each one of the distinct phases are described below.

4. Adjusting to the unknown.

The initial stage of the therapy was characterised by participants slowly getting used to wearing SenseCam, the unusualness of the images as well as building trust with the researcher. SenseCam therapy was a big unknown for the participants and it took them some time to adjust to it. It was observed that, initially, all three participants were a little apprehensive about wearing the

device and it was the carers (where present) who provided the needed encouragement. The next challenge to overcome was the unusualness of the SenseCam images. Participants were used to staged and posed photographs in which they were able to identify people and objects easily. Deviating from standard photographs, SenseCam images were distorted because of the lens' focal length, blurry because of movement and they captured the environment rather than stills of people posing for the camera. This confused participants in the initial stages and gave the impression of failed attempts to cue discussions about their recent past. The last aspect was the adjustment necessary towards the therapist at the beginning, as I was just an outsider in their life. Thus, the first phase of the therapy was characterised by confusion, adjustment and scepticism. The opening conversations were very generic and not much personal detail was revealed. The participants continued, after their before-therapy interview, to present a somewhat censored version of their identity. However, a more holistic version of participants' identities began to emerge through the images. This stage is described in detail in the individual case studies presented in the previous chapter.

John, David and Dolores had distinctive attitudes during the initial sessions. They were polite, sceptical and had little trust in the therapist. Dolores consented to the therapy but always expressed her uncertainty about committing to take part until the end. She often worried about wearing the camera and expressed that she would not want to wear it to dinner parties or other occasions where her friends might notice it and ask questions about it. She was also careful about what aspects of her life she wanted to discuss and only wore the camera when it did not capture anything she did not want to disclose. Thus, initially, SenseCam captured very selective sets of images that were mostly from indoors. Similarly, David acted very politely and rarely initiated conversations. Initially it seemed he had no trust in the researcher. He was careful about what aspects of his life he wanted to discuss and used the images very cautiously without revealing any personal details of his life. While John was adjusting to SenseCam and its images, the initial sessions also unveiled some contextual factors that affected the delivery of therapy outside of John's control, resulting in the therapy being tailored to suit his needs. Furthermore, it resulted in a questioning of the suitability of the therapy to people categorised with early dementia.

In all cases it took the participants approximately five sessions to get used to SenseCam, its images and to build up trust in the researcher before they could freely discuss the events presented to them.

5. Enjoying the sessions.

The next distinct phase was confined to the middle sessions of the therapy. This phase was characterised by the participants' adjustment to wearing the SenseCam device, recognising aspects in SenseCam images and sharing stories about them within a trusting relationship with the researcher. The participants had become comfortable wearing SenseCam and their duration of wear increased, resulting in more images. When asked how they found wearing SenseCam in the middle stages, their responses were as follows:

"No problem" - John

"I have no problem wearing the camera I like having it on me" - David

"I am very used to it now. I put it on automatically in the AM" - Dolores

The initial surprise of the unusualness of SenseCam images had also faded in this phase and participants were able to recognise objects in the images without confusion. In the two latter cases, this also enabled the cueing of their recent memories and evoked narrative shared from their recent past. This was a rather rare occurrence in the first case due to the participant's suitability as discussed earlier. Lastly, the most discernible pattern of this phase was the trusting relationship formed between the participants and the researcher. The participants were more relaxed and comfortable having discussions with the researcher. This enabled them to share more personal details and narrate through some unexpected exposures taken by SenseCam images about their lives. This in turn allowed the researcher to develop a more comprehensive understanding of their identities. Similar to the first phase, this stage is also described in detail in the individual case studies presented in the previous chapter. Once again, I will now call upon the main patterns from each of the cases to illustrate this phase of the therapy.

For John, the middle stages brought some improvements to his enjoyment and benefits gained from the therapy. The process of tailoring the therapy to his needs resulted in John being able to enjoy the SenseCam image reviews without relying too much on Mary's memory. Some successful sessions took place. SenseCam images evoked some memories and encouraged John to

provide narratives; however, this was still a rare occurrence. Additionally, John never got used to wearing SenseCam and continued to rely on his wife to encourage its wear. He also never fully comprehended the concept of SenseCam images being captured automatically during his wearing. On the contrary, for David and Dolores, the middle stages presented more enjoyment and less confusion. They were at ease with SenseCam and looked forward to the sessions. They also became more open in the stories they shared. There was a feeling of mutual respect and trust between the participants and the therapist. Dolores started wearing SenseCam more often, including outdoors. She became much more confident in recognising objects, places and people in the images which in turn cued her memory and helped her to access some details otherwise inaccessible.

6. Exiting with apprehension.

The last phase focussed on the last few sessions of the therapy. It was characterised by some anxieties in the participants about the ending of the therapy and overall sadness about the nearing end. In the cases of David and Dolores, the final phase consisted of sessions filled with enjoyment and a continuous sharing of narratives. They seemed reluctant to end the therapy and expressed some apprehension about finishing their use of SenseCam. Their anxieties about finishing the therapy were expressed directly in the final sessions.

"I would love this to continue...It is so interesting could you extend it please"-

David

"I will miss her wk (weekly) visits"- Dolores

On the contrary, in the case of John, it seemed that the therapy had reached the end of its lifespan and neither him nor Mary displayed any interest in its continuation. It appeared that John never got used to wearing SenseCam or reviewing the images and even developed some techniques to avoid discussing the images. There was a lack of routine around SenseCam wear, which perhaps did not help with understanding the concepts of the device and resulted in a reduced number of images captured. Nevertheless, his wife displayed some apprehension about the ending of the therapy, similar to the other two cases. As Mary was using the time that John was engaged in the session as independent time, she expressed that she was going to miss that opportunity.

7.3 Summary

In this chapter, I have presented the main findings of the case studies in SenseCam use with people with early stage dementia. The findings were grouped into two sections concerning SenseCam identity and the delivery of the therapy. They offered insight into the value of SenseCam to support the identity of people with dementia. This was illustrated by considering the way identity was constructed during the sessions, participants' responses to this constructed identity and their unconscious identity awareness after the therapy. The findings also improve understandings of the ethical risks associated with SenseCam use and the processes of using SenseCam in a therapeutic manner. This was demonstrated by considering participants' contextual factors, which impacted on the delivery and suitability of the therapy and the evolving therapy stages. The significance of these findings is demonstrated in the discussion chapter, where I return to the research questions posed in Chapter One and answer them in light of the interpretations presented here.

Chapter 8

Discussion

This chapter provides a general discussion on how this research shaped the understanding of SenseCam to support the identity of people in the early stages of dementia. I will attempt to provide a synthesis of the findings presented in the previous chapter and the literature reviewed in Chapters Two to Four. However, this is challenging, as incorporating technology, especially lifelogging technology, into therapeutic dementia interventions is only in the early stages of its development and as such, there is limited literature on the topic. Thus, there is little opportunity for direct synthesis as normally seen in discussion chapters of doctorate dissertations. Nevertheless, I will start by reviewing the rationale for the study and situating the findings within the broader context of early psychosocial interventions in dementia. I will then progress to a detailed discussion of the findings in light of the research questions, highlighting any ethical issues associated with these.

8.1 Review of the rationale for the present study

Living with dementia is a life-changing experience that can cause significant difficulties in many important areas of a person's existence, including their sense of identity. While diminishing identity is perceived as the most debilitating and feared effect of dementia, there is a growing body of research suggesting that identity can be maintained long into the illness. One of the factors necessary to uphold one's sense of identity in light of dementia is

engagement in psychosocial interventions from the early stages of the disease's trajectory. These psychosocial approaches are also influenced by the current trend of incorporating technology into almost all aspects of our everyday lives. The purpose of the present research was to explore the incorporation of lifelogging technology into a therapeutic approach aimed at supporting people in the early stages of dementia in maintaining an awareness of their sense of identity.

The empirical and philosophical literature reviewed in Chapters Two to Four informed the design of the SenseCam therapy. Selected philosophical insights on identity in humans reviewed in Chapter Three indicated that identity depends on both inner and outer processes (Small et al. 1998, Locke 1690, McAdams 2004, Mead and Morris 1934, Erikson and Erikson 1998). Consequently, this study adopted an understanding of identity as a dynamic momentary perception that changes as influenced by inner processes including memories as well as by outer process associated with being situated in the world. Both inner and outer processes are affected by dementia and it is possible that it is these impairments that result in a diminishing identity.

Thus, SenseCam therapy was designed with the aim of stimulating these inner and outer processes and in turn was intended to support the sense of identity in people with dementia. There is a growing body of evidence suggesting that new lifelogging technology can stimulate people with dementia in recalling recent events (inner memory processes) (Berry et al. 2007, Bengtsson and Kikhia 2010, Doherty et al. 2012, Loveday and Conway 2011, Microsoft Corporation 2011). In order for SenseCam to stimulate outer processes as well as the anticipated recall of recent memories, the technology was incorporated into a psychosocial, therapeutic approach.

The aim of this research was to develop and then describe the processes of using SenseCam as a therapeutic approach within the context of people with dementia. Apart from improved memory recall, to date little was known about how SenseCam affects a person with dementia, and specifically their identity. Therefore, a complementary aim was to provide an understanding of how this approach may support the identity of people with early stage dementia.

8.2 Situating the findings within a dementia context

In summary, the findings from this research, explicitly the Twenty Statements Test results, suggest that reviewing SenseCam images within a therapeutic approach did increase participants' awareness of their sense of identity in the present. Nevertheless, the findings also suggest that participants' identities are continuous with their distant memories and that they seem to reject the idea of recent events captured by SenseCam as representative of their identity. Along with exposing some private details from participants' lives, these findings raise a number of ethical concerns with regard to using lifelogging technology to support the identity of people with dementia. Furthermore, other factors including the level of cognitive impairment, existing coping mechanisms and the relationship with a carer can also act as potential barriers or enablers in the delivery of the therapy.

In order to situate the above findings within the context of psychosocial interventions in dementia, I refer back to the literature reviewed in Chapters Two to Four. As described in Chapter Two, the psychosocial understanding and its associated interventions derive from a view which focuses on psychological and social factors and their impact on the experience and progression of the condition. At the heart of this understanding is Kitwood's (1997) person-centred care, which highlights how, by upholding many psychosocial factors including one's identity, we uphold one's personhood despite neurological impairment. According to the psychosocial perspective, the focus is on the person and not on the disease.

SenseCam was used within the ethos of a psychosocial understanding, with emphasis on social interaction and communication during therapy sessions. Due to the images being presented from a first-person perspective and capturing mundane details of everyday lives, each individual's experience was highlighted during the lifelog review. Hence, SenseCam images steered attention towards the everyday life of people with dementia participating in this research. This ensured that the focus was always on the person and their continuous existence in the world and not on their physiological condition. Moreover, throughout the therapy, it was never deemed necessary to remark on dementia unless the participants expressed the desire to explicitly discuss their condition. In such circumstances, the therapist adopted the same expression

(i.e. *memory problems, confusion*) as used by participants to refer to their dementia. Overall, the findings from this research suggest that, with clear guidelines, it is possible for SenseCam to be used as an innovative therapeutic approach for people in early stage dementia with some benefits for the person with dementia. Thus, the present research adds to existing knowledge and options for psychosocial interventions.

The literature reviewed in Chapters Two and Three described how dementia and dementia diagnosis poses various challenges to one's identity, including memory impairment and dealing with the double stigma of age and dementia. I also discussed theories on how individuals might cope with these challenges. Recent research suggests that people continuously go through a balancing act of self-maintaining versus self-adjusting (Clare 2003). Likewise, this research observed signs of participants going through a similar endeavour in balancing their identity. Despite gaining greater awareness of themselves in the present as illustrated by the Twenty Statements Test results, the participants in this study perceived their identity as continuous with distant memories. The idea of perceiving recent events captured by SenseCam as being representative of their identity seemed to be rejected by the participants. Instead, the findings of this study showed that participants valorised their identities from their past. This may be due to various reasons. In some cases, resistance in an association with recent life events as depicted in SenseCam images may be due to the stigma associated with being old or having dementia. In other cases, this disassociation with recent life events might be due to recent memories no longer being accessible and therefore not forming part of their perceived identity in the present.

In Chapter One, I introduced how, currently, there is a push for early diagnosis and for access to psychosocial interventions from an early point in dementia's trajectory (Moniz Cook and Manthorpe 2009). In Chapter Two, I explored the complexity of understanding early diagnoses and the early stages of dementia. I described how the current shift from a biomedical to a psychosocial understanding of the condition results in the meaning of *early* being in a constant state of flux. This research found itself in a similar milieu, reflecting the broader context surrounding the staging of dementia. Despite having set criteria to ensure participants were in the early stages of dementia, their levels of cognitive impairment and functioning varied significantly

between cases. One of the findings from the present research highlighted the importance of considering individuals' contextual factors as opposed to their dementia stages. This was mainly based on ethical risks observed when using SenseCam with John, who had a more severe memory impairment despite having early stage dementia. The main concern was whether it was ethical to confront John with memories he had no access to. This ethical concern is universal to any person with dementia with severe memory impairment faced with lifelogging technology. This finding can be perceived as a reason for questioning the value of dementia stages as a criterion for using lifelogging technology. Given that the use of lifelogging technology can cause stress and confusion to people even when they are in the early stages of dementia, it can be suggested that suitability should be determined based on individual's experience and other contextual factors. One of the most specific of these factors is the level of impairment in episodic memory experienced, which may be a better indicator for using this novel technology within ethical boundaries.

Adopting individualised criteria for determining the suitability of lifelogging technology is in line with previous research reviewed in Chapter Five. This suggested that the use of technology should not be overly concerned with technical sophistication; rather, efforts should be made to understand the processes of its use within the context of people with dementia (Wey 2005). Furthermore, holistic assessment of the suitability of the technology for a person with dementia might result in discovering that, in many cases, it is not suitable to use the technology even though the person is in the early stages of dementia. However, the same individualised criteria may open up the possibility of using the technology with people who are considered to be in moderate stages of dementia. Given that the staging of dementia is a complex process with no definite boundaries, in addition to its experiences being very individualised, the use of lifelogging technology should acknowledge these factor when determining whether it is suitable, and the potential benefits available to the person. There are cases of people with dementia who are considered in the moderate stages but still have some access to memories of recent events (Gauthier and Rosa-Neto 2011). Assuming that all contextual factors are considered, some people in the moderate stages may then potentially benefit from using lifelogging technology; however, more importantly, some people in the early stages may avoid being unduly harmed.

In Chapter One, I discussed how the current trend of embracing technology in most aspects of our every day life is unavoidable, even in the context of dementia interventions. Furthermore, as introduced in Chapter Five, the embracing of technologies also raises sceptical views and ethical concerns associated with the use of technology in dementia (Nuffield Council on Bioethics 2009). Deeply embedded in this inexorable embracing of technology that we are all part of are the questions of who we are, what our identity is, how can we control or even manage our own identities and what now defines our identities in the modern world. As discussed in the introductory chapter, lifelogging is an emerging phenomenon of recording our activities digitally, much of which involves us interacting with our own identities.

SenseCam and other lifelogging technologies help capture our actions, enabling more access to our own identities. However, as this information is stored digitally as opposed to within a person's mind, this enables others to easily gain access to uncensored versions of our identities. As presented in the findings of this study, SenseCam enabled exposure of such uncensored identities to the therapist and to carers. The person with dementia seemed to have less control over which aspects of their life they were asked to discuss, as it was the content of the images that was largely guiding this process. In comparison, narratives or even socially constructed identities involve careful processes when it comes to choosing the content we wish to share in any given social situation. Thus, granting access to all this personal information raises ethical concerns in terms of the individual themselves and others who may be reviewing the images with them.

In the present research, the findings from the TSTs suggest that participants themselves had a greater sense of their identities in the present. While concerning from an ethical perspective, the therapist also gained an increased sense of awareness of each participants' identity by reviewing and discussing images from their everyday lives. Overall, the participants seemed to have a greater understanding and awareness of themselves and the therapist also developed a similar awareness of each participant with dementia. Hence, while SenseCam can be seen as a gateway to get to know the person with dementia, there are nonetheless ethical risks associated with such exposure that need to be addressed and recommendations that need to be put in place to

ensure that lifelogging technology is used within safe ethical boundaries. These are outlined in detail in the discussion of the research questions below.

In Chapter Four, I reviewed some existing psychosocial interventions which use technology, and their potential benefits for people with dementia. Given that the therapy developed for this thesis used SenseCam, this work also reflects the current context of the adoption of technology into psychosocial approaches in dementia. The existing literature on SenseCam reviewed in Chapter Four is experimental and often lacks descriptions of personal contexts. Thus, these seem to be in line with the industrial thrust to commercialise technology. This thesis adds to the body of literature by providing context and signifying the views of the user – the person with dementia. It explores how memories are cued and the effects of these on people with dementia and their social environments. Moreover, the findings contribute to existing knowledge on lifelogging technology from a perspective that is broader than testing memory alone. This thesis had a direct aim to explore how SenseCam can be used to support the maintenance of identity in people with dementia.

In light of the current trend to incorporate technology into dementia interventions and its associated ethical concerns, this research attempts to remain pragmatic and transparent. The thesis refrains from proposing SenseCam as an ultimate solution to diminishing identity in dementia. Instead, I aim to understand how it is best used and to raise any ethical issues associated with its use. The findings of this thesis are situated in light of the broad context of psychosocial interventions, technology use and identity in dementia. I will now consider the findings in more detail as guided by the research questions, raised earlier in the thesis.

8.3 Discussion of the Research Questions

The main aim of this thesis was to explore an innovative therapeutic intervention aimed at supporting people with early-stage dementia to continue having a sense of identity. The main questions raised were to explore whether SenseCam images can cue a person's recent memories and encourage meaningful discussions about them within social interactions. This in turn proposed the anticipated effect of supporting people with dementia to maintain their identity. Other objectives included providing qualitative data on the

processes of using SenseCam so that the success or failure of the intervention could be captured. I aim to address these questions by discussing them in light of the major findings as presented in the previous chapter. Although this discourse does not aim to give definite answers to these questions, it provides clarifications which are fundamental to understanding therapeutic SenseCam use aimed at supporting identity.

8.3.1 Does SenseCam therapy encourage discussions around memories as cued by SenseCam images within social interactions?

The discourse on selected theories of identity presented in Chapter Three suggests that discussions around memories within social interactions are the key inner and outer processes necessary to establishing a sense of identity in the present moment. Hence, exploring whether SenseCam therapy encourages discussions around memories seems fundamental to understanding its usefulness in supporting the identity of people with dementia. Therefore, the research question outlined above is addressed first. The philosophical literature reviewed in Chapter Three also suggests that a diminishment in the inner processes of memory and the outer processes of social interaction can lead to a weakening of identity. The review of empirical studies of identity in dementia further confirmed that dementia impairs these resources and simultaneously erodes the processes of maintaining identity (Mills 1997, Addis and Tippet 2004).

The findings of this research indicated that the possibility of encouraging discussions about memories cued by SenseCam images within social interactions was conditional on the contextual factors of the individual with dementia. Thus, it can be assumed that supporting a person's identity through SenseCam therapy is also dependant on individual contextual factors. These factors include the level of impairment of the person's cognitive functioning, mainly the impairment of memory from recent events, the person's coping strategy and the presence or the nature of interactions with their carer. Combined, these form the participants' context, which can either enhance or challenge the delivery and experience of the therapy. Where the formulations seem problematic for SenseCam therapy, each factor should be considered in terms of its possible ethical risks to the person with dementia and their carer as discussed below.

Ethical concerns around using SenseCam with people with dementia with a high level of cognitive impairment.

The level of cognitive impairment, especially that of memory impairment, was deterministic of the ability of the SenseCam therapy to cue memories and discussions about them. In the cases of David and Dolores, where these participants had some memories of recent events but had difficulty accessing them, SenseCam images worked very well in helping them access detailed memories about these events. The review of SenseCam images evoked discussions about these recent events, which included additional details when compared to the discussions generated through standard prompts used by their carers. These additional details included information from other senses like smell and sound, which were not represented in the images.

In the case of John, where the impairment of episodic memory reduced his ability to have memory of past events, even when prompted or cued, SenseCam images also failed to cue discussions about his recent events on most occasions. Furthermore, some discomfort and confusion was observed in John when viewing the SenseCam images. John even developed techniques to avoid discussing SenseCam images whenever he could not remember the captured events, as described in detail in Chapter Six. On all such occasions, the therapist refrained from reviewing the images and made sure the participant was still happy to continue with the session.

The failure of SenseCam images to cue John's access to these memories may explain his confusion when confronted with them. John did not remember these events due to the severity of his memory impairment, but given that there were many visual cues, he might have still recognised them as captured from his recent past. Thus, reviewing SenseCam images from recent events, which a person with dementia has no memory of, can cause them some discomfort and confusion. Unless SenseCam images can cue and help the person with dementia access memories of recent events, it poses ethical risks and questions the reasons for using lifelogging technology with people with dementia.

Thus, confronting people with dementia whose episodic memories for recent events are severely impaired with images from their recent life raises concerns around the potential risks to their confidence and relationships. Furthermore, it places people with dementia in situations which are bound to expose their forgetfulness and can

potentially be more damaging than beneficial. This raises concerns around what seems like a general misconception that SenseCam can be used with all people in early stages of dementia. Furthermore, it mirrors the broader dementia context related to the complexity of understanding early diagnosis and the early stages of dementia. Chapter Two presents a detailed discussion on the current shift from a biomedical to a psychosocial understanding of dementia which has led to the meaning of *early* being in a constant state of flux. This complexity of understanding *early* stages has resulted in people deemed to have early dementia having varied levels of impairment. Similarly, in this research where participants were confined to people with early dementia, this category still proved too broad to determine suitability for SenseCam therapy. As illustrated above, John's early dementia included his highly impaired episodic memory which seemed too diminished for SenseCam to benefit him above any other therapies using generic images. SenseCam did provide some benefits to John, as some discussions were encouraged by the images, but their meaning was mostly disassociated from recent life events as the images failed to cue these memories. The main concern is that, if the cognitive level is too impaired, SenseCam may become a source of confusion and anxiety which may outweigh its potential benefits, especially if used outside of a therapeutic framework.

Nevertheless, in the present research, SenseCam therapy was used within a therapeutic approach as guided by the frameworks of CST (Appendix A), which purposefully avoids focusing on remembering. This enabled the images to be used as starting points to opinion-based discussions. Hence, even in situations where discussions about episodic memories were not cued, reviewing the images within these frameworks still encouraged some general discussions about views or feelings surrounding the objects or people present in the images. Without adopting CST frameworks to SenseCam therapy, the failure to cue memories and discussions about them may have confused people with dementia and may also have become a source of humiliation about their lack of capacity to remember in front of the therapist or carer. The CST frameworks also provided guidance on how to avoid making participants feel as if they were being tested on their memory as part of the therapy.

Ethical concerns around using SenseCam with people with dementia and their carers

Existing social interaction patterns between the person with dementia and their carers impacted on social interactions during the therapy sessions. Regardless of the nature of existing interaction patterns, for example whether they were in line or counter

to a person-centred care ethos, they were mirrored during the therapy sessions. Furthermore, it was challenging to encourage the carers to adopt the frameworks of CST and change their existing patterns for the duration of the therapy sessions. Hence, including carers in the therapy sessions proved to be problematic, especially if their interactions with the person with dementia contradicted the frameworks of CST. This was illustrated in the case of John where his wife would often prompt him about factual details of recent days. As mentioned earlier, the frameworks of CST sway away from fact-oriented discussions in order to avoid damaging confidence and self-esteem. Consequently, Mary and John's interaction patterns were problematic when reviewing SenseCam images. Moreover, as in John's case, some people with dementia develop coping mechanisms to memory impairment which consist of relying on their carer's memory. This further complicates the use of SenseCam as a cue for memories and as a result, Mary stopped participating in the sessions, the reasons for which were discussed in detail in Chapter Six.

However, excluding carers in favour of technological advancements seems to raise concerns about further reducing the social interactions of people with dementia instead of nurturing them. Impairing social interaction is an ethical concern of using lifelogging technology in general (Jacquemard et al. 2013), as there is a risk that people might replace communication with others when using lifelogs as source of information. As a result of accessing information without benefitting from human emotions such as compassion and empathy, people may have less subjective experiences and become de-humanised (Jacquemard et al. 2013). Furthermore, it is argued that people might become dependent on the lifelog collections for memories. Some even suggest that there is a potential risk for cognitive laziness associated with lifelogging (Jacquemard et al. 2013). As people rely more and more on the technology to remember, they may reduce their own cognitive capacity to remember. In this way, the concept of SenseCam acting as a memory prosthesis is reversed, as it could possibly reduce the natural capability of remembering. In light of these ethical concerns, it seems that SenseCam technology may not be more beneficial to people with dementia than interactions with their carers. Even if such social interactions might seem negative, they are usually driven by well-meaning carers. As it stands, it seems that the negative effects associated with social withdrawal in dementia pose greater challenges than the benefits of SenseCam therapy. Thus, in cases where a choice needs to be made between carers and technology, efforts should be maintained to support social interactions that the person with dementia encounters over and above implementing the use of new technology.

Similar to questioning the suitability of carers' interaction patterns with the therapy, the skill of the researcher or therapist using SenseCam with people with dementia also needs to be considered. According to Rogers (1966), most people need to establish a trusting relationship in order to feel emotionally safe and to discuss emotions associated with past experiences. This makes using SenseCam by researchers problematic. In most cases, the researcher is an outsider to the person with dementia with no prior relationship, yet it is expected that people with dementia would share details of their private everyday lives with them. Most of the researchers using SenseCam have a background in psychology; however, a number of them come from other backgrounds including information technology, computing or engineering. Furthermore, their experience of working with people with dementia may be quite minimal or non-existent. Some psychologists may have little contact with people with dementia throughout their career and some computer engineers may have experienced dementia very closely through personal relations. All of these factors impact on the experiences of the therapy and the extent of the details people with dementia and their carers may want to discuss. For the purposes of this study, the researcher undertook a number of steps to ensure that SenseCam was used in a therapeutic manner. I reflected upon my roles as a researcher / therapist in detail in Chapter Five. In summary, various training as well as adopting CST frameworks ensured that SenseCam was used in a therapeutic manner. However, remaining sceptical, I observed that had I not taken these steps and had less-developed skills, participants may have experienced some discomfort or been potentially harmed by the use of SenseCam.

This observation leads to a question as to whether SenseCam is a completely meaningless tool without the therapist. The results of quantitative studies would seem to contradict this view (Berry et al. 2007, Bengtsson and Kikhia 2010, Doherty et al. 2012, Loveday and Conway 2011, Microsoft Corporation 2011). The methodologies described in these works were of an experimental nature, suggesting that SenseCam exclusively caused improved memory recall. It may be that SenseCam did improve memory recall, but the effects this had on people remains unknown. On the other hand, one can question whether, in these experimental studies, some form of therapeutic relationship formed between the researcher and the person with dementia which simply was not reported. Thus, it could be questioned whether SenseCam is only beneficial within a therapeutic relationship or whether it is capable of offering any extra benefits outside of the therapeutic relationship. While SenseCam remains an interesting focus,

others would argue that all technology can help but that it should not take centre stage; it can only be additional to human input (Mulvenna et al. 2010).

Notwithstanding the above discourse, SenseCam is a commercial product, and researchers, people with dementia and carers around the world have the opportunity to obtain it and use it. Consumers are usually persuaded to purchase and to use SenseCam technology because of growing awareness of its benefits to memory. People are given hope in terms of curing a lost ability to remember, with quotes such as the two below: *“I don’t feel that my new life is being lost; I know it’s still there for me whenever I want to re-live it”*

“She used to apologise all the time, ‘I can’t remember, I’m sorry’ was her stock phrase but I haven’t heard her say that for a long time now”

(<http://viconrevue.com/applications.html>)

However, there seems to be less clarity or warning on potential risks and ethical concerns with using the device by unskilled professionals or informal carers. This potentially puts people with dementia at risk of being confronted, embarrassed and forced to embrace their forgetful identity. Furthermore, it highlights the need for guidelines on SenseCam use with people with dementia.

Summary

In summary, to respond to the earlier posed question, SenseCam therapy can be successful in encouraging discussions about memories cued by SenseCam images of recent events. However, contextual factors for each individual such as the level of cognitive impairment, interactions with a carer and their coping mechanisms, can either enhance or challenge this success. Certain coping mechanisms may problematise the delivery of therapy as discussed in the case of John. However, they can also enhance the experience of SenseCam use as in the case of Dolores, where SenseCam worked as an expansion to her diary as a coping mechanism for her memory impairments. Thus, similar to considering the interaction patterns and the skills of the researcher, existing coping mechanisms are yet another contextual factor which needs to be considered as part of SenseCam therapy. Ideally, coping strategies should be incorporated into the sessions and the way SenseCam is used, i.e. tailored to enhance these in order to maximise the potential benefits for people with dementia. Where any one or a combination of contextual factors seem problematic for SenseCam therapy, the ethical risks to the person with dementia and their carer should be considered as discussed above. This highlights the need for guidelines on using SenseCam safely by

professionals for research purposes, as well as by family carers for leisure purposes. Furthermore, the therapy should be tailored to suit each individual's context rather than attempt to change existing behaviours or improve impaired memory.

8.3.2 Does SenseCam therapy support people with dementia in having a sense of identity?

The question of whether SenseCam therapy supported people with early-stage dementia in having a sense of identity cannot be answered independently of the above discussion, as they are all intimately connected. The value of the therapy to the sense of identity of people with dementia is impacted by the suitability of SenseCam use to the specific contextual factors of each individual. Nevertheless, some points can be made directly in response to this question as guided by the findings presented in the previous chapter around identity and SenseCam use.

There were clear indications that the narrative identities created during sessions involving the review of SenseCam images and the narratives created without using SenseCam were distinct from one another. There were certain processes or aspects of the SenseCam images which seemed to guide participants in constructing this unique SenseCam identity. These included the exposing of private and unexpected details from everyday life. While these exposures were dealt with in an ethical manner and did not seem to cause participants any distress, it is unclear whether participants would share these details in circumstances that did not involve SenseCam. As the biographical narratives elicited without using SenseCam images during the before- and after-therapy interviews did not include any details which could present their identity in an undesirable way, this raises ethical concerns around intruding on participants' privacy by reviewing personal lifelogs. In addition, the participants themselves seemed to disassociate with the idea that SenseCam images are representative of their identity. Nevertheless, there were also clear indications suggesting that participants had a greater awareness of their identity in the present, as seen in the TST results. However, the ethical risks associated with the possibility of SenseCam confronting participants with a rather undesirable perception of their identity, or one they have no association with, and exposing this version to the therapist, need to be considered.

Ethical concerns around confronting people with dementia with identities embedded in images from the recent past.

The findings presented in Chapter Seven suggest that the therapy enabled the co-construction of a specific version of each participant's identity, embedded in the context of the discussions between the researcher and the person with dementia and cued by the content of SenseCam images. The research design of this study enabled a comparison of this version of *SenseCam identity* with the version produced during interviews before and after the therapy. The latter types of discussions were well rehearsed, composed of lifetime achievements and seeming to focus on distant past memories, while in comparison, SenseCam identity was very unpredictable, composed of mundane and unexpected details from recent events.

While participants mostly enjoyed discussing their lives as cued by SenseCam images, on occasion, there were observable patterns suggesting their self-perceptions were not in line with these images. John developed mechanisms to avoid viewing the images and David questioned the value of reviewing some of the more mundane details captured at times in the images. Furthermore, when asked about the identity presented by SenseCam directly, Dolores simply denied its existence. In comparison, randomly, SenseCam often cued discussions about memorable and important distant past events like weddings or children, and there seemed to be a sense of pride in discussing these events. The participants did not seem to associate with the identity cued by SenseCam and felt that their identity remained in their past achievements or lifelong roles. There may be a number of reasons for participants' disassociation with SenseCam identity.

In the case of John, reviewing SenseCam images of recent events for which he had no memory might have been confusing to his sense of identity in the present. As discussed in Chapter Three, the level of memory impairment is somehow indicative to one's perception of identity in the present moment. As Locke (1690/2012) stated, one can only have the same identity if that identity remembers the identity of the past. If, for a person with dementia, the memory of recent events is non-existent (through a lack of accessible memories), this memory does not form part of their perceptions of their identity in the present moment. Therefore, John's identity in the present may have been continuous with his memories from the distant past that are still accessible to him, as opposed to inaccessible recent memories. For that reason, it was considered that, in John's case, it might be more empowering to support John in self-maintaining his identity as opposed to adjusting or making meaning of this recent identity presented in

cues from SenseCam images. This was explored by using only personal photographs from the distant past in one of the sessions described in detail in Chapter Six. However, using photographs from the distant past did not seem to result in any changes to the nature or types of discussions compared with the narratives elicited through SenseCam. This may be indicative of the type of artefact, i.e. photographs, used not being effective in cueing John's memories, or of the severity of John's memory impairment.

Thus, as already mentioned, confronting John with SenseCam images may have confused his perceptions of identity, as he did not remember these events and thus they did not impact on his sense of identity. However, given that there were many visual cues that indicated they had been captured in his daily environment, he might still have recognised them as captured from his recent past. This clearly indicates the limited value of SenseCam images for people whose identity is continuous with distant past memories. Unless SenseCam images can extend the continuity link from identity awareness in the present to the distant past to the more recent past, it poses ethical concerns that the technology may become a purely voyeuristic tool enabling unwarranted access to the lives of people with dementia.

Furthermore, there is also a connection between accessible memories and the way people cope with dementia, namely that if people can only access memories from their distant past, they are more likely to cope by self-maintaining their identity status to their identity prior to developing dementia or to a status based on an even more distant past (Clare 2003). As discussed in a number of chapters of this thesis, people with dementia should not be forced to either self-maintain or self-adjust but instead should be supported in finding a balance unique to each individual (Clare 2003). Given this fact, the nature of SenseCam images which focus on memories of recent events may be confrontational to people who cope solely by self-maintaining their identities.

However, people do not only self-maintain due to poor access to recent memories. Studies from illness representation research suggest that there is a drive for continuity among people faced with a chronic illness (Charmaz 1994, Gillies and Johnston 2004, Harman and Clare 2006, Clare, Goater and Woods 2006). The illness threatens that continuity due to its physical symptoms as well as by challenging the perceived meaning of identity. People often manage this threat by normalising the changes and attempting to maintain pre-illness ways of living. Furthermore, the privileged nature of distant past memories enable people faced with a chronic illness to reclaim their identity by reflecting upon earlier life where they can find pride and achievements (Charmaz 1994, Gillies and Johnston 2004, Harman and Clare 2006,

Clare, Goater and Woods 2006). This is in contrast to the increasingly frequent reminders of decline in the recent past.

“The fragility of their sense of identity is ameliorated by drawing on sources of self-esteem from the past, demonstrating the power of memory of the past in shoring up the present” (Gillies and Johnston, pg. 438)

Similarly, as discussed in Chapter Two, people may also use denial as a coping strategy to self-maintain their identity in light of dementia, and this is not always a negative coping strategy. As pointed out in Chapter Two, dementia diagnosis is still highly stigmatised, which often leads people to re-negotiate their new “diseased identities” (Clare 2003, Beard and Fox 2008). While some people self-adjust, the majority develop coping mechanisms to maintain their identity prior to dementia. Some of these mechanisms include denial and a lack of awareness, which can be perceived as efforts to maintain their previous societal identity status. Hence, it may be unethical to impose on people with dementia to adjust to their new, often-stigmatised, forgetful identity, especially if they are making efforts to conceal it.

In the present study, I found that Dolores and David echoed these mechanisms in response to their SenseCam identity. It seemed they still had access to their recent memories and, contrary to John, their identity in the present was continuous with their distant and recent past. Nonetheless, they did not want to associate with this SenseCam depiction of their identity. In the case of Dolores, she had an awareness of her memory impairments but had developed effective coping mechanisms to mask them. It also seemed that it was not the stigma associated with dementia per se, but the stigma of ageism, that steered her to self-maintain her identity. As mentioned in Chapter Two, older people with dementia often face a double stigma associated with ageing and dementia. Dolores did not want to be perceived as old or frail in any way. In contrast to Dolores’ self-descriptions as a very active, capable and socially engaged person, SenseCam images mostly depicted her spending time on her own in her apartment. Agreeing with SenseCam images that represented her identity differently would undermine her endeavour of self-maintaining an identity as an active and fully-functioning adult.

In the case of David, who was in the processes of receiving a dementia diagnosis and was also aware of his memory problems, he was also trying to self-maintain his identity status prior to that of experiencing his first symptoms. In his interviews, David described how the memory problems, as well as some other impairments associated with another illness, have recently forced him to become unemployed. Yet, he focused

on his hardworking ethos in his narrative elicited without SenseCam images. David was reluctant to agree that SenseCam images were representative of his identity, as they only depicted his recent events, which were marked by many disempowerments enforced upon him due to illness. Thus, seeing SenseCam images as representative of David's identity would only reconfirm the disempowering effect his illness can have on his otherwise empowered identity.

The findings suggest that the recentness of SenseCam images directed a particular view of participants' identity that they may not normally present when describing their identity. As described in Chapter Three, identities are socially constructed and a person may not be able to completely separate their identity from what society and the surrounding context implies upon them. However, regardless of whether people have dementia or not, they should be able to choose whether to include any details about their identity that may have a negative societal perception. In cases where people with dementia developed mechanisms to mask their forgetfulness and deny their memory problems in order to continue to be perceived as capable adults instead of "diseased" or "ill", this should be respected in the same manner as for the general population. SenseCam images seemed to limit participants' control over the way they could present their identity to the therapist as well as to their carer. This highlights ethical concerns associated with lifelogging technology breaching the autonomy of people with dementia.

In summary, the reasons for the participants' disassociation with SenseCam images can vary, from their identity not being continuous with their recent past, or from seeing their recent past as unfavourable to their overall sense of identity in the present. The issue with this finding is whether it is ethical to confront people with dementia with large volumes of images of their recent events.

Ethical concerns around exposing undesired identities.

Following on from the concerns around confronting the person with dementia with memories of recent events comes the question of whether it is ethical to expose these potentially-undesired identities to carers or researchers throughout the therapy processes. Predominately, ethical concerns are raised in relation to the processes by which SenseCam enables the construction and exposure of this identity embedded in the recent past to the researcher. People with dementia focus on the distant past, whereas SenseCam encourages a focus on a recent past but also unveils unexpected details which may not have been

discussed had they not been exposed. As discussed in Chapter Three, identity is artfully formulated through the processes of selecting and editing its components for the different contexts in which it may be located (Holstein and Gubrium 2000). Participants in this study showed surprise at some of the details revealed by SenseCam, as described in the previous chapter. John's wife seemed uncomfortable with his joy at the notice of wine glasses in the images and David described his pipe smoking, saying "*it was meant to be a secret*". SenseCam enabled the exposure of such uncensored identities to the therapist and to carers. The person with dementia seemed to have less control over aspects of their life that were discussed, as it was the content of the images that was largely guiding this process. Such a loss of control in relation to the particulars of participants' lives that were discussed can be interpreted as a loss of autonomy, therefore raising another ethical concern.

Furthermore, participants did not always remember some of the details exposed by SenseCam. One of the processes by which identity is constructed is through forgetting details that a person no longer wants included in his or her identity. It would be too complex to establish whether this forgetting was due to dementia or whether it was simply a selection process necessary for identity construction. Regardless of whether people with dementia make the choice not to remember and not to include certain details as part of their identity, or are simply incapable of remembering certain events, this forgetfulness and the right to construct and present desired identities should be respected.

The stopping of the process of forgetting is usually perceived as a positive aspect of the use of lifelogging technology in dementia. However, the same concept has been acknowledged as an ethical risk for the broader population (Jacquemard et al. 2013). It has been argued that forgetting serves an important function to human existence, including the ability to have a fresh start in life, free of past deeds, the ability to change opinions and forgetting in order to support reconciliation among people. Lifelogs are potentially damaging to these processes and functions of forgetting, as they can trigger memories that one would prefer forgotten. Consequently, a person can lose control over constructing his or her identity, as they can no longer choose what to forget. It should not be assumed that forgetting can be impeded just because people have dementia.

Thus, the ethical risks of impeding the forgetting process seem to also apply to the use of SenseCam or other means of lifelogging with people with dementia. Lifelogging technology may simply be a way to overcome the processes of constructing identity and expose forgotten or undesirable aspects of identity to researchers and carers. The issue here is whether exposing certain aspects of the identity of people with dementia to carers and researchers is ethically challenging their privacy and freedom of choices. Once again, this highlights the need for forewarning and clear guidelines on dealing with such exposure, and discussing the issues surrounding the transformation of identities in dementia. Researchers and carers using SenseCam images should be informed about respecting the opinions and the reality of people with dementia in order to avoid the risk of SenseCam acting as a source of embarrassment and damage to their self-esteem.

Summary

Notwithstanding the above discussion, the participants' awareness of their sense of identity did increase after the therapy, as indicated by a 100% increase in statements on the TST. This suggests that SenseCam can be used to support the sense of identity of people with dementia, however clear guidelines are needed to prevent potentially damaging effects such as embarrassment or confrontation with identity based largely in the recent past. At present, SenseCam might be seen as before its time; however, the potential of lifelogging to uphold the sense of identity of people with dementia is only at the early stages of its development. Given that current emphasis is on early diagnosis and enabling people with dementia to remain in their homes for longer, the point at which people may enter residential care will shift to much later in the disease trajectory, when their cognitive skills are more severely impaired. At this point, they may not be able to inform their healthcare professionals about their identities, and in turn their personal preferences may not be attended to. Thus, encouraging people with dementia to collect lifelogs throughout their present lives, with clear guidelines and with the capacity to choose information they wish to share or delete, may act as a gateway to discussing and sharing their identity with carers and healthcare professionals.

8.3.3 Why and how to use SenseCam.

The findings on the evolution of the therapy discussed in Chapter Seven suggest that SenseCam should be used over a period of time in order to allow participants to experience therapeutic benefits. There seemed to be distinct phases throughout the

delivery of the therapy. It appears that it takes time for participants to adjust to the technology, the unusualness of the images and to build a trusting relationship with the therapist / researcher. This should be taken into consideration and this adjustment period should be allowed prior to anticipating any benefits from the therapy. Moreover, if SenseCam use becomes beneficial to the individual with dementia, and they associate it with part of their routine, they may experience some anxiety in the ending phases of the therapy. Researchers and therapists should be aware of this and have a strategy in place for maintenance sessions or alternative psychosocial approaches for the individual with dementia.

Additional to the use of SenseCam over a period of time, the earlier discussions presented in this chapter also partly answer the overarching question of how and why to use SenseCam as a therapeutic intervention. In summary, SenseCam's potential to cue discussions about memories within social interactions is dependent on how the therapy is tailored to suit the individual's contextual factors. This in turn suggests that SenseCam therapy may only be suitable for a very specific category of people within early-stage dementia, as many factors may result in the therapy being inappropriate for some individuals. Thus, it may not have wide scale applicability, but neither do the majority of dementia interventions. At the moment, the comparison of psychosocial interventions is challenging as they come from a variety of theoretical backgrounds. Despite efforts being made, psychosocial interventions do not yet have a set of evaluative criteria like the set of criteria for medical interventions. There is some consensus being reached on which psychosocial measures should be used (Moniz-Cook et al. 2008b). Despite this, many Cochrane reviews continue to show inconclusive evidence in evaluating psychosocial interventions (Bahar-Fuchs, Clare and Woods 2013, Neal and Briggs 2003, Woods et al. 2005).

Similar to previous empirical results from other psychosocial interventions as discussed in Chapter Four, this study also showed the common difficulties of measuring the effectiveness of individually-tailored interventions in a quantifiable way as outlined by way of explaining the term "*therapeutic*" in Chapter One. Furthermore, currently, there is a shortage of studies of psychosocial interventions showing international evidence. Most often, they are limited to a specific country or even a specific nursing home. Therefore, psychosocial interventions usually do not have wide-scale applicability. Similarly, the present findings showed that SenseCam may have applicability to a small number of people who meet very specific criteria. SenseCam seemed to work very well to enhance specific coping mechanisms such as the diary

used in the case of Dolores, suggesting that it may be suitable to be incorporated as part of cognitive rehabilitation depending on individual goals. Thus, SenseCam shows potential for some universal benefits depending on the contextual factors of individuals and if used within a therapeutic framework, while also highlighting some ethical concerns when used outside of this.

Apart from the ethical concerns raised as part of the discussion of the research questions, there are also some general ethical risks with using SenseCam which were introduced in Chapter Five. I will now reconsider these general ethical risks in light of the findings of the present study. While the literature discussing ethical issues associated with the use of lifelogging technology is limited, the most commonly discussed danger associated with using SenseCam is breaching individuals' privacy (Jacquemard et al. 2013, Kelly et al. 2013). These general privacy issues are dealt with by recommending that users filter the images prior to the researcher reviewing them, as there is potential for SenseCam images to reveal unexpected details as seen in the findings of this study. However, in the case of using SenseCam with people with dementia, asking participants to filter images may be problematic, as they may not have the capacity to carry out this task. This may be due to both their level of cognitive impairment and their level of computer skills. As described in Chapter Six, the technology seemed too confusing for John, yet even his wife struggled with it, while David could use it with the help of Patricia. In cases where cognitive impairments prevent people with dementia from carrying out this task, one could argue that the carers may substitute for them if the person with dementia consents. Nevertheless, even the carer may have a low level of computer skills. Additionally, it still poses ethical risks associated with carrying out activities by proxy for people with dementia. Allowing the carers to review personal details of the people in their care just because they have dementia raises further concerns about privacy issues. Nonetheless, privacy is breached in any method of recording; if applied with the intention to benefit the person with dementia, there should be a balance struck between advantages and disadvantages based on individual understandings. One could argue that the greater breach of rights would be to prohibit use of technology in dementia.

The second most common concern in the literature on ethical issues associated with SenseCam is the privacy of other people captured by SenseCam (Jacquemard et al. 2013, Kelly et al. 2013). In the present research, this would mainly involve the capture of the carers of people with dementia, but also any people encountered on a daily basis. In all cases, the carers were aware that

they were being photographed and they gave consent before commencing the study. However, given that SenseCam is an automated wearable camera, third parties may be captured knowingly or unknowingly and will not have the opportunity to provide consent (Kelly et al. 2013). This can be compared to covert research, which is subject to ethical issues. However, the focus of the present study was not on the third parties but on cues to personal memories. It can be argued that we do not provide consent to memorise something visually, and if SenseCam was used solely for the expansion of this process, it would be illogical to ask strangers for informed consent. The current guidelines state that it is unnecessary to obtain consent when capturing images in public places when there is no intention to publish them to allow for recognition of third parties (Prosser and Loxley 2008). Nonetheless, the privacy of third parties was respected by informing participants not to wear SenseCam in places such as changing rooms, where recording is explicitly prohibited (Kelly et al. 2013). Furthermore, the images were only used to stimulate personal memories about events experienced by people with dementia and their carers.

Lastly, the visibility of SenseCam may also raise some ethical concerns around further stigmatising people with dementia. An electronic device hanging on a person's chest, which is visible to all, may impact on how they are perceived by society and expose them to possible inquisition. The issues associated with the visibility of SenseCam were particularly apparent in the case of Dolores, as she refused to wear the device to social events. In John's case, he seemed to be proud to wear SenseCam and happy to answer any questions from the public. However, this ethical concern may be out-dated as lifelogging devices are consistently being improved and made smaller and less visible (King et al. 2013). The most recent developments include a smaller version of SenseCam with a clip-on option – Autographer - and a camera built into glasses – Google Glass⁴.

These findings provide a novel way of understanding why and how SenseCam may work to cue discussions about a person's recent memories. This is distinctive to the existing research presenting cause and effect quantifiable results without clear understanding of the reasons behind them. Furthermore, SenseCam therapy is a useful tool to learn about the identity of people with dementia, assisting in the perceptions of

⁴ More information on Google Glass and Autographer can be found at <http://www.google.com/glass/start> and <http://www.autographer.com/> respectively.

each person as an individual through discussing the mundane aspects of their everyday life. Thus, it can help to support the identity of individuals with dementia by enabling their social network to construct and understand their continuing identity despite the progression of the disease. However, as each individual has a subjective interpretation of his or her identity, this version of identity of the person with dementia should be respected. The therapist should have no right to access undesirable details about participants' identities. There is a need for recommendations on how to use SenseCam so that a situation where the therapist learns about participants' identities in an unethical manner is avoided. As mentioned earlier, healthcare professionals can also use SenseCam to help curate the identity of people with dementia. Residential care staff and primary care staff often do not get the opportunity to get to know the person with dementia. SenseCam helped with the process of getting to know all participants in this study regardless of their cognitive impairment and their place in the trajectory of the condition. Review of SenseCam images was also a source of fun and enjoyment among the three participants and their carers. Participants were often reminded through cues in the images of small details about recent events that they enjoyed but have forgotten about, like the taste of tomatoes in David's sandwiches or the good weather during one of Dolores' walks. Despite the unusualness of SenseCam images being perceived as an obstacle to their review at times, participants seemed to enjoy the peculiar angles or blurriness of SenseCam images. When compared to standard, staged photographs, the odd perspectives of these images seemed to leave everyone guessing and laughing, and never resulted in people with dementia being the only ones unable to recognise the scenes or events. The carers and the therapist were often left puzzled when presented with a particularly distorted or blurred image. This allowed for the embracing of humour as part of the sessions and enabled the following of CST principles of opinion-based discussions as opposed to factual questions. While some adjustments to the delivery of the therapy were necessary in the first case, in the latter two cases, enjoyment was one clearly observable benefit of using SenseCam.

8.4 Summary

This chapter has reviewed the rationale for the study and situated its findings within the broader context of early psychosocial interventions in dementia. I then provided a detailed discussion of the findings in light of the research questions, highlighting any ethical issues associated with them. In summary, I addressed the research questions on the effectiveness of SenseCam images at cueing peoples' recent

memories, encouraging discussions and supporting social interactions. The answer to this question also shaped an overarching understanding of the usefulness of SenseCam in supporting identity in early stage dementia. I then explored the processes of using SenseCam as a therapeutic intervention for early stage dementia.

It seemed that SenseCam therapy could be successful in encouraging discussions about memories cued by SenseCam images of recent events. However, contextual factors for each individual including the level of cognitive impairment, interactions with their carer and their coping mechanisms can either enhance or challenge this success. Ethical concerns were highlighted in relation to SenseCam for use with people with dementia with a high level of cognitive impairment, and to SenseCam use with carers inexperienced in therapeutic frameworks. It was disputed that SenseCam can be used to support the sense of identity of people with dementia, but that clear guidelines are needed to prevent potentially-damaging effects such as embarrassment due to the exposing of private details or confrontation with their identity based largely in the recent past. It was suggested that SenseCam therapy should be used over a period of time to allow participants to experience therapeutic benefits. In addition, any use of lifelogging over a period of time should be accompanied by an embracing of a process of on-going consent, where constant checking for the willingness to participate is adopted. It was also highlighted that general ethical risks associated with lifelogging, including the privacy of participants and third parties and the visibility of devices, should always be considered when using this technology with people with dementia.

The use of lifelogging technology has insidiously seeped into psychosocial interventions with little public debate about its moral implications. While experimental studies praise the improvements in memory recall associated with the use of such technologies, they place little focus on considering their effects and ethical ramifications on the person with dementia. The use of state of the art lifelogging technology in dementia is at a crossroads in terms of experimenting with technology and maximising potential benefits or abstaining from using them altogether due to potential risks. However, the priority lies in the way that the technology is used. As the above discussion showed, it is important that the research considers the technology users and their contexts. The findings of this study showed that lifelogging technology offers some benefits over other therapies to some people with dementia, once used within a therapeutic framework and following ethical guidelines. Thus, SenseCam is not the ultimate intervention for all people with dementia but is a potential tool which may be more beneficial in some cases than in others. The individual's context and needs

should guide the decision as to whether to use SenseCam or not. Thus, other psychosocial interventions should be carefully considered when choosing the most beneficial option for the person with dementia.

This chapter provided a general discussion on how this research shaped the understanding of using SenseCam in supporting the identity of people in the early stages of dementia. The research questions posed at the start of the thesis have now been addressed and the full significance of this discussion will be seen in the implications of this research, illustrated through the recommendations for SenseCam use with people with dementia presented in the concluding chapter.

Chapter 9

Conclusion

This chapter will provide a summary of the major findings in this thesis and consider the implications of these findings by presenting practical recommendations on the use of SenseCam with people with dementia. I will also review the theoretical influences and the limitations of the study. Firstly, however, I will present a summary of the entire thesis.

In the introductory chapter, I set the context for dementia prevalence and its cost projections. I stated how a diminishing identity is the most debilitating effect of dementia and outlined how early psychosocial interventions aiming to stimulate cognition and social interaction can support identity in dementia. I then introduced the concept of lifelogging and associated SenseCam technology. I briefly discussed the emergence of pervasive health technologies and the potential of SenseCam use to support psychosocial stimulation. With this in mind, I proposed to investigate whether using SenseCam could encourage discussions about recent events by cueing episodic memories. Furthermore, I planned to explore if this in turn would support the identity of people with dementia. I also set out to explore how to use SenseCam as a therapeutic intervention for dementia. Lastly, I introduced the understanding of some of the predominant terms used throughout the study.

Chapters Two to Four formed the literature review of this thesis. In Chapter Two, I explored the complexity involved in understanding dementia as influenced by the biomedical and psychosocial approaches. The effects of diverse perspectives on

diagnosing and understanding early dementia were discussed. In light of this discourse, I explained the rationale for predominately grounding the current study in the ethos of a psychosocial perspective, while accepting that the biomedical approach has yielded important insights into dementia aetiologies and treatments. In Chapter Three, I reviewed selected philosophical theories on identity in humans. I presented an integrated view of identity by situating identity in both inner and outer human processes. I also discussed the impact that dementia has on a person's identity. With this in mind, I proposed the possibility of supporting identity by stimulating the inner processes of memory and outer processes of social interaction. In Chapter Four, I provided an overview of existing early psychosocial and technological interventions aimed at stimulating cognition and social interaction in dementia. I then outlined a rationale by merging together the theoretical assumptions of identity and existing interventions in order to illustrate how SenseCam therapy can be designed as an intervention to support identity in early-stage dementia.

In Chapter Five, I outlined how adopting the constructivist assumptions of a socially constructed reality and a subjective knowing enabled an exploration of SenseCam therapy through contextual understanding and the social interactions of each individual taking part in the research. Based on this, I also provided theoretical rationales for the use of a case study methodology to best answer the research questions. I also outlined the data collection and data analysis methods. I described the processes of seeking ethical approval for the study and considered additional ethical concerns relating to research with people with dementia and research using lifelogging technology.

Chapters Six and Seven were concerned with the findings of this thesis. In Chapter Six, I presented the individual case study reports of John, David and Dolores. Each report described a chronological journey of their experience with SenseCam therapy, highlighting emerging issues and the effects on a person's identity. Chapter Seven presented the common findings based on a cross-case analysis. The data from these three cases was triangulated and subjected to analysis, with common themes emerging. These were organised around the main aim of this study: delivering an intervention to people with early-stage dementia and its usefulness in maintaining the person's identity. I highlighted how the findings are embedded in these social interactions and diverse realities of each participant. Furthermore, the findings presented make suggestions on how contextual factors can impact on the effectiveness of the therapy.

In Chapter Eight, I situated the findings within the broad contexts of psychosocial interventions, technology use and identity in dementia. I then returned to the original research questions and answered them in light of the findings reported in Chapters Six and Seven. I also highlighted the ethical issues associated with the use of lifelogging technology with people with dementia.

9.1 Review of theoretical influences

The idea to design a new dementia intervention by combining psychosocial approaches with lifelogging technology stemmed from the increased evidence base of early psychosocial interventions and developments in pervasive health technologies. However, the particular focus on supporting the identity of people in early-stage dementia originated from the psychosocial perspective of dementia. The theoretical foundations guiding the intervention to support identity through a sharing of narratives about recent events within social interactions was expounded from the literature review. Yet it was the constructivist assumptions of a socially constructed reality and of subjective knowing that enabled an exploration of SenseCam therapy through contextual understandings and the social interactions of each individual taking part in the research. The therapy's effectiveness was observed in light of these social interactions and was embedded in the different realities of each participant and therapist.

One of the most fundamental influences of constructivism and the psychosocial perspective of dementia on this thesis is that it diverted the study away from a search for a faultless intervention, universal for all people with early-stage dementia. Remaining true to psychosocial and constructivist principles, where human experience is conditional to social interactions and situated in its locality and a specific time frame, enabled an understanding of the complex processes behind therapeutic SenseCam use within the context of people with dementia. This understanding demonstrated that a *“universal fit for all formula”* simply does not exist, nor is a *“fit for now”* formula static over time. However, understanding the processes of SenseCam use and how each persons' reality may affect its delivery enabled the development of contextually-sensitive recommendations for future SenseCam use with people with dementia. These recommendations aim to increase the awareness of the potential therapist to the type of contextual factors which may affect the delivery of SenseCam therapy. However, they are not fixed criteria and will differ depending on each individual and their reality.

Similar to acknowledging that the delivery of SenseCam therapy depends on the context of the individual and is not universal to all people with early-stage dementia, the constructivism-influenced approach used also enabled an understanding of supporting a person's identity as contextual to the status of an individual's inner and outer processes. The research findings demonstrate that participants' senses of identity in the present are dynamic, as shaped by inner processes of their available memories and outer processes of social interactions. As observed to differing degrees among the three participants, their senses of identity in the present seemed to centre mainly on the distant past and not on the recent past per se. Using SenseCam enabled a construction of a specific version of a participant's identity embedded in the recent past, as cued by the images and bound by the interactions between the person with dementia, the carer and the therapist. While this focus on the recent past did seem to increase participants' awareness of their sense of identity in the present, it also posed ethical risks related to the exposure of this version of identity to the therapist. In particular, the ethical concern of exposing undesired versions of participants' identities and denying people with dementia the right to present a version of identity they feel comfortable with was raised. Thus, exploring SenseCam images through a contextual understanding highlighted how the benefits of SenseCam use depend largely on individual circumstances. Furthermore, it highlighted how failing to account for the contexts of people with dementia can result in unethical SenseCam use.

9.2 Limitations of the study

There are number of limitations involved in adopting a constructivism philosophy, including the classical argument that socially constructed truth does away with any authenticity about any findings because no absolute truth exists, only those versions of truth dependent on social interactions, and that any version of truth is as good as another. Thus, critics argue that this temporary and context-laden nature of findings derived from constructivist inquiry is of little value when placed in the context of generalising implications (Phillips 1995, Rickert 2009). However, the socially constructed nature of findings is seen as an advantage in this study as it is in keeping with the psychosocial understanding of dementia, enabling me to see each person's individual experiences of the disease in place of false accounts of generalised perceptions about how dementia is experienced. Similarly, in light of the therapy, each participant's individual experience of SenseCam use was explored and captured by detailed observations and participant reflections, and was presented through in-depth

reports. Furthermore, embracing a constructivist approach enabled me to recognise that regardless of where people are placed in early or moderate dementia categories, individuals within each group will have diverse realities, and it is only by studying the way in which these are constructed can we understand them. Exploring SenseCam use guided by constructivist philosophy enables one to reach a contextual understanding and to present findings specific to the participants of this study. Moreover, attempting to use SenseCam in a uniform manner with all individuals with early-stage dementia would simply be a failure and an over-simplification of the complexity of living and coping with dementia. Nevertheless, detailed observations and interactions with people with dementia in their context as part of the therapy enabled the suggestion of a set of recommendations based on contextual factors, which may have an affect on SenseCam therapy benefiting people with dementia. These factors are transferable to different realities as they are not definite; rather, they are possibilities that need to be taken into consideration when contemplating the use of SenseCam in a therapeutic manner. Thus, the specific criticism of constructivism that its use in research enquiry results in a mere version of the truth with little value among other versions seems insignificant, as the aim of the current research is to present just one understanding as based on the truth constructed during the research process. The research was undertaken predominantly to explore and understand therapeutic SenseCam use with the participants of this study, and to inform other users about this version of understanding. This understanding serves to inform other researchers and challenges the existing perceptions of experimental SenseCam use with people with dementia. Furthermore, the developed recommendations may be adapted as needed to specific settings and contexts and may guide future SenseCam use with people with dementia. Rather than presenting the ultimate way of using SenseCam, I demonstrated that the suitability, delivery and effects of SenseCam therapy may be different for each individual taking part, subject to their contextual factors and reality.

Another common criticism of constructivism is that the findings are based on the subjective interpretations of the researcher (Rickert 2009, von Glasersfeld 2002). These subjective interpretations refer to the *meanings* given to the experiences or environment, not the environment itself. As opposed to other philosophical ways to make sense of the world, phenomena or problem, in constructivist inquiry, researchers cannot arrive at findings independently of acknowledging their own role and moral judgement in the research processes. Critics argue that this leads to biased findings representative merely of the sole researcher's point of view, with little impact on implications for dementia

interventions. However, as I engaged in reflexive practice through supervisory meetings throughout the research process, I have been aware of my input into the therapy and findings and no attempt has been made to dismiss this. I am aware that, had a different researcher or different participants been part of the research process, the findings and conclusions of the research may have been different. The aim of this research was to embrace one approach to socially constructed reality and to use it to understand and fully explore SenseCam use and its usefulness in identity maintenance within the context of these cases. A constructivism approach is more informative to early psychosocial interventions as it implies that interactions and personal experiences impact on the progression of the disease in the same manner as biological pathology. Furthermore, it enabled me to observe how people with dementia interpreted SenseCam therapy, including their perceptions of their continuing identity. The focus of the research was to present findings appreciative of participants' and the researcher's co-constructed understandings and interpretations of identity and reality during the therapy sessions.

Given that this thesis is influenced by a constructivism paradigm, it would be flawed to respond to criticisms of sample size, randomisation, validity and reliability, as such concerns originate from a positivist approaches. The current research does not attempt to match this type of rigour. In its place, *trustworthiness* criteria have been developed to assess and criticise constructivist inquires (Lincoln and Guba 1985). I will now outline how the four elements of these *trustworthiness* criteria were considered throughout the research process, namely credibility, dependability, confirmability and transferability.

Credibility is defined as the process of understanding the depth and scope of the issues under investigation and is generally achieved by triangulating different methods of data collection, including continued engagement in the field, participant observation and member checks (Lincoln and Guba 1985). To ensure this research fits the criteria of credibility for each case, I visited the participants in their homes and/or their preferred locations on different times and days for the duration of therapy over a period of seven weeks. In addition to administering the therapy, each visit involved participant observation, informal conversations, and before- and after-therapy interviews.

Dependability is the demonstration of the appropriateness of methodological decisions to constructivist principles. I provided a detailed account of combining a case study methodology with constructivist approaches in Chapter Four. Furthermore, Rodwell (1998) suggests that a methodological log should be maintained throughout the

research. To ensure dependability, I described any amendments to the emergent case study design in the individual case study reports presented in Chapter Five.

The criterion of confirmability, which refers to assuring the findings represent the researcher's interpretation of what took place and are not simply a product of the researcher's cognitive processes, (Rodwell 1998) is addressed above in response to the limitation that findings are based on a subjective interpretation by the researcher.

Transferability refers to the relevance and applicability of understandings gathered in one setting compared to another setting. This criterion is also addressed above in response to a criticism of constructivist enquiry leading to a version of the truth not applicable in other settings. Despite this research not creating an ultimate solution, recommendations were developed to help future therapists with SenseCam use. The opportunity to understand and transfer these to other environments has been presented to the reader through thick-description reports of each case study provided in Chapter Six. The usefulness and applicability of these guidelines depends on the specific environment of the reader or future therapist.

9.3 Summary of the major findings

The main goal of this thesis was to design, deliver and explore an innovative intervention which incorporated lifelogging technology and aimed to support the identity of people with early stage dementia. The research presented an in-depth qualitative depiction of the processes of the intervention and illustrated the subjective experiences of people with dementia and their carers. In summary, the research provides some major insights into the use of lifelogging with people with dementia.

SenseCam images can be effective at cueing a person's recent memories, encouraging discussions and supporting social interactions. However, contextual factors for each individual, including the level of cognitive impairment, interactions with their carer and their coping mechanisms, can either enhance or challenge this success. For example, this research showed that SenseCam was most beneficial to people with a low degree of cognitive impairment and with some retained capacity to remember recent events. Ethical concerns were raised in cases where the contextual factors challenged the intended benefits of SenseCam use. Namely, there were observed risks associated with using SenseCam with people with dementia with a high level of cognitive impairment and with carers who found it challenging to work within the therapeutic frameworks of CST.

SenseCam did seem to increase participants' senses of identity in the present, however clear guidelines are needed to prevent some potentially damaging effects such as possible embarrassment due to exposure to private details in the processes of reviewing SenseCam images. Furthermore, it was observed that participants based their identity in the distant past and there are ethical concerns related to confronting participants with an identity based largely in the recent past as depicted in SenseCam images.

Lastly, the findings of this study suggest that SenseCam therapy should be used over a period of time to allow participants to adjust to the technology and to experience therapeutic benefits. It was also highlighted that general ethical risks associated with lifelogging, including the privacy of participants and third parties and the visibility of devices, should always be considered when using this technology with people with dementia.

In summary, adopting a qualitative approach driven by the constructivism philosophy enabled a better understanding of the effects of providing people with dementia with cues to their recent memories, as well as the overall processes of using lifelogging technology within a dementia context. Essentially, this thesis challenges the notion that SenseCam is suitable for all individuals with dementia. Instead, the present research suggests that it is beneficial but only to a very specific category of people with very early stage dementia. Furthermore, it implies there should be clear recommendations on SenseCam use. Using SenseCam outside of this specific group and outside the recommendations provided raises potential ethical risks. Accordingly, this research has implications for therapeutic practice and future dementia research. The implications for therapeutic practice include some detailed recommendations on SenseCam use, focusing on the individual and their life context. Implications for future dementia research include recommendations on investigating identity in dementia, and in general, the processes of evaluating psychosocial therapeutic interventions.

9.4 Implications for therapeutic practice

This thesis is relevant to therapeutic practice as it explores a novel therapeutic approach to supporting people with early diagnosis of dementia. The approach uses lifelogging technology to stimulate the cognition of a person with dementia in a person-centred manner, with identity support as its primary goal. I have explored the processes of using SenseCam with three participants with very different contexts, preferences and

needs, and from this I have learned some valuable lessons concerning the use of lifelogging technology with people with dementia. While the SenseCam therapy did show potential for some universal benefits, there were many associated risks with its delivery. Thus, using SenseCam within a therapeutic approach leads to multiple recommendations suitable for potential therapists, carers or researchers planning to use SenseCam with people with dementia. These recommendations are neither sufficient nor suitable for all SenseCam use, as different approaches may require additional or more specific guidelines. For instance, as discussed earlier, SenseCam may be used effectively as part of cognitive rehabilitation therapy, where using the images as factual prompting might be ascribed. In this section, I present recommendations which may guide future SenseCam use within but not limited to therapeutic practice. These recommendations follow directly from the discussion of findings and associated ethical issues presented in the previous chapter. Nevertheless, they do not aim to solve or address all ethical issues; at most, they act as safeguards to warn potential users of their existence and empower these people to alleviate potential harm.

9.4.1 Recommendations for SenseCam use with people with dementia

The recommendations for using SenseCam and other lifelogging technology with people with dementia are broadly divided into four key areas. Based on the findings of the present research, it is recommended that, if using SenseCam with people with dementia, the researcher or therapist proposing to use lifelogging technology should ensure the ethical safety of people with dementia, should consider contextual factors of each individual and tailor the therapy accordingly, should use the technology within a therapeutic approach, and should adapt the use of lifelogging so that it supports the participant's perceptions of their identity.

Ensure ethical safety

Despite the phenomenon of using lifelogging technology with people with dementia being rather recent and despite research into its benefits and risks still being in the early stages, potential users should be supported as much as possible in making an informed decision about their preferences in whether to use the technology or not. Alongside presenting potential benefits in improved memory recall, the aim should be for participants to have a good understanding about the technology, the potential positive and negative effects of sharing large volumes of images representing their life with their carers and researchers, and of any other risks associated with using lifelogging

technology. Even when participants make an informed decision to use the technology, this should be reassessed at each point of contact between the researcher / therapist and the person with dementia. The aim for using lifelogging with people with dementia should be grounded in providing therapeutic intervention as opposed to gaining quantitative evidence of its potential benefits. The suggestions below may be used to ensure lifelogging technology is used in an ethical manner:

- *Provide a clear plain-language statement and practice informed, on-going consent.* Ensure participants have an understanding of SenseCam use and are aware of the potential risks to their privacy and autonomy associated with exposure of other to large volumes of images representing their recent life events. Explain clearly that it is possible that some unwanted and uncensored details may be revealed as part of reviewing SenseCam images. Always practice on-going consent, as participants may only express a desire to stop using the technology as time passes and they have more understanding of what it involves. Similarly, the therapist's self-awareness of the effects of this exposure as the therapy progresses should be discussed via reflective practice with other clinicians or therapeutically-qualified researchers.
- *Provide clear instructions as to when to wear and when not to wear SenseCam.* Stress the importance of wearing SenseCam only at times during which the participants feel comfortable. Provide a list of places where wearing the camera may not be suitable, including changing rooms or public toilets. Explain the risks associated with the capture of mundane, day-to-day events. If it appears that a large numbers of images are captured which reveal intimate or private details that participants are uncomfortable with, reconsider the suitability of SenseCam use by discussing this issue with participants.
- *Ensure participants are comfortable discussing intimate and unexpected details from their lives.* As SenseCam is a wearable and automatic camera, it may capture unexpected aspects of participants' lives. These may include some lifestyles choices or practices that participants might find embarrassing when revealed to their carer or researcher. They might be as minor as accidental pictures of a visit to the bathroom, or more contextually-complex, for instance revealing previously-unnoticed excessive alcohol intake. Regardless of the type

of unexpected details captured in the images, the therapist should treat all such content and discussions with ethical sensitivity and trust.

- *Provide clear explanation of the risks associated with confronting the person with dementia with large volumes of images of the recent past.* The potential user of lifelogging technology should be aware of their memory impairment and have enough insight to understand their condition. Despite this, the severity of their forgetfulness may only become apparent to them during SenseCam review. Additionally, the person with dementia might valorise their distant past and base their identity perceptions in their distant past. They may feel uncomfortable when confronted with a large number of images from their recent past. The potential user with dementia should understand this risk, but must also be informed that, by using SenseCam within a therapeutic approach, the images will not be used to test their memory recall or measure their forgetfulness.

Consider the contextual factors of the person with dementia

Similar to other psychosocial interventions, a number of contextual factors need to be considered when determining the suitability of SenseCam therapy for each individual. These include the level of cognitive impairment, existing coping mechanisms, and the presence of and interaction patterns with a carer. These factors will affect whether using SenseCam will be beneficial to the person with dementia or will guide how the therapy should be tailored to suit their specific needs. This research demonstrated that SenseCam did not suit all participants with early-stage dementia and that a more specific contextual assessment was necessary in order to establish its suitability.

- *Consider the level of cognitive impairment.*
Using SenseCam seemed to provide more benefits to people in the very early stages of dementia, with some ability to remember recent events still intact. This research demonstrated ethical concerns associated with the use of this technology with people with severe impairment in episodic memory. It seemed that if participants had no access to their recent memories, these memories did not form part of their sense of identity. Using SenseCam with people who have no access to their recent past memories may be confrontational and may possibly cause confusion and anxiety. Lifelogging technology can become a voyeuristic tool with no clear benefits to the person with dementia. Lifelogging

use should only be considered with people with low levels of cognitive impairment and who have an ability to access recent memories when cued.

- *Consider how the person is coping with their condition.* As discussed throughout this thesis, people with dementia may cope with their condition in various ways, usually including strategies that can be broadly divided into self-maintaining and self-adjusting. If the person is self-maintaining, there is a need to ensure that SenseCam is not too confrontational to their sense of identity. Additionally, using SenseCam may prove to be problematic alongside some specific, existing coping mechanisms. Nevertheless, SenseCam should not replace or diminish any existing coping strategies. SenseCam use should be tailored to enhance existing coping mechanisms.
- *Consider the existing relationship with the carer*
Lifeloggging poses a risk of influencing the therapist and carer to hold factual discussions about recent events captured in the images. The cues presented in the content of the images may act as a lure to test or correct the accuracy of the recall of an event provided by the person with dementia. However, this is not in line with the therapeutic frameworks of CST, which aim to empower the person with dementia. The researchers or therapist should have the ability to use the images as cues to opinion-based discussions and avoid factual questions. Furthermore, if the carer is to take part in using the technology, they should be informed about the therapeutic approach to using lifeloggging.
- *Tailor the use of lifeloggging to suit the individual needs of the person with dementia and their carer.* Once contextual factors are considered and continue to be considered while using SenseCam, the aim should be to improve the technology's fit to an individual's reality and not to force the person to change their reality to suit the technology. The lifeloggging process should be meaningful to the individual, providing them with choice, and being familiar and sensitive to their personal preferences.

Use SenseCam within a therapeutic framework

SenseCam use should cue the person's memory and facilitate meaningful discussions about these memories, in turn supporting the person's identity. It is

important that this is achieved within a pleasurable therapeutic process and not by intimidation or embarrassment.

- *Apply a therapeutic framework.* In order to avoid asking factual questions and correcting individuals while reviewing the images, it is recommended that a therapeutic framework be adopted such as the CST framework adopted for this study (Appendix A). It is clear that SenseCam can have potentially damaging implications if used outside these guidelines.
- *Allow the therapy to evolve over time.* It is recommended that the person with dementia and their carer are given time to adjust to the therapy, due to the novelty of the technology and the unusualness of the SenseCam images. The anticipated benefits may only be observable once participants are familiar with the technology, the images and the therapist.
- *Develop a trusting therapeutic relationship with the participant.* As the therapy progresses and is delivered within a therapeutic framework, the participant and researcher should develop a trusting but temporary therapeutic relationship. This should enable the participant to feel at ease discussing details from their life. The participants should not feel as if they are being patronised or tested by the technology or the researcher.
- *Plan follow-on maintenance sessions or alternative psychosocial support in advance before ending the therapy.* The therapy may become part of the participants' routines. The daily wearing of SenseCam, and twice-weekly review of images, can easily become a pattern for people with dementia, and if it is benefiting them, should be continued. Anxiety associated with the end of the therapy was observed in this study. Thus, whether it is ensuring maintenance sessions take place by involving the carer or by offering alternative psychosocial interventions available in the community, such supports should be planned in advance.

Adapt the use of lifelogging so that it supports the participant's perceptions of their identity

Lifelogging poses a risk of influencing the therapist or researcher to encourage people with dementia to adjust their identities to the recent past. However, as this research showed, participants valorised their identities based on their distant past. This

is not to say that there are no people with dementia willing to self-adjust their identity. As previously mentioned, the way people cope with dementia varies on an individual basis, with some self-maintaining and some self-adjusting. Lifelogging technology should be used to support people with dementia and should manage the conflicting endeavours of maintaining and adjusting a person's identity in the present.

- *Explore how the person with dementia views their identity and support that view during the image review.* Draw attention to details of importance to the participants and guide the discussion by connecting the distant past with the recent past and the present. Appreciate the person's identity and do not suggest that their version of identity needs to be adjusted. The SenseCam images may present a version of a participant's identity that does not match their descriptions directly. While this impression of participants' "*SenseCam identity*" may enable the therapist to continuously tailor the therapy to suit the day-to-day reality of the participant, it is important to respect the version of identity that the participant may present to the therapist. The participant's version may be one based on the concept of what they perceive as the most desired and preferred factors of themselves to present to others.

In conclusion, SenseCam can be used with people with dementia in a safe and ethical therapeutic approach, once the above recommendations are adopted. Firstly, it should be ensured that lifelogging is used in an ethical manner. Potential users should be able to make an informed decision on whether to use SenseCam or not based on the provision of a clear plain-language statement and through the process of embracing informed, on-going consent. Participants should be informed about their freedom of choice as to when to wear SenseCam and also of the restrictions on wearing the device in some specific places. Potential participants should be informed about the possibility of SenseCam exposing intimate and unexpected details from their lives. Participants should be aware of the potential effects of being confronted with large numbers of images from their recent past. Participants should also be informed of the potential moral benefits when SenseCam use within a therapeutic approach is effective. This includes providing participants with a stimulating but errorless setting with thousands of cues to their recent events. Such a setting is of benefit to participants as it offers an opportunity to freely discuss their past events without the anxiety associated with testing memory recall. The focus is on working with the person's strengths without underscoring their impairments, which seems morally obligatory when providing any

intervention, including those that incorporate lifelogging devices. This in turn seems to increase awareness of their sense of identity in the present.

Secondly, in order to determine the suitability of lifelogging technology, a number of contextual factors should be considered. These include the level of cognitive impairment (SenseCam seems to be suitable only to people with low level of cognitive impairment and with some access to recent memories), existing coping mechanisms (it might be confrontational to some existing coping strategies), and the relationship with the carer (the carer needs to adopt the frameworks of CST in order to take part in the use of SenseCam). These factors will affect whether using SenseCam will be beneficial to the person with dementia and guide how the therapy should be tailored to suit their specific needs.

Thirdly, SenseCam should be used within a therapeutic framework in order to ensure the focus is on pleasurable experiences and not on testing or correcting the person's memory. The person with dementia should be given time to adjust to the technology and the unusualness of the images. Simultaneously, a therapeutic relationship should be developed between the researcher / therapist and the person with dementia.

Lastly, SenseCam should be used to support people with dementia in managing the conflicting endeavour of maintaining and adjusting their identities in light of their condition. The findings from this research suggest that if SenseCam is used outside of these recommendations, it poses ethical risks to the person with dementia and can cause potentially damaging effects to their well-being and identity.

9.5 Implications for future research

This thesis contains important messages for future research. Firstly, it should encourage researchers using SenseCam or other lifelogging technology with people with dementia to be vigilant about the ethical implications associated with its use. This thesis demonstrated that, while the experimental research provides promising but short-term results with SenseCam improving memory recall, it is unclear how the technology was used and whether there were any ethical issues associated with such factual image reviews. These effects may include anxiety or disempowering relations between the researcher and people with dementia. This thesis demonstrated that exploring a therapeutic intervention by using a qualitative methodology enabled the identification of ethical issues deeply embedded within the context of SenseCam use. This includes the impact of individual contextual factors on the effectiveness and suitability of SenseCam

use. Researchers should resist the prosperous credits associated with reporting quantifiably-successful results in light of the potential harm experimental designs may have on people with dementia “*We must avoid shortcutting ethical concerns for short-term benefits*” (Jacquemard et al. 2013). Hence, the implications for therapeutic practice also apply to future research.

Secondly, this thesis showed that SenseCam involuntarily aids the construction of a particular version of participants’ identities. The associated ethical issues around participants’ privacy have been discussed in previous chapters and researchers should be aware of them. However, more research should be carried out on whether exposing this identity can have a positive impact on the person with dementia. For example, in cases where the person with dementia has difficulties verbalising their preferences in terms of daily activities or hobbies, SenseCam may be a useful tool to inform carers about these and enable them to, in turn, encourage the person with dementia to stay involved.

In this thesis, I presented an early but thorough exploration of understandings of the processes of therapeutic SenseCam use aimed at supporting the identity of people with dementia. The in-depth investigation of the processes of SenseCam use based on individual cases reflects previously reported difficulties of translating RCTs into practice (Woods 2004, Moniz-Cook et al. 2008a). Throughout the delivery of the therapy, the specific needs and preferences of participants in this study were my priority, as opposed to providing evidence for SenseCam applicability to all people with dementia. Nevertheless, future research should aim to build on the findings from this research, with the aim of developing a standardised protocol for the evaluation of SenseCam use within clear guidelines and with specific samples of the broader category of people with early-stage dementia, thus adding to the growing body of evidence in early psychosocial interventions in dementia.

9.6 Summary

In this final chapter, I outlined the way that the psychosocial understanding of dementia has influenced the current study. I have briefly responded to the limitations of the study. Lastly, I have presented implications for therapeutic practice and future research.

Taken as a whole, this thesis draws attention to the potential of SenseCam technology use within a therapeutic intervention in early-stage dementia. It provides a detailed exploration through a case study methodology as influenced by the

psychosocial understanding of dementia and the philosophy of constructivism. This research provided new insights on translating lifelogging technologies into clinical dementia applications. It presented an innovative, therapeutic approach to supporting the maintenance of identity in people with dementia, thus adding to the knowledge of meaningful psychosocial interventions in early-stage dementia care. Throughout the research process, I have endeavoured to maintain reflexivity and became aware of my own role in interpreting the research. I realise that the research may have been conducted and interpreted differently had different philosophical and theoretical assumptions been chosen to guide the research process. Thus, I make no claim that the current research presents universal findings; rather, it offers an alternative view to common experimental designs of SenseCam research and studies of identity in dementia. The findings and associated ethical issues enabled me to suggest some practical recommendations for future therapeutic SenseCam use. This has also opened the door to further opportunities for the exploration of SenseCam use within a therapeutic approach and its potential to support identity in dementia.

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Appendix A

Ground Rules of CST

- Mental Stimulation: get peoples' minds active and engaged
- New ideas, thoughts and associations: while talking about past memories, encourage the participant to talk about the present as new ideas and thoughts are also important.
- Using orientation sensitively and implicitly: Rather than asking direct questions about the time of the year (which is often demoralising if the person doesn't remember), people can be orientated by use of prompts (e.g. looking at images of snow during winter time).
- Opinions rather than facts: Focusing on peoples' strengths by concentrating on opinion questions rather than memory questions (i.e. what do you think of politicians rather than who is the prime minister)
- Providing triggers and prompts to aid recall and concentration: Individuals should have something (e.g. a photograph) to look at or touch to encourage attention and focus on the activity.
- Continuity and consistency between sessions.
- Implicit learning: People shouldn't be too aware that they are learning and being stimulated, perceiving the sessions more as fun activity.
- Person-centred: Each person is unique and the person needs to be seen first rather than focusing on dementia.
- Respect, involvement and inclusion: People with dementia come from a variety of backgrounds; their views, opinions and beliefs should be respected. The person should always be involved in the discussion (the person should talk more than the therapist)
- Choice: Individuals should always be offered choices, and alternative approaches if those offered do not suit.
- Fun: The sessions should provide a learning atmosphere that is fun and enjoyable rather than a strict school-like setting.

- Maximising Potential: The person with dementia might be able to carry out an activity today that he/she wasn't able to carry out yesterday. There is evidence that people with dementia can learn new information, with the right encouragement.
- Building and strengthening relationships: The sessions should help the carer and the person with dementia strengthen their relationship, especially ensuring that the carer does not take on a teacher role.

Appendix B

Psychometric Tests

Quality of life-AD (QoL-AD), (Logsdon et al. 2002)

Described as the shortest instrument and the most widely used internationally (Whitehouse, Patterson et al. 2003). The scale has 13 items covering the domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole. Each is scored from 1 (poor) to 4 (excellent), with a possible score range of 13-52. It has been found to have good internal consistency (alpha 0.82), inter-rater reliability (all intra-class correlation coefficients > 0.75) and test retest reliability (all intra-class correlation coefficients > 0.60). Concurrent validity was demonstrated through moderate correlations with other QoL measures.

Mini-Mental State Examination (MMSE) (Folstein, Folstein and McHugh 1975)

This is a brief, well established test of cognitive function with good reliability and validity. It has a maximum score of 30 and a higher score related to better cognitive function.

Alzheimer's Disease Assessment Scale (ADAS-Cog) (Rosen, Mohs and Davis 1984)

This is a more detailed assessment of cognition than the MMSE and includes more items that assess short term memory. It has a maximum score of 70 with higher scores relating to poorer cognition. It has been widely used in pharmaceutical trials and its validity and reliability are well established.

Clinical Dementia Rating (CDR) (Hughes 1982)

It is a global scale that stages dementia in 5 categories 0= No impairment, 0.5= very early dementia, 1= mild dementia, 2= moderate dementia and 3= Severe dementia. Good reliability and validity have been demonstrated for this scale (inter-rater reliability = 0.89).

Cornell Scale for depression in Dementia (CSDD) (Alexopoulos et al. 1988)

This is a 19 item scale scoring 0-2 for each item. It will use information from the researcher's interviews with the person with dementia and their carer. A score of 7 or more indicates clinical depression. It has good validity and reliability (internal consistency = 0.84).

Rating for Anxiety in Dementia (RAID) (Shankar et al. 1999)

This is an 18 item scale with a score out of 0-3 on each item. A score of 11 or above indicates clinical anxiety. Again information will be gathered from the researcher's notes and the interview with the carer and the person with dementia. It has good validity and reliability (internal consistency = 0.83).

Holden Communication scale (Holden and Woods 1982) This is a measure of communication and interaction. It is a 12-Item scale completed by the researcher scoring 0-4 on each item. A higher score on this measure indicates greater impairment. The scale correlates well with other measures (e.g. CAPE-BRS, $r=0.78$).

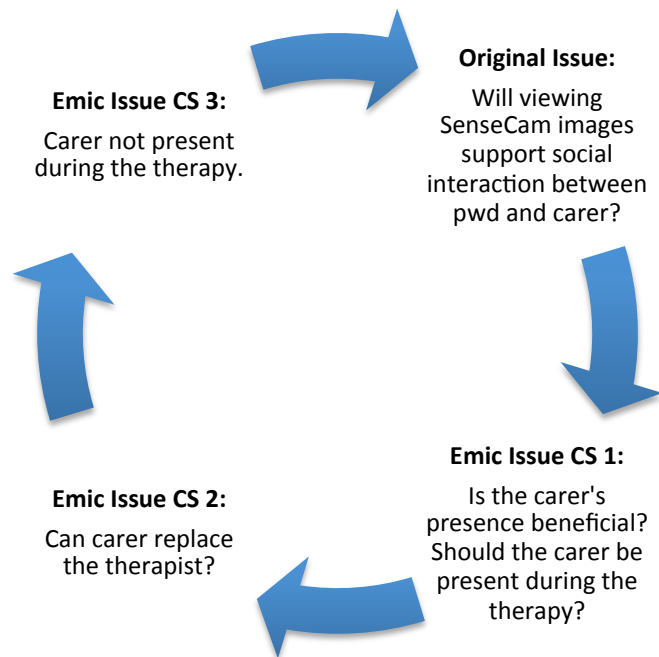
Twenty Statements Test (TST) (Kuhn and McPartland 1954) The TST is a long-standing psychological and social psychological "test" for use in regards to one's "sense of self." In particular, it helps identify those self-designations which may be due more to our "roles" than who we really are or could be. It's very simple to administer by asking to finish the sentence *I am...* 20 times.

Carer strain Index (CSI) (Robinson 1983)

CSI is a brief, easily administered instrument, which identifies strain in informal care providers. A score of 7 or higher of a possible 13 indicates a high level of stress. Internal consistency (Cronbach's alpha) for the 13-item CSI on 81 cases was 0.86. Evidence of construct validity was obtained in three areas: ex-patient characteristics; subjective perceptions of the care-taking relationship by caregivers; and emotional health of caregivers.

Appendix C

Sample Evolution of Issue Question.



Appendix D

Evolution of Issue Questions

Each of the three cases gave light to new emic questions emerging from the data. These emic questions were organised according to the original issues as summarised in the table below. This new list of issues enabled a cross case analysis which examined what evidence was present for each issue across the three cases and the different data sources.

Original Issue	Emerging emic questions CS1	Emerging emic question CS2	Emerging emic question CS3
Why and How to use SenseCam within Cognitive Stimulation Therapy framework as an intervention for Early-Stage Dementia?	<p>Is the SenseCam technology too confusing for someone with severe recent memory impairment?</p> <p>Should feedback at midpoint of the therapy be part of the frameworks of the therapy?</p> <p>Should the SenseCam be worn by the carer also? With clear instructions like “try to sit across the person with memory problems”</p>		Does using SenseCam conflict or complement any existing coping mechanisms to memory impairments?
Will the images derived from SenseCam represent person’s recent past and be meaningful and enjoyable for the person with dementia?		SenseCam usefulness in stimulating the semantic as well as the episodic memories?	<p>SenseCam images special cues to access otherwise inaccessible memories?</p> <p>Does reviewing and discussing events represented on SenseCam images formulate new SenseCam memories? New SenseCam memories or usual episodic memories recalled on repeated events reviews?</p>
Will viewing the images derived from SenseCam encourage rich opinion based discussion		SenseCam usefulness in stimulating the semantic as well as the episodic memories?	Should just meaningful events be recalled?
Does viewing the SenseCam images promote interaction between the person with dementia and their relative (carer)?	Is the carer’s presence beneficial to the therapy sessions? Should the carer be present during the therapy?	Can the carer replace the therapist?	

Will SenseCam use within CST framework work as an intervention aimed at identity maintenance in early stage dementia	Should the narrative be explored differently in both the “before” and “after” therapy interview in order to allow use of more recent past? By asking more recent aspects like: “what do you do regularly?” or allowing finishing as many “I am...” statements?		
Will SenseCam use within CST framework provide any other benefits to the people with early stage dementia?		Can a specific part of the therapy be identified as most beneficial to the participant? How to deal with an anxiety associated with the ending of the therapy?	
New Issues	Emerging emic questions CS1	Emerging emic question CS2	Emerging emic question CS3
Is SenseCam therapy suitable for everyone with early stage dementia?	Is early dementia stage enough of a criterion to determine the suitability of the person to participate in the therapy?		
How ethical is it to discuss private details of participants as revealed by SenseCam?		How ethical is it to discuss private details of participants as revealed by SenseCam – that may not otherwise be revealed?	

Appendix E

An example of the analytical process used

This appendix illustrates the process of data analysis from initial interpretations to final conclusions. This process will be illustrated by focusing on how I reached the conclusion of **“Considering the contextual factors of people with dementia when using SenseCam”**.

The analytical process was carried out in number of steps:

Step 1 – Direct interpretation of individual cases by immersion in data

Step 2 – Categorical aggregation

Step 3 - Memoing and “Patches”

Step 4 - Thematic analysis – sorting all data according to themes

Step 5 - Chronological report

Step 6 - Cross case analysis (full table Appendix I)

Step 7- Drawing final conclusion and referring back to the issue questions

Step 1 – Direct interpretation of individual cases by immersion in data,

In the first instance I have read and re-read the transcripts and other data sources of individual cases to identify any emerging patterns and write short interpretations (codes).

Transcript Excerpts	Direct interpretation
<p>Case study 1 "he still doesn't know what we are doing" (line 22) he wouldn't remember them (images) at all afterwards in the session I don't know oh ehm I was trying to lead him to talk to Paulina (line 78)</p> <p>Observations of John being confused about the camera and how it captures images session session 2, 3, 4 Observations of John not remembering the events represented in the images session session 3, 9, 10 Observations of John discussing long distance past instead of the recent past session session 4, 10, 9</p>	<p>Is early dementia enough of a criterion to participate in SenseCam therapy?</p>
<p>Case study 3 Sometimes when we click into a set of images she notices the day and then flicks back through her diary to check what she was doing. She has two types of written diaries one just a regular pocket size diary where she writes all her appointments for the day. These are very detailed things like phone calls get written in also. The other diary is freer in style where she writes about her day, for example how she was feeling and what she done or thought about. She refers to them a lot before looking at the images to set herself about what she is going to say. They seem to work very well for her and I'm not sure if SenseCam "diary" will be able to</p> <p>Dolores referring to her diary during the interview "I write everything down I wouldn't remember unless I write everything down" "I must go in now and look on the note I put on the notice board I wonder if I put it in the diary the last time" line "no I mustn't put it in the diary maybe I hadn't the diary with me that day (reading things out loud from her diary dates etc)" line</p> <p>Dolores on how SenseCam complemented her coping mechanism "ehm that I I would only have noted it there but then I knew that I was doing what I actually planned it wasn't just on the book but then I knew that I was doing what I actually planned I was doing what I planned to do for that day"</p>	<p>Diary use as a coping mechanism by Dolores.</p>

<p>Case Study 1</p> <p>I began playing the pictures and clicking through them. I said to John something like “hmm that’s a nice picture I think you are having breakfast John.” He said “oh I think I am, I must of have. I must wait to ask Mary.”</p> <p>Mary returned and and said that indeed they were having breakfast. I turn to John and ask if he enjoyed the breakfast. He responded by saying “I must have been.” He looked at Mary with that look waiting for confirmation and said, “we usually do don’t we?” Mary doesn’t respond.</p>	<p>Relying on Mary’s memory as a coping mechanism for John.</p>
<p>Case study 2</p> <p>Some therapeutic interactions expressed by the carer "I’m always goofing with him everywhere on the street and he’d always laugh and I’d never get out of bed in the morning without making him laugh just silly stuff but I find myself putting a bit more into getting that you know I can’t explain" line 172</p> <p>The carer on using the browser "the idea of being able to stop and option to go back I didn’t do it the first time but certainly the other times I was there I did it and I was always nudging on to him now press it and stop it you know you can do it as well" line 14</p>	<p>Interaction with carer can support the therapy</p>

Step 2 – Categorical aggregation

In step two I aggregated each code into a category.

Initial coding	Category
Is early dementia enough of a criterion to participate in therapy	Suitability of SenseCam to level of impairment
Diary use as a coping mechanism by Dolores.	Coping mechanisms and their impact on the use of SenseCam
Relying on Mary's memory as a coping mechanism for John.	
Interaction with carer can support the therapy	Interaction patterns and their impact on the use of SenseCam

Step 3 Memoing and “Patches”

In step 3 I developed each category into a memo. I use an example of a memo on the theme of **Suitability of SenseCam to level of impairment**.

Was the therapy suitable for John’s level of impairment?

The main symptom of dementia is impairment in working and episodic memory.

While SenseCam can be a very successful tool in cueing memory it is necessary that the person with dementia has a carer or is in an environment where people can assist them in remembering to wear it, take it off at night time, switching it on and charging it up.

One of the criteria for inclusion in the study was that the person is in the early stages of dementia. Theoretically in early stage the person with dementia has some capacity to recall recent events and has some communication skills. However, the dementia stage assessed by psychometric scales, measuring memory among many other cognitive domains can be misleading. John scored to be in the early stages of the disease with well-maintained overall cognitive and mathematical reserve. However, as it turned out during the therapy John had a very severe memory impairment. This resulted in some difficulties, as the participant could not maintain memory of wearing the camera few days or a few hours ago. It caused confusion as to who took the photos and eliminated conscious experience of them being part of their past. This is described fully in another memo.

The growing issue for the process of administering the therapy is how to identify someone in early stage dementia with enough memory skills to retain memory of what SenseCam is and what it does. The scales give an overall dementia rating and maybe for the purpose of this therapy the focus should only be on the subscale of memory. This however would make the process of recruiting a lot more complicated as the memory alone could only be assessed once the person is interviewed but even then memory may seem less impaired than what it is. It is throughout the therapy when a real insight can be gained about one’s memory impairments.

Step 4 - Thematic analysis – sorting all data according to themes

In this step I checked for evidence for or against this theme from other sources of data collected as part of the case study. (Within case triangulation) I use an example sorting the data according to the theme of **Suitability of SenseCam to level of impairment**.

DATA SOURCES	EVIDENCE FOR OR AGAINST: “Suitability of SenseCam to level of impairment”
Before Therapy int PWD	A lot of repetition observed throughout the interview. Even after few minutes of stating something (line 10,12,18,20) Suggesting very impaired recent memory
Before Therapy int CARER	"Although just only not full details of the event just slight slightly sort of ehm scart details of what's" On John's ability to remember recent events (line 25)
After Therapy int PWD	A lot of repetition observed throughout the interview. Even after few minutes of stating something (line 27,31) Suggesting very impaired recent memory
After Therapy int CARER	"he still doesn't know what we are doing" (line 22) he wouldn't remember them (images) at all afterwards in the session I don't know oh ehm I was trying to lead him to talk to paulina (line 78)
Observation field notes	Observations of John being confused about the camera and how it captures images session session 2, 3, 4 Observations of John not remembering the events represented in the images session session 3, 9, 10 Observations of John discussing long distance past instead of the recent past session session 4, 10, 9
journal entries PWD	
journal entries CARER	
psychometric tests	The MMSE and CDR showed early stage dementia however Individual scores of memory on CDR revealed severed memory impairment

Step 5 - Chronological report

I would work the memos by describing each theme into a chronological report showing at which time point each endeavour took place and to further check if evidence varied across time.

These reports are represented in Chapter 6 of this thesis as three individual case studies.

Step 6 - Cross case analysis (full table appendix I)

Once all the themes were identified and developed into individual case reports, I then carried out a cross case analysis. In other words this is a process of triangulation across all cases to explore whether there is evidence in the data for the same themes.

Furthermore this process allows checking if there is other issues that may have been missed in individual reports.

In the summary table below I show how for each data source I have marked and colour coded which case showed evidence for the theme of **Suitability of SenseCam to level of impairment**. The cases marked in red showed negative findings and the cases marked in green show positive findings in terms of level of impairment and the use of SenseCam.

Suitability of SenseCam to level of impairment	
Before Therapy int PWD	CS1 CS2 CS3
Before Therapy int CARER	CS1 CS2
After Therapy int PWD	CS1 CS2 CS3
After Therapy int CARER	CS1 CS2
Observation field notes	CS1 CS2 CS3
journal entries PWD	CS2 CS3
journal entries CARER	CS2
psychometric tests	CS1 CS2 CS3

Step 7 Drawing final conclusion and referring back to the issue questions

The final step was to draw conclusions. One of which was the level of impairment of cognitive functioning needs to be taken into consideration when determining suitability of SenseCam. This conclusion was further grouped into a category describing other factors, which needed to be considered when determining suitability of SenseCam. They included coping mechanisms and interactions with carers. The overall conclusion was then formed highlighting the importance of **“Considering the contextual factors of people with dementia when using SenseCam”**.

Initial coding	Category	Finding / Conclusion
Early dementia enough of a criterion to participate in therapy	Level of impairment and their impact on the use of SenseCam	Contextual factors of people with dementia
Diary use as a coping mechanism by Dolores.	Coping mechanisms and their impact on the use of SenseCam	
Relying on Mary's memory as a coping mechanism for John.		
Interaction with carer can support the therapy	Interaction patterns and their impact on the use of SenseCam	

Appendix F

Individual Case Analysis matrix

Case Study 1

Why and How to Use SenseCam within CST frameworks as an intervention for early-stage dementia?

Process of Administration		Feedback at midpoint	Carer wears SenseCam
Before Therapy int PWD		"how did I do" line 374	
Before Therapy int CARER			
After Therapy int PWD		"I'd have to get Mary now to see what she thinks" line 452	
After Therapy int CARER			
Observation field notes	<p>HOW</p> <p>45 minutes isn't enough time for set up and upload of images</p> <p>45 minutes should be spent viewing and discussing images</p> <p>The upload of images takes approx 20min</p> <p>sessions 3,5,6</p> <p>The therapy should be administered over time (like a duration of 7 weeks) confusion about the technology and images only observed in the first half of the therapy sessions 1,2,3,4,5,6,7,8</p> <p>WHY</p> <p>Stimulating Cognitive skills: "semantic memory, episodic, long term memory, problem solving framing" session 8</p> <p>Laughter observed in sessions 1,2,3,4,5,8,11,14</p> <p>Meaningful communication reported in sessions 3,5,7</p>	<p>Mary questioning the researcher</p> <p>how is he doing, whispering behind his back, reported in session 3, 4,6</p>	<p>John's excitement</p> <p>every time he recognises himself in the images either in a reflection in a mirror or if Mary has worn the camera observed in sessions session 1, 7</p>
journal entries PWD			
journal entries CARER	<p>The images need to be reviewed over a period of time as they take time to get used to</p> <p>"Take time to get used to it" session 2</p>		<p>"Try Mary wearing the SenseCam 50% of the time" session 3</p>

psychometric tests

Will the images derived from SenseCam symbolize person's recent past and be meaningful and enjoyable for the person with dementia?

	symbolize and cue discussion/ narrative about recent memories	Image type stimulating long vs recent memories	Access otherwise inaccessible memories?	new SenseCam memories?
Before Therapy int PWD				
Before Therapy int CARER				
After Therapy int PWD				
After Therapy int CARER		Indication that in general his memory is beetter for long distance past than recent events "I mean he'd be good about things that had happened in the past he can remember the war that kind of thing" line 277		
Observation field notes	Narrative of recent memories session 3, 13 General discussions observed about food or travel rather than discussions about memories session 6, 9, 2	identifying questioning things in images session 1,4,8,9,12,13 recent memories session 3 Long distance memories session 3, 13	session 3,13	observation of John memorising an aspect of discussion which was based on SC images and carrying this aspect into the next discussion. (i.e conversation about food and soups, next discussion looking at images from restauratn John would identify all dishes as soup) session 8
journal entries PWD				
journal entries CARER	"enjoyed it but not sure it has helped him to remember" session 2			
psychometric tests	ADAS-cog showed no difference in scores suggesting no improvement in memory			

Will viewing the images derived from SenseCam encourage rich opinion based discussion?

Nature of discussions?	Image type semantic vs. episodic	Meaningful events
------------------------	----------------------------------	-------------------

Before Therapy int PWD	During the narrative the main themes mentioned included the same themes mentioned during the general discussions i.e. travel, books, sport lines 8-20		
Before Therapy int CARER	Early indication communications should take place at ease "I think communicates with ease as long as he's comfortable" line 413	Indication of some semantic memory impairments in general "I don't know how to answer these questions because one day he'd know all his family you know you don't ask (about) all his grandchildren" line 396	Indication in the interview that even memory of major events is very impaired may suggest that daily events may be difficult to be discussed even with cues like sensecam images. "Int: Does he completely forget a major event like a trip or a party within weeks of the event M: yes" line 35
After Therapy int PWD	During the narrative the main themes mentioned included the same themes mentioned during the general discussions i.e. travel, books, sport lines 7-41		
After Therapy int CARER	"an unusual picture I think to me anyway you know he has ehm really really intact social skills really intact conversational skills and really pronounced forgetfulness or amnesic features"		
Observation field notes	There was a small number of lively discussions or narratives about events present in the images observed in sessions 3,13 A lot of cueing, identifying, questioning things in images observed in session 1,4,8,9,12,13 There was a large number of general discussions where images were used as a starting point rather than focus of the discussion on themes like travel, sports observed in sessions 6,7,8,9,10,13	identifying questioning things in images session 1,4,8,9,12,13 Mainly semantic memories cued by the images like remembering his wife's name, grandchildren observed in sessions 2,3,6,12 , Some episodic memory recall observed in two sessions where the images have some connection to John's past employment (some of a club of retired gentlemen - associated with John's work, and some of the city which John recognised as he used to work nearby) session 3,13	When reviewing images from daily routine not much discussion or even recognition, at times even slight embarrassment about the images "these are not particularly interesting" observed session 6, 8 , When reviewing images from exciting events more recognition, stimulation observed

session 2, 3, 4, 5, 13,

journal entries PWD
journal entries CARER

"Only wear camera
when things are
happening. E.g take it
off at TV"

psychometric tests Communication score decreased after the therapy indicating slight improvement in
communication

Will viewing the SenseCam images promote interaction between the person with dementia and their carer?

	Dynamics of Interactions	Is carer's presence beneficial	Can carer replace therapist
Before Therapy int PWD	strong coping mechanism in Mary as listed before line 14,94,224		Same evidence as for prior two questons strongly suggestsing a negative answer to this question

Before Therapy int CARER	<p>Early indication of teacher-student interactions between John and Mary</p> <p>"See how well he answered when you were there and when I when there is nobody else there" line 10</p> <p>"sometimes like that when I prompt him like he knows we are going to this event on Sunday" line 16</p>	<p>Early expression by the carer of need of some away time</p> <p>"well nobody comes and offers help which is interesting" line 516</p> <p>"we are very good friends and she sort of says is there anything I can do but I never heard her ask to sit with him (to sit with him sometimes) she'll never say now I'll sit with you and let you out but she'll do all sorts of things to help me" line 518</p>	<p>Same evidence as for prior two questions strongly suggests a negative answer to this question</p>
After Therapy int PWD	<p>strong coping mechanism in Mary as listed before line 41,452,510,528</p>		<p>Same evidence as for prior two questions strongly suggests a negative answer to this question</p>
After Therapy int CARER		<p>"I felt since I opened my mouth he'd stop the conversation with me and I may run it I do my best not to do that" line 78</p>	
Observation field notes	<p>Some rather negative interactions were observed throughout the sessions some of them due to the existing coping mechanism where John asked for Mary observed in most sessions. Specifically discussed in session 1, 9,14</p> <p>Also some teacher-student like interactions were also observed where the carer would correct John or prompt him observed during the before therapy interview session and 1,2,4</p> <p>Some positive interactions were observed between the participant and the researcher sessions 3,5,13,14</p>	<p>During the sessions when only researcher and the person with dementia were present more lively and comfortable discussions took place including reliving of some memories observed in session 3, 4, 5, 7, 13</p>	<p>Same evidence as for prior two questions strongly suggests a negative answer to this question</p>
journal entries PWD	<p>"Paulina is a very interesting person and I would like to know her better" session 2</p>		
journal entries CARER	<p>"Always very enjoyable pleasant and interesting" on interactions between the carer and researcher session 1</p>	<p>"Think it would be better if I stayed out of the discussions" session 2</p>	<p>Same evidence as for prior two questions strongly suggests a negative answer to this question</p>

psychometric tests

Small increase in the caregiver strain 5-6 (evidence for midpoint baseline, as similar to anxiety this could be due to ending of the therapy and awareness of that free-time ending)

Will SenseCam use within CST frameworks work as an intervention aimed at identity maintenance in early stage dementia?

before/after narratives and sessions		I am...	
Before Therapy int PWD	The narrative contained a lot of long distance past details and very little recent details. Lines 8-20		
Before Therapy int CARER			
After Therapy int PWD	The narrative didn't change much from the one given before therapy it contained a lot of long distance past details and very little recent details. Lines 7-41		
After Therapy int CARER			
Observation field notes	The narratives induced by SenseCam images were a rare occurrence throughout the therapy. They included some details from long distance past but not as much as the before and after therapy narratives. The SenseCam induced narratives were more discussions based on past related to present and they were hard to compare the before and after narratives. session 3,13	Because of the major differences in the narratives a question was formulated if the narrative should be explored differently in the "before" and "after" therapy interview in order to allow use of more recent past? By asking more recent aspects like: "what do you do regularly?" or allowing finishing as many "I am..." statements?	overall not much evidence on identity in case 1
journal entries			
journal entries PWD			
journal entries CARER			
psychometric tests			

Will SenseCam use within CST frameworks provide any other benefits to the people with dementia?

Benefits or negative effects?	benefits and specific aspects of therapy	Anxiety towards the end?
Before Therapy int PWD		
Before Therapy int CARER		

After Therapy int PWD

"well that's great now I have great now what's the word admiration for you" **session 320**

After Therapy int CARER

"mean I enjoyed paulina is so lovely I enjoyed having her company and you know it brightens up his day so it obviously brightens up my day keeps him busy and that part of it has been nice" **line 24**
"he said oh they're going to be checking me out it was always that he's going to be checked out think you're not going to be checked out" **line 22**

"I think his entirely enjoyed having the company" **line 4**
"the company was great..." **line 6**

"...I'm going to miss these two mornings a week" **line 6**

Observation field notes

Laughter observed in **sessions 1,2,3,4,5,8,11,14**
Other signs of enjoyment observed in **session 3, 5, 13**
Some confusion about the technology and images observed in the first half of the therapy **sessions 1,2,3,4,5,6,7,8**
Some negative interactions also observed, however they weren't caused by the therapy per se, rather mirrored from everyday life

It was observed that John was enjoying the discussions but not based on reviewing the images. John would use objects in the house like books or framed photographs to avoid discussing SenseCam images **session 11,13**

Some observations made on the carer reduced effort to encourage John to wear SenseCam towards the end of the therapy - suggesting that they were not as involved in participating. **Session 8,10,13**

journal entries PWD

"Paulina comes across as a very talented person"

journal entries CARER

psychometric tests

The QUALad scores increased from 38.3 to 41.33 suggesting better quality of life
Communication score decreased after the therapy indicating slight improvement in communication

slight score increase from 1.5 to 3 on **RAID**

How to determine the most suitable profile of potential participant?

Early dementia enough of a criterion?

Before Therapy int PWD

A lot of repetition observed throughout the interview. Even after few minutes of stating something (**line 10,12,18,20**) Suggesting very impaired recent memory

Existing Coping mechanism

Coping mechanism in his carer/wife
"I'd have to ask Mary " **line 14**
"I think Mary might know better answer to these questions" **line 94**
"maybe Mary should be in on this" **line 221**

Before Therapy int CARER	"Although just only not full details of the event just slight slightly sort of ehm scart details of what's" On John's ability to remember recent events (line 25)	"he can bring it up he can bring them all up only when I push him" line 16 "...I mean he doesn't really know them all without prompting" line 396
After Therapy int PWD	A lot of repetition observed throughout the interview. Even after few minutes of stating something (line 27,31) Suggesting very impaired recent memory	"my memory dims a bit if Audrey was here she would be able to remember" line 41 "I'd have to get Mary now to see what she thinks" line 452 "I have to get Mary and tell her that" line 510 "well let me get Mary in will I" line 528
After Therapy int CARER	"he still doesn't know what we are doing" (line 22) he wouldn't remember them (images) at all afterwards in the session I don't know oh ehm I was trying to lead him to talk to paulina (line 78)	"I don't know how to get him of it (relying on Mary) I don't think I'll ever will" line 28
Observation field notes	Observations of John being confused about the camera and how it captures images session session 2, 3, 4 Observations of John not remembering the events represented in the images session session 3, 9, 10 Observations of John discussing long distance past instead of the recent past session session 4, 10, 9	asking for Mary observed in most sessions. Specifically discussed in session 1, 9,14
journal entries PWD		
journal entries CARER		
psychometric tests	The MMSE and CDR showed early stage dementia however Individul scores of memory on CDR revealed severed memory impairment	

How to deal with the personal details being exposed during the therapy?

Private details?	Ethics
Before Therapy int PWD	
Before Therapy int	

CARER

After Therapy int PWD

After Therapy int CARER

(debriefing) lengthy discussion took place on the subject of alcohol and dementia in after [line 387 - 407](#)

Observation field notes It was observed on number of occassions how the carer was a little uneasy about John's excitmnet about noticing wine glasses in the images. It was certainly a detail that she may not have wanted to be revealed [session 2,4,7,13](#)

journal entries PWD

journal entries CARER

psychometric tests

Appendix G

Individual Case Analysis matrix

Case Study 2

Why and How to Use SenseCam within CST frameworks as an intervention for early-stage dementia?				
	Process of Administration	Feedback at midpoint	Existing Coping mechanism	Carer wears SenseCam
Before Therapy int PWD				
Before Therapy int CARER				
After Therapy int PWD				
After Therapy int CARER	Bluriness of images "no the only thing I would comment about the images they were blurry they were simply a bit blurry that's the only thing" line 12			
Observation field notes	<p>Due to the slow upload of the images a solution was worked out to review images already available in the browser - this meant the images reviewed weren't as recent. Session 3</p> <p>There were many images from John using the restroom he mustn't rememeber to use the privacy button. If possible the images were filtered before the session with any indecent ones deleted. session 5.</p> <p>Most of the sessions took place at cafe's and restauratns at participants request - it was observed this did not pose any difficulty and good to be aware of such possibility session 1-14 (except 7)</p> <p>If too many images captured the camera crashes and it was necessary to bring it home to try and reset it and upload the images (session 10)</p> <p>Comments on the bluriness of the images (session 2)</p>			The carer wore the camera on number of occassions providing variety to who is captured by the images (session1,4,11,12)

Camera resetting itself to incorrect date
(session 11)

journal entries PWD

"I like to see them to see who can I
identify" session 6
"I like controlling the buttons... the
images were going faster" session 7
"I would like the sessions to go on longer"
session 11

journal entries CARER

psychometric tests

**Will the images derived from SenseCam symbolize person's recent
past and be meaningful and enjoyable for the person with dementia?**

**symbolize and cue discussion bout
recent memories**

**Image type stimulating long vs recent
memories**

**Access otherwise inaccessible
memories?**

new SenseCam memories?

Before Therapy int PWD

Before Therapy int CARER

After Therapy int PWD

After Therapy int CARER

"the idea of it thought to let somebody go
back over their life it does help remember
its funny a lot of them are the same" line
14

"he's able to tell a story whenever the
story interests him you know but I always
say to him when he'd gone down the
town for coffee etc. or something like
that I say to him well did you meet
anybody he'd say no no one around... I'd
have to draw it out of him but I always
have to cuz he's quieter than I am so I
would have to draw him out but if he says
something like that..." line 34

One of the major events was also recalled
to the carer outside the therapy sessions -
unclear if this was after or before the
sensecam images review if after it may
suggest repeated event review leads to
sharing the stories outside of therapy
sessions "yes I thought it was a great idea
cuz he got a real buzz out of telling that
story I remember him telling me that" line
24

Observation field notes	<p>The images did seem to symbolize the recent past and evoke discussions about it.</p> <p>Narratives of recent events based on images session 2,3,5,10,11,12,13,14</p> <p>Narratives of recent events cued by images but not based on them 4</p> <p><u>Factual discussions based on specific aspect identified in an image 1,6</u></p>	<p>Long distance past session 3, 7,</p> <p>Recent memories recall session 3, 5,10, 11,12</p> <p>Past to present recall / comparison session 2, 3, 6</p> <p>Some overlap of sessions stimulating both recent and long distance past</p> <p>Also only one type of recall in specific sessions usually surrounding topics which trigger family or childhood memories</p>	<p>John recalling events otherwise forgotten session 5, 8, 10, 11, 14</p> <p>John rarely recalled recent events without SenseCam images but it was hard to know if this was due to not being able to access them without cues or John simply not sharing them</p>	<p>Two major events were reviewed twice and on the second recall John was much more confident describing them, even making jokes. He would focus on the exact same aspects of the event which I might have explored with him in detail i.e. one event I would explore further if he was talking to the gardai after calling them and only then he described how he wasn't but met them on the road on his way home. On second review of same event he brought up that detail without me asking for it session 10,13</p>
journal entries PWD	<p>"Sometimes you can't see anything other times you can see clearly and it's great" session 13</p> <p>"I see routines and it reminds I used to do a lot of walking and forgetting it drove me mad" session 14</p> <p>"It's always worthwhile to go through them, it helps you remember. The more you see the more you get out of them" session 14</p>			
journal entries CARER				
psychometric tests	<p>ADAS-cog showed no difference in scores suggesting no improvement or disimprovement in memory</p>			
Will viewing the images derived from SenseCam encourage rich opinion based discussion?				
	Nature of discussions?	Image type semantic vs. episodic	Meaningful events	
Before Therapy int PWD				
Before Therapy int CARER	<p>"yeah yeah I would say sometimes... (communicates with ease)" line 269</p>			
After Therapy int PWD				
After Therapy int CARER			<p>"he's able to tell a story whenever the story interests him you know" line 34</p>	

Observation field notes

Lively and meaningful discussions were observed in most sessions throughout the therapy
narratives about events present in the images observed in sessions 2,3,4,5,6,8,10,11,12,14
General Discussions with images used as a starting point session 1,2,3,7,8,13,14
A lot of self - reference "I was walking,... I went,...I met" sessions 3,11,12

Episodic memories recall was observed in session 2,3,5,10,11,12
Semantic memories recall was observed in all sessions 1-14

During one session David seemed a little annoyed viewing images of his daily routine and commented jokingly "you'd be sick looking at these" session 9
There was no major events identified as meaningful by the participants (something they were looking forward to) during the course of the therapy however, there were some events which seemed more interesting to David than others and resulted in much more lively narratives session 3, 11

journal entries PWD**journal entries CARER****psychometric tests**

Communication score decreased
suggesting slight improvement in communication

Will viewing the SenseCam images promote interaction between the person with dementia and their carer?

Dynamics of Interactions**Is carer's presence beneficial****Can carer replace therapist****Before Therapy int PWD****Before Therapy int CARER**

some therapeutic interactions expressed by the carer "I'm always goofing with him everywhere on the street and he'd always laugh and I'd never get out of bed in the morning without making him laugh just silly stuff but I find myself putting a bit more into getting that you know I can't explain" line 172

After Therapy int PWD

After Therapy int CARER	Evidence of enjoyment and interaction with the participant "I tell you why very very simply Owen loved it" line 4 "he always admired Paulina she's such a lovely person like" line 50	the carer on using the browser "the idea of being able to stop and option to go back I didn't do it the first time but certainly the other times I was there I did it and I was always nudging on to him now press it and stop it you know you can do it as well" line 14
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Observation field notes	Mostly positive interactions were observed between the person with dementia and the carer while discussing sensecam images sessions 2,4,6,7,13 Laughter, joking and enjoyment was observed between the person with dementia and the carer in session 2,6,7,13 Positive interactions were observed between the researcher and the participant in most sessions 1-14 (except 9)	Positive interactions and enjoyment were observed during the sessions the carer also took part session 2,4,6,7,13 Encouragemnt from the carer for the person with dementia to open up was also observed in these sessions 2,4,6,7,13	Both the carer and the person with dementia expressed their willingness to extend the therapy and based on the positive interactions during the sessins it was decided to leave the sensecam with them.
journal entries PWD	"Its always positive. There is no stress in it. Its easy to talk about the images" session 12	"I like it more when Patricia is there" session 8 "Its more special when there is the three of us" session 14	"I would love this to continue" session 5

journal entries CARER
psychometric tests

Will SenseCam use within CST frameworks work as an intervention aimed at identity maintancec in early stage dementia?

	before/after narratives and sessions	I am...
Before Therapy int PWD	Mostly long distance past details focusing on negative aspects like mistreatment in school, illnesses, unemployment line 4-24	1. I am happy and laugh a lot 2. If I get tired sometimes I can get groumpy 3. When I'm working on a job I would give 100% 4. My best friend in the world is Patricia 5. I would do all to help any one friend 6. I save wildlife and I look for ways of saving wildlife 7. I am a political activist

Before Therapy int CARER

After Therapy int PWD

Mostly long distance past details focusing on employments - less focus on negative aspects like mistreatment in school or illnesses line 2-8

1. I am a 57 year old
2. unemployed kind of unemployed person
3. I am a nice guy
4. I am good with my hands
5. I am good in gardens
6. I am good with people
7. I am interesting in wild life
8. I am interesting in local of history
9. I am political
10. I am very kind
11. I am very gentle person
12. I am very good to my friends
13. I am funny
14. I am very generous
15. I am good at woodwork
16. I am I can dance
17. I am glad I have been in this research
18. I am I will miss it
19. i am I am I loved every minute I was in it

After Therapy int CARER

"...but I'm saying it's had a huge impact on his confidence on his sense of self..."
line 50

when asked if the researcher would get an insight into David's identity
"only partly"
well I suppose she would have picked up that he's not out he's not in big crowds or he's quite alone he's quiet reserved guy but he is he's very calm he's very quiet and he's very gentle person
I hope so but I don't know what I'd like to think she'd picked up that sense from him and then talking to him

Observation field notes

The narratives induced by SenseCam were completely different to the before and after therapy narratives. They concentrated mainly on recent events and at times included discussions of past related to present. It was a very rare occurrence for just long distance past to be discussed while viewing SenseCam images sessions 1-14

journal entries**journal entries PWD****journal entries CARER****psychometric tests**

TST increase in statements from 7 to 19

Will SenseCam use within CST frameworks provide any other benefits to the people with dementia?

	Benefits or negative effects?	benefits and specific aspects of therapy	Anxiety towards the end?
Before Therapy int PWD			
Before Therapy int CARER			
After Therapy int PWD	"I am glad I have been in this research I am I will miss it ... I loved every minute I was in it" line 16		"...I will miss it..." line 16
After Therapy int CARER	but I'm saying it's had a huge impact on his confidence on his sense of self and the project with Paulina was all positive he looked forward to something every week he always admired Paulina she's such a lovely person like you've said easy relaxed no big arrogant ego you know I'm the god here you know there was none of that so you know he came out of the room and he was actually high and I wasn't crying I wasn't distressed I wasn't and I was so distressed the last time cuz I thought he's distressed and he's gone back from that day sure I was the same sure I couldn't stop crying all the time and I felt like saying to the girl well whoever you are good luck to you and have a good life line 50 : now he is in that he is more confident more happy and more secure	"Paulina is lovely natural normal perfect so I thought it was great and I tell you I have no doubt he is saying the same thing in there that he loves it he really really love it" line 8 "he always admired Paulina she's such a lovely person like" line 50	"but very very slight and in the last week I mean I think we are both aware of the ending of the project and I think I know he doesn't want to do it he really wants to keep in contact with Paulina"

Observation field notes	Laughter observed in sessions 2,3,6,7,10,12,14 Other signs of enjoyment observed in sessions 4,7,10		
journal entries PWD	"We ask each other questions its always nice and interesting and we laugh about things" session 11	"was looking forward to seeing Paulina" session 7	"I would love this to continue" session 5 "It is so interesting could you extend it please" session 12 "I can't get enough of this would you like to extend it" session 12
journal entries CARER			
psychometric tests	slight decrease in QUAL-ad suggesting no changes in quality of life		

How to determine the most suitable profile of potential participant?

	Early dementia enough of a criterion?
Before Therapy int PWD	Not much repetition observed and memories of recent events are still fairly intact
Before Therapy int CARER	"yeah I would say usually between usually and sometimes" "the details I wouldn't think so " "no not all the details " - about David's ability to recall recent events line 2,12,14
After Therapy int PWD	Not much repetition observed and memories of recent events are still fairly intact
After Therapy int CARER	"sure he was bussing coming home" about David's feelings after therapy sessions line 36
Observation field notes	There were no observations of David being confused about the images or completely not remebering an event in them Observations of David telling stories based on semantic cues present in the images alongside narratives of an event session 1-14

Long distance past session 3, 7,

journal entries PWD

"I like the pictures because it helps my memory"
session 7
"I can identify nearly 90% of the images"
session 10

journal entries CARER

psychometric tests

The CDR and MMSE indicated early or questionable stage dementia with more less equal impairments across cognitive skills (no evidence of severely impaired memory specifically)

How to deal with the personal details being exposed during the therapy?

Private details?

ethics

Before Therapy int PWD

Before Therapy int CARER

After Therapy int PWD

After Therapy int CARER

Observation field notes

Some personal details were revealed during the SenseCam sessions including David's pipe smoking session 2
Intimacy between David and Patricia session 2
David's outbreaks in healthy diet session 6

All revelations happened within a trusting non-judgemental therapeutic setting. The participants were comfortable sharing the details once they were revealed in the sessions through viewing images

journal entries PWD

"Its always positive. There is no stress in it. Its easy to talk about the images"
session 12
"It was like three friends having a little chat about things and lots of funny comments a fun and happy time" session 14

journal entries CARER

psychometric tests

Appendix H

Individual Case Analysis matrix

Case Study 3

Why and How to Use SenseCam within CST frameworks as an intervention for early-stage dementia?				
	Process of Administration	Feedback at midpoint	Existing Coping mechanism	Carer wears SenseCam
Before Therapy int PWD			<p>Dolores referring to her diary during the interview</p> <p>"I write everything down I wouldn't remember unless I write everything down"</p> <p>"I must go in now and look on the note I put on the notice board I wonder if I put it in the diary the last time" line</p> <p>"no I mustn't put it in the diary maybe I hadn't the diary with me that day (reading things out loud from her diary dates etc)" line</p>	
After Therapy int PWD	<p>Dolores explaining how it takes time to get used to SenseCam "I found it very useful very useful yeah and as I went along I got into it at the beginning it took me a while to get used to it but then it became part of me but then I put it on in the morning..." line 2</p> <p>Dolores on getting used to images line 26</p> <p>"ehm at the beginning they weren't cuz I found I couldn't I didn't identify with them at the beginning but gradually I have identified with them no problem"</p> <p>Dolores stating that the Images were "most interesting when I went out" line 10</p>		<p>Dolores on how SenseCam complemented her coping mechanism</p> <p>"ehm that I I would only have noted it there but then I knew that I was doing what I actually planned it wasn't just on the book but then I knew that I was doing what I actually planned I was doing what I planned to do for that day"</p>	

Observation field notes	<p>Comments on Bluriness or unusualness of images observed in sessions 1,2,3,4,6,7</p> <p>Confusion about images, technology or browser observed in sessions 1,2,3,4,5,6</p> <p>Dolores commenting how it took her time to get used to the images observed in sessions 7,8, 10</p> <p>Confusion about wearing Sensecam outdoors and underneath clothing observed in sessions 1-4</p> <p>Uploading new images while viewing images already available in the browser was practiced in most sessions and worked very well. sessions 1-14</p> <p>The session should be given a time frame of 60min including set up etc - out of which 45minutes should be spend viewing and discussing images sessions 1-14</p>	Dolores voluntarily commented how it took her the first four or five sessions to get used to the images - her presenting feedback unofficially to the researcher session 7	Established coping mechanism in the use of a diary observed in most sessions specifically discussed in session 2, 6, 7, 8,9, 12,14	No carer present however SenseCam was placed at a table left on and produced some interesting images discussed in session 11
journal entries PWD	<p>"I am still getting used to what the pictures are representing" session 2</p> <p>"its part of me now no problem inside or outside" session 5</p>			
psychometric tests				

Will the images derived from SenseCam symbolize person's recent past and be meaningful and enjoyable for the person with dementia?

	symbolize and cue discussion bout recent memories	Image type stimulating long vs recent memories	Access otherwise inaccessible memories?	new SenseCam memories?
Before Therapy int PWD				
After Therapy int PWD	<p>Dolores on images representing her past</p> <p>"oh yes that would be my routine anything that was there would be a routine thing for me to do a daily routine</p>		<p>Dolores on how the images cued recall</p> <p>"oh yes I would I would find it very useful yes definitely because sometimes I don't like notice there some things I wouldn't have picked up things unless you have started it off and then it kind of pointed to me and then it would come back to me but without having the kick off start thing I wouldn't have recalled some things"</p>	

Observation field notes	Narratives of recent events sessions 5-14 Other discussions cued by certain aspect in the images observed in sessions 5,6, 10	Recent memories observed in session 3, 6,7,8,9,11,12,13,14 Long distance past session 10,	Dolores recalling events otherwise forgotten session 8,9, 13, 14, Dolores was often surprised by certain memories evoked by SenseCam as she often commented that she would never recall them otherwise sessions 12,14	Two major events were reviewed twice and on the second recall Dolores narratives would included discussion parts inputted by the researcher at the initial review. The participant would use the exact same wording as the researcher alongside her own parts sessions 8,14
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journal entries PWD	"It took a while for me to identify the pictures and what they represented" session 1 "I found it very useful I can recall what I was doing at a specific time" session 3 "..it helped my memory to recall where I wasat that time and what I was engaged in" session 7		" I found it very useful ,one is able to recall things that has happened and you forgotten about" session 8
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psychometric tests	ADAS-cog slight increase in score from 11 to 12 - suggesting no real cognitive (memory) impairment
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Will viewing the images derived from SenseCam encourage rich opinion based discussion?

	Nature of discussions?	Image type semantic vs. episodic	Meaningful events
Before Therapy int PWD	Dolores expressing her concern about her diminishing communication skills " I feel now that im losing confidence in myself that if im in a group talking discussing that I will lose my ven of talk and that I cant contribute as well as I used to yes definitely im very conscious of that " line		

After Therapy int PWD

Dolores on communicating during the therapy "in the sense that I was able to talk about images that I saw I was able to express what was happening because there was nobody else competing against me I was there was nobody making any remark about it or criticising what I have said or anything from my point of view"

Dolores on images were "most interesting when I went out" line 10
Dolores on events
"do I would say this is very interesting I hope that turns up and that we'll be able to talk about from this point of view it was most interesting like the day I was at the show" line 28

Observation field notes

Identifying, cueing and questioning observed in sessions 1,2,3,4
Narratives about events present in the images were observed in sessions 3,5,6,7,8,9,10,11,12,13,14
General discussions cued by certain aspect in an image sessions 5,6,10

Episodic memory recall observed in sessions 3,5,6,7,8,9,10,11,12,13,14
Semantic memory recall observed in all sessions 3-14

Excitement and lively narratives were observed when reviewing two meaningful events in particular observed in session 6,9,
Annoyance or slight embarrassment was observed when reviewing images of mundane things like breakfast, Dolores would often comment "am I still at it?" observed in sessions 9,12,

journal entries PWD

Some semantic memories of the number and names of grandchildren was also reflected in the diary by Dolores "I would like to talk about the relationship of grandchildren towards granny" session 4

psychometric tests

Will viewing the SenseCam images promote interaction between the person with dementia and their carer?

Dynamics of Interactions**Is carer's presence beneficial****Can carer replace therapist****Before Therapy int PWD****After Therapy int PWD****Observation field notes**

Positive interactions were observed between the participant and the researcher in all sessions, they developed to be more friendly and trusting as the sessions progressed sessions 1-14

As there was no carer included in this therapy one can assume their presence is not necessary but only with the suitable profile of a participant. However, this isn't to say carers presence is not beneficial.

journal entries PWD

"I am looking forward to the Paulina's visit now as we are open to each other and can share any problem that arises"
session 10

psychometric tests

Will SenseCam use within CST frameworks work as an intervention aimed at identity maintenance in early stage dementia?

Before Therapy int PWD

before/after narratives and sessions

" I feel now that I'm losing confidence in myself "
The narrative given before the therapy seemed like a very well rehearsed story involving mainly long distance past life

I am...

1. I am a happy person
2. I am over 60 years of age
3. I am slow walking at times
4. I am the eldest of my family
5. I am grateful that I am living here
6. I am happy that my children are all happy and settled
7. I am in a kind person
8. I am good at making friends
9. I am slow to get angry
10. I am in a healthy person

After Therapy int PWD

The narrative given after the therapy seemed like a very well rehearsed story involving mainly long distance past line Dolores on how the sessions made her aware about herself
"aware of activities and things I would have a routine but I would never realise that di fit so much into my day like I considered like when something is put before you on a screen you say oh my god the day must be very long I got so much fitted into it I didn't sit down or sit in the cafes or I didn't but I had an activity every day I had kind of a planned day really that's the way I operate"

1. I am middle aged woman
2. i am happy with my lot
3. I am able to look after myself
4. I am easy to get on with
5. I am a person that lives day by day
6. I am not regretful of anything I have done in my life
7. I am resourceful and content
8. I am happy most of the times
9. I am not a person that automatically agrees with whats happening in our country at the moment
10. I am a very approachable person
11. I am attending to anyone that needs my help
12. I am grateful for life that I have lived
13. I am supportive of anyone that needs help even financially or materially
14. I am glad I travel and had the health and fitness to do it
15. I am sorry for the state of our country at the moment and how our young people are not responding to things
16. I am not a person that reflects and analyses things very much I just accept it as it is
17. I love my country and
18. I love my family
19. I am general with what I have and
20. I give up when Im not able to walk

Observation field notes

The narratives induced by SenseCam were completely different to the before and after therapy interviews. The narratives given before and after therapy seemed like a very well rehearsed story narrated in a beautiful manner at times keeping in suspense as well as evoking emotions of empathy within me the researcher. The narratives induced by SenseCam were more rough and exciting and evoking emotions of surprise, joy and laughter among the participant

journal entries**journal entries PWD**

"I feel I have a routine in my life I noticed that in pictures" session 2

psychometric tests
Will SenseCam use within CST frameworks provide any other benefits to the people with dementia?

	Benefits or negative effects?	benefits and aspects of therapy	Anxiety towards the end?
Before Therapy int PWD			
After Therapy int PWD	<p>"I found it very useful very useful yeah and as I went along I got into it" line 2</p> <p>"I did miss it this morning yes" line 4</p> <p>Dolores when asked if the therapy was a positive experience</p> <p>"oh lord yes without any doubt" line 30</p>	<p>"yes I think individually they wouldn't have meant anything I do think I have decided for me anyway maybe different for other person but for me if the three were not connected and integrated it wouldn't have meant anything for me" line 18</p>	<p>"I did miss it this morning yes" line 4</p>
Observation field notes	<p>Laughter observed in sessions 8,9,10,11,14</p> <p>Other signs of enjoyment observed in sessions 6, 9, 11, 13</p> <p>Some confusion about the images observed in the first half of the therapy perhaps stopping the enjoyment sessions 1-4</p>	<p>Dolores did state she would use SenseCam independently, however she also stated without the interaction it wouldn't mean anything to her</p>	<p>Dolores would often state she would use SenseCAM by herself as she finds it very beneficial now sessions 7,10,14</p>

journal entries PWD	<p>"I found it very encouraging and useful" session 1</p> <p>"I feel it has helped me with my recall, which is very important to me" session 13</p>	<p>"I now would say all three are important. If I had not recognised the image I would not have anything to say" session 9</p> <p>"I find recognising the images, telling the story they represent to Paulina" session 10</p>	<p>"I will miss her wk (weekly) visits" session 13</p>
psychometric tests	AD8 increase from 4 to 5 suggesting no improvement or disimprovement in dementia stage		slight increase on RAID from 2 to 3

How to determine the most suitable profile of potential participant?

	<p>Early dementia enough of a criterion?</p>
Before Therapy int PWD	<p>Not much repetition observed throughout the interview, however it was observable the communication skills are very diminished with very frequent use of a collective noun instead of specif noun</p> <p>"when he left the thing and went down to work in L" line 21</p> <p>"the lunch and the thing for the meal and we'd take it out" line</p> <p>"business thing and my accounts"</p>
After Therapy int PWD	<p>Dolores on choosing suitability of the person to the therapy "you'd have to be very selective about who you would you'd want to know the person quite well beforehand and what they're disabilities were or whether there were a person that would be able to first recognise what it was about and whether they'd be able to part take in it it would be selective no doubt about that"</p>

Observation field notes

It was observed Dolores was able to use SenseCam including remembering to wear it, charge it and switch it off at night despite her early stage dementia. Initially some confusion about the SenseCam images was observed but as the sessions progressed she got used to them sessions 1-4
It also took few sessions to incorporate the use of SenseCam into Dolores existing coping mechanism her diary sessions 1-6

journal entries PWD

psychometric tests

The AD8 and MMSE showed early stage dementia with equal impairments across cognitive skills.

How to deal with the personal details being exposed during the therapy?

	Private details?	Ethics
Before Therapy int PWD		
After Therapy int PWD	"im not a very open person im not a talkative person im not a great listener and im not a person that opens up very easily about myself that's just part of me I have a lot that im the listener" line 34	
Observation field notes	It was observed Dolores wore the camera very selectively rarely presenting a full day of image capture. This could have been her way of preventing any unwanted details to be revealed. Certain aspects Dolores perhaps wouldn't discuss without the SenseCam images included her routine of applying make up (surprisingly the camera was good at capturing the reflection in the mirror) sessions 4,5	
journal entries PWD		"I find it very encouraging she puts one at ease" session 5
psychometric tests		

Appendix I

Cross Case Analysis matrix

CROSSCASE EVIDENCE SUMMARY TABLE

Why and How to Use SenseCam within CST frameworks as an intervention for early-stage dementia?

	Q1.1	Q1.2	Q1.3	Q1.4
Before Therapy int PWD		CS1	CS1 CS3	
Before Therapy int CARER			CS1	
After Therapy int PWD		CS1	CS1 CS3	
After Therapy int CARER	CS2 CS3		CS1	
Observation field notes	CS1 CS2 CS3	CS1 CS3	CS1 CS3	CS1 CS2 CS3
journal entries PWD	CS2 CS3			
journal entries CARER	CS1			CS1
psychometric tests				

Will the images derived from SenseCam symbolize person's recent past and be meaningful and enjoyable for the person with dementia?

	Q2.1	Q2.2	Q2.3	Q2.4
Before Therapy int PWD				
Before Therapy int CARER				
After Therapy int PWD	CS3		CS3	
After Therapy int CARER	CS2	CS1 CS2	CS2	CS2
Observation field notes	CS1 x CS2 x CS3	CS1 CS2 CS3	CS1 CS2 CS3	CS1 CS2 CS3
journal entries PWD	CS2 CS3		CS3	
journal entries CARER	CS1			
psychometric tests	CS1 CS2 CS3			

Will viewing the images derived from SenseCam encourage rich opinion based discussion?

	Q3.1	Q3.2	Q3.3
Before Therapy int PWD	CS1 CS3		
Before Therapy int CARER	CS1 CS2	CS1	
After Therapy int PWD	CS1 CS3		CS1 CS3
After Therapy int CARER	CS1 CS2		CS1 CS2

Observation field notes	CS1	CS2	CS3	CS1	CS2	CS3	CS2	CS3
journal entries PWD		CS2	CS3					CS3
journal entries CARER							CS2	
psychometric tests	CS1	CS2	CS3					

Will viewing the SenseCam images promote interaction between the person with dementia and their carer?

	Q4.1		Q4.2		Q4.3
Before Therapy int PWD	CS1				CS1
Before Therapy int CARER	CS1		CS1		CS1 CS2
After Therapy int PWD	CS1				
After Therapy int CARER	CS1	CS2	CS1		CS1 CS2
Observation field notes	CS1 x CS2	CS3	CS2 CS3 x		CS1 CS2
journal entries PWD	CS1	CS2 CS3	CS1 CS2		CS2
journal entries CARER	CS1		CS1		CS1
psychometric tests			CS1		

Will SenseCam use within CST frameworks work as an intervention aimed at identity maintenance in early stage dementia?

	Q5.1		Q5.2
Before Therapy int PWD	CS1 CS2 CS3		CS2 CS3
Before Therapy int CARER			
After Therapy int PWD	CS1 CS2 CS3		CS2 CS3
After Therapy int CARER		CS2	CS2
Observation field notes	CS1 CS2 CS3		CS1
journal entries			
journal entries PWD		CS3	
journal entries CARER			
psychometric tests		CS3	CS2 CS3

Will SenseCam use within CST frameworks provide any other benefits to the people with dementia?

	Q6.1		Q6.2		Q6.3
Before Therapy int PWD					
Before Therapy int CARER					
After Therapy int PWD		CS2 CS3	CS2 CS3		CS2 CS3
After Therapy int CARER	CS1 CS2		CS2	CS1 CS2	

Observation field notes	CS1 CS2 CS3	CS3	CS1 x CS3
journal entries PWD	CS2 CS3	CS2 CS3	CS2 CS3
journal entries CARER			
psychometric tests	CS1 CS2 CS3		CS1

How to determine the most suitable profile of potential participant?

	Q7.1
Before Therapy int PWD	CS1 x CS2 CS3
Before Therapy int CARER	CS1 x CS2
After Therapy int PWD	CS1 x CS2 CS3
After Therapy int CARER	CS1 x CS2
Observation field notes	CS1 x CS2 CS3
journal entries PWD	CS2 CS3
journal entries CARER	CS2
psychometric tests	CS1 x CS2 CS3

How to deal with the personal details being exposed during the therapy?

	Q8.1	Q8.2
Before Therapy int PWD		
Before Therapy int CARER		
After Therapy int PWD		
After Therapy int CARER		CS1
Observation field notes	CS1 CS2 CS3	CS2 CS3
journal entries PWD	CS3	CS2 CS3
journal entries CARER		
psychometric tests		

Appendix J

SON EAC Letter

December 13, 2010

Ms Paulina Piasek
School of Nursing
DCU

Dear Paulina,

The School of Nursing Ethics Advisory Committee (EAC) reviewed your ethics application form for the second time for the project: **Case studies in SenseCam use for cognitive stimulation therapy in early-stage dementia.**

The approach that the School of Nursing Ethics Advisory Committee (SON EAC) takes is to make recommendations on your submission. These should be discussed with your supervisor and taken into account in preparing your final submission to the DCU Research Ethics Committee (REC). Please note that the comments from the School of Nursing EAC *do not* constitute ethics approval. Within DCU, ethics approval is only granted by the DCU REC.

The following comments are given to help facilitate your application through the DCU REC. The EAC recommends that you address the following points prior to submitting your application to DCU Research Ethics Committee. You do not need to reply to the EAC about these points.

- Concerns were raised about the small sample size. While acknowledging that this is a case study approach and a large volume of data is being collected should one of the three participants withdraw a large amount of data will be inaccessible. As a large volume of data is being collected over a 7 week period it is likely that participants might withdraw. Have you considered this? Would it be feasible to increase sample size numbers? Or would a consideration be to conduct the study in two phases with phase one focusing on small numbers to generate a small number of focused questions which could be asked of larger population?

Please note that the DCU REC requires that you submit a copy of this letter with your revised final application to them. We wish you all the best with your application. For our records, please send me a copy of the ethics approval letter when you obtain it.

Yours Sincerely,

Veronica Lambert, PhD
Ethics Advisory Committee
School of Nursing, Dublin City University

Appendix K

DCU REC Ethical Approval Letter

Dublin City University
Ollscoil Chathair Bhaile Átha Cliath



Dr. Kate Irving
School of Nursing

23rd March 2011

REC Reference: DCUREC/2011/002

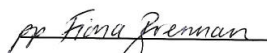
Proposal Title: Case Studies in SenseCam use for Cognitive Stimulation Therapy in Early-Stage Dementia.

Applicants: Dr. Kate Irving, Prof. Alan Smeaton, Ms. Paulina Piasek

Dear Kate,

Further to expedited review, the DCU Research Ethics Committee approves this research proposal. Should substantial modifications to the research protocol be required at a later stage, a further submission should be made to the REC.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Dr. Donal O'Mathuna'.

Dr. Donal O'Mathuna
Chair
DCU Research Ethics Committee



Office of the Vice-President
for Research
Dublin City University,
Dublin 9, Ireland
T +353 1 700 8000
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E research@dcu.ie
www.dcu.ie

Appendix L

DCU REC Ethical Amendment Communication

From: Paulina Piasek [mailto:paulina.piasek2@mail.dcu.ie]

Sent: 17 January 2013 12:44

To: fiona.brennan@dcu.ie

Cc: Kate Irving

Subject: Amendment to the approved research proposal entitled "Case Studies in SenseCam use for Cognitive Stimulation Therapy in Early-Stage Dementia"

Dear Fiona,

I would like to request an amendment to the approved research proposal entitled "*Case Studies in SenseCam use for Cognitive Stimulation Therapy in Early-Stage Dementia*" based on the analysis of the first two case studies. The amendment would regard section 2.4 "*PARTICIPANT PROFILE*" of the ethics research proposal. In the original proposal we had stated that the person would live with a carer so they could assist in reminding the person to wear the camera. While we had specified recruitment of people with early stage dementia, this is a broad category and it is becoming clear that the earliest part of the early stage is most beneficial for sense cam therapy. In the initial phase of early dementia many people still live independently and alone but would be capable of remembering to use the camera with some cues. So we propose to recruit further participants who may also live alone. As in the original proposal all participants will be able to sign informed consent to participate with our adapted rolling consent methods.

Thus the section 2.4 "*PARTICIPANT PROFILE*" after the amendment would read as follows:

2.4 PARTICIPANT PROFILE

Purposive sampling will be used to recruit 3 participants who have Early-Stage Dementia and may or may not be living with a carer. Carer is the person chosen to be in partnership with the person with dementia and views care from the position of consideration, protection, serious attention, and commitment (West 2003). If the person is living with a carer he or she may also participate in the therapy. If the person is living alone they can participate in the therapy independently. Screening for inclusion criteria will be done by the manager of the relevant facility referring the participant.

Inclusion Criteria:

- Diagnosis of dementia (DSM IV) with Clinical Dementia Rating Scale score of between 0.5 and 1.
- Can hear well enough to participate in a discussion
- Can have a meaningful conversation
- Vision is good enough to see the screen
- Is likely to be able to remain seated for 45 minutes
- Wants to participate

The original ethics proposal is also attached.

Kind Regards,

Paulina Piasek.

RE: Amendment to the approved research proposal entitled "Case Studies in SenseCam use for Cognitive Stimulation Therapy in Early-Stage Dementia"

1 message

Fiona Brennan <Fiona.Brennan@dcu.ie>
To: Paulina Piasek <paulina.piasek2@mail.dcu.ie>
Cc: Kate Irving <Kate.Irving@dcu.ie>

1 February 2013 at 09:3

Hi Paulina – please note that this amendment is now approved.

Kind regards, Fiona.

Fiona Brennan

Research Officer

Appendix M

Plain language Statement: person with memory problems

PLAIN LANGUAGE STATEMENT: PERSON WITH MEMORY PROBLEMS

DUBLIN CITY UNIVERSITY

Plain Language Statement

Title of Project:

Case Studies in SenseCam use for Cognitive Stimulation Therapy in Memory Problems.

Principle Investigators:

Dr. Kate Irving (Tel: +35317007985) EMAIL: kate.irving@dcu.ie

Ms. Paulina Piasek (Tel: +35317007793) EMAIL: paulina.piasek2@mail.dcu.ie

Introduction:

You are being invited to take part in a research study. The research is funded by The School of Nursing and Faculty of Science and Health, Dublin City University. Before you decide to take part or not, it is important that you understand why the study is being done and what it will involve. Please read the following information carefully and discuss it with others, if you wish. If you require further information, or would like to ask any questions, please contact the principle investigators, contact details above.

Researchers in the School of Nursing and Centre for Sensor Web Technologies (CLARITY) at DCU are conducting a series of studies to see if viewing photographs taken by Microsoft SenseCam within the frameworks of Cognitive Stimulation Therapy (CST) can encourage discussion, allow enjoyment and improve relations among individuals with memory problems and their partners.

A SenseCam is a small camera you wear around your neck, which passively takes photographs of your activities throughout the day without you being aware it is working. The dimensions of SenseCam 6.5cm w x 7cm h x 1.7cm the weight is 94g.

SenseCam photographs from your daily life will be incorporated into discussions, exercises and activities. This approach is called Cognitive Stimulation Therapy and aims at general enhancement of thinking and social functioning.

We believe viewing these photographs within the frameworks of CST can enhance the quality of life, improve cognitive and psychosocial well-being, and help maintain your valued sense of identity. The purpose of this research is to contribute to the knowledge of meaningful interventions in memory problems.



SenseCam

Details of what involvement in the Research Study will require:

Phase 1: Before therapy interview

This phase will involve you and your partner or next of kin taking part in an interview. Your medical and social history will also be documented. This will also involve administration of questionnaires which will assess things like quality of life and your mood. The interview will take place over two sessions of one hour each. This interview will be audio-taped. No one will listen to these tapes except the members of the research team listed above. Information will be kept confidential at all times.

Phase 2: Cognitive Stimulation Therapy using SenseCam.

Phase two will consist of a total of 15 visits over a period of 7 weeks.

- The first visit will last approximately 1 hour. You will be introduced to the SenseCam. The SenseCam is a camera that you can wear around your neck. When you wear the SenseCam it can take pictures automatically of the places, people and things around you. During this visit you will be shown how to use this camera. If you wish to participate in the study you will sign an informed consent form and you will wear a SenseCam for the duration of the therapy - 7 weeks. You will wear the SenseCam throughout the whole day or as much of the day as you wish or feel comfortable doing.
- After the first visit the therapist and the researcher will call at pre-arranged appointments 45 minutes each – twice a week for duration of 7 weeks. During these visits the therapist will engage you in the therapy which will involve looking at the photographs taken by SenseCam with you and your carer, and engaging in discussion about them.
- You and your partner or next of kin will also be required to keep a journal each reflecting on any observations you might have throughout all sessions during the 7-week period.

Phase 4: After therapy interview

This phase will involve you and your partner or next of kin taking part in an interview. Your medical and social history will also be documented. This will also involve administration of the same set of questionnaires as at the start of the research. The interview will take place over two sessions of one hour each. This interview will be audio-taped. No one will listen to these tapes except the members of the research team listed above. Information will be kept confidential at all times.

III. Potential risks to participants from involvement in the Research Study (if greater than that encountered in everyday life)

We do not envisage any risks that are greater than those encountered in everyday life. However, if at any stage during the interview or the therapy using SenseCam you feel uncomfortable or distressed, you can withdraw without any consequences. In addition, the research team will support you in accessing suitable support systems, including free highly confidential Counselling and Psychotherapy service will be provided through the Healthy Living Centre, at Dublin City University.

IV. Benefits (direct or indirect) to participants from involvement in the Research Study

Currently in Ireland a therapy for memory problems is rarely provided. Participation in this study will provide free intervention for both you and your partner or next of kin. It is possible that there will be direct benefits to you in terms of improved thinking, well-being and maintaining your valued identity. It is also possible that there will be direct benefits to you and your partner or next of kin in terms of social functioning and conversational skills.

V. Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations

If you agree to take part, all information collected will be kept strictly confidential within the limitations of the law. All information will have your name and address removed so as to preserve confidentiality. Any information that will identify you in any way will also be removed.

VI. Advice as to whether or not data is to be destroyed after a minimum period

All the data collected will be stored for a maximum of 5 years. Thereafter the documentation will be destroyed. It is important to recognise that at no stage will the SenseCam photographs be stored in DCU. The photographs will be used only for Cognitive Stimulation Therapy administration. Once the Cognitive Stimulation Therapy is finished you will have a choice to retain some of the photographs for individual purposes.

You may wish to voluntarily give a selection of photographs for research teaching and illustrative purposes. All such photographs will be altered to protect the identity of any person or place contained. For example faces or names on signage will be blanked out and photographs will be shown to you after this has taken place to ensure they are happy with the photograph. Otherwise all images will be deleted.

VII. Statement that involvement in the Research Study is voluntary

You have volunteered to take part in this study. You may withdraw your participation at any time. If you decide not to participate, or if you withdraw, you will not be penalized. There will be no penalty for withdrawing from the study before all stages of the research study have been completed.

VIII. Any other relevant information

If participants have concerns about this study and wish to contact an independent person, please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Office of the Vice-President for Research, Dublin City University, Dublin 9. Tel 01-7008000

Appendix N

Plain language Statement: the carer

PLAIN LANGUAGE STATEMENT: THE CARER

DUBLIN CITY UNIVERSITY

Plain Language Statement

Title of Project:

Case Studies in SenseCam use for Cognitive Stimulation Therapy in memory problems.

Principle Investigators:

Dr. Kate Irving (Tel: +35317007985) EMAIL: kate.irving@dcu.ie

Ms. Paulina Piasek (Tel: +35317007793) EMAIL: paulina.piasek2@mail.dcu.ie

Introduction:

You are being invited to take part in a research study. The research is funded by The School of Nursing and Faculty of Science and Health, Dublin City University. Before you decide to take part or not, it is important that you understand why the study is being done and what it will involve. Please read the following information carefully and discuss it with others, if you wish. If you require further information, or would like to ask any questions, please contact the principle investigators, contact details above.

The primary aim of this research is to explore your partners (person with memory problems) responses to viewing images derived from Microsoft SenseCam, secondary aims include exploring whether the images enable rich opinion based discussion, under what conditions, and whether discussing such images is meaningful and enjoyable. The photographs will be captured on SenseCam.

SenseCam is a lightweight wearable camera which records photographs of your activities throughout the day without you being aware it is working. The dimensions of SenseCam 6.5cm w x 7cm h x 1.7cm the weight is 94g. SenseCam photographs from your daily life will be incorporated into discussions, exercises and activities.

This approach is called Cognitive Stimulation Therapy and aims at general enhancement of thinking and social functioning. SenseCam photographs from your partners (the persons with memory problems) daily life will be incorporated into discussions, exercises and activities. This approach is called Cognitive Stimulation Therapy and aims at general enhancement of thinking and social functioning.



SenseCam

Details of what involvement in the Research Study will require:

Phase 1: Before therapy interview

This phase will involve you and your partner (the person with memory problems) taking part in an interview. Their medical and social history will also be documented. This will also involve administration of questionnaires which will assess things like quality of life and their mood, as well as your strain. The interview will take place over two sessions of one hour each. This interview will be audio-taped. No one will listen to these tapes except the members of the research team listed above. Information will be kept confidential at all times.

Phase 2: Cognitive Stimulation Therapy using SenseCam.

Phase two will consist of a total of 15 visits over a period of 7 weeks.

- The first visit will last approximately 1 hour. You and your partner (the person with memory problems) will be introduced to the SenseCam. The SenseCam is a camera that can be worn around your neck. When the SenseCam is worn it can take pictures automatically of the places, people and things around. During this visit you and your partner (the persons with memory problems) will be shown how to use this camera. If you wish to participate in the study you will sign an informed consent form and assist your partner in wearing the SenseCam for the duration of the therapy - 7 weeks. You will also assist your partner (the person with memory problems) whether to wear SenseCam throughout the whole day or as much of the day as they wish or feel comfortable doing.
- After the first visit the therapist and the researcher will call at pre-arranged appointments 45 minutes each – twice a week for duration of 7 weeks. During these visits the therapist will engage your partner and you in the therapy which will involve looking at the photographs taken by SenseCam, and engaging in discussion about them.
- You and your partner (the person with memory problems) will also be required to keep a journal each reflecting on any observations you might have throughout all sessions during the 7 week period.

Phase 4: After therapy interview

This phase will involve you and your partner (the persons with memory problems) taking part in an interview. Their medical and social history will also be documented. This will also involve

administration of the same set of questionnaires as at the start of the research. The interview will take place over two sessions of one hour each. This interview will be audio-taped. No one will listen to these tapes except the members of the research team listed above. Information will be kept confidential at all times.

III. Potential risks to participants from involvement in the Research Study (if greater than that encountered in everyday life)

We do not envisage any risks that are greater than those encountered in everyday life. However, if at any stage during the interview or the therapy using SenseCam you feel uncomfortable or distressed, you can withdraw without any consequences. In addition, the research team will support you in accessing suitable support systems, including free highly confidential Counselling and Psychotherapy service will be provided through the Healthy Living Centre, at Dublin City University.

IV. Benefits (direct or indirect) to participants from involvement in the Research Study

Currently in Ireland a therapy for memory problems is rarely provided. Participation in this study will provide free intervention for both you and your partner. It is possible that there will be direct benefits to you in terms of social functioning and conversational skills. It is also possible that there will be direct benefits to your partner (person with memory problems) in terms of improved thinking, well-being and maintaining their valued identity.

Appendix O

Informed Consent Form

INFORMED CONSENT FORM

DUBLIN CITY UNIVERSITY

Informed Consent Form

Title of Project:

Case Studies in SenseCam use for Cognitive Stimulation Therapy in memory problems.

Principle Investigators:

Dr. Kate Irving (Tel: +35317007985) EMAIL: kate.irving@dcu.ie

Ms. Paulina Piasek (Tel: +35317007793) EMAIL: paulina.piasek2@mail.dcu.ie

Clarification of the purpose of the research

The primary aim of this research is to explore your responses to viewing images derived from Microsoft SenseCam, secondary aims include exploring whether the images enable discussion, under what conditions, and whether discussing such images is meaningful and enjoyable to you.

Participant – please complete the following (Circle Yes or No for each question)

Have you read or had read to you the Plain Language Statement	Yes/No
Do you understand the information provided?	Yes/No
Have you had an opportunity to ask questions and discuss this study?	Yes/No
Have you received satisfactory answers to all your questions?	Yes/No
Are you aware that your interview will be audio taped?	Yes/No
Would you like to voluntarily give a selection of photographs for research, teaching and illustrative purposes?	Yes/No

Confirmation that involvement in the Research Study is voluntary.

I have read, or had read to me this consent form. I have had opportunity to ask questions about the consent form and all the questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, which respect my legal and ethical rights. I am aware that I may withdraw at any time, without giving reason, and without this decision affecting me in any way. I have received a plain language statement.

Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations.

My identity and other personal information will not be revealed, published or used in further studies. All information will have my name and address removed to protect confidentiality. Any other information that may identify me will also be removed.

Confidentiality is assured but I am aware that confidentiality of information provided can only be protected within the limitations of the law. It is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

Signature:

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project

Participants Signature: _____

Name in Block Capitals: _____

Witness: _____

Date: _____

Appendix P

On-going consent form

METHOD AND DOCUMENTATION OF CONSENT PROCESS FOR INDIVIDUALS WITH IMPAIRED/ABSENT CAPACITY TO CONSENT TO TAKE PART IN THE RESEARCH PROJECT

Participant's name _____

Researcher's name _____

ASSESSING CAPACITY TO CONSENT:

Guidance:

- Begin by assuming individual has capacity to consent to take part, and look for evidence that may prove this in their day-to-day life and care
- Make every effort to communicate with the person to explain what is happening
- Make every effort to try to help the person make the decision or communicate choice using communication aids
- See if there is a way to explain or present information about the decision in a way that makes it easier to understand. If the person has a choice, ask if they have information about the options
- Find out if the person understands what decision/choice they need to make and why they need to make it
- See if the person understands information about the decision and if they can retain it, use it and weigh it to make the decision or choice
- Where capacity fluctuates, see if the decision can be delayed to take time to help the person make the decision, or to give them time to regain the capacity to make the decision for themselves

INITIAL CONSENT

Outline the approach to seeking consent from the client

(make notes on the location, time, information given, props or equipment used, questions and answers)

In what ways did the client indicate their consent?

(Identify verbal, non-verbal and behavioural signs. Does it match up with their usual way of indicating consent?)

Who else was consulted (usually a family member involved in the person's care and interested in their welfare)?

Name_____

Relationship to participant_____

Family member may advise on whether the person who lacks capacity should take part in the project, and what they think the person's feelings and wishes would be, if they had the capacity to decide whether to take part:

ONGOING CONSENT MONITORING

Date and Time notes made:

If you involve the participant in more than one episode of conversation you may need to treat each episode as a new interaction and make additional notes

Was on-going consent provided?

At the end of the conversation / interview the person's level of well-being was:

(Provide a description of behaviour, verbal and non-verbal signs and relative well being level).

Has anyone independently tracked this person's wellbeing during any of the consent process?

(if so make a note of their observations in relation to the person's level of well being/ill being)

Feedback given to carers

(Specify if this was verbal or written)

State why you gave this feedback:

Your key responsibility is to ensure anything the person would wish to be kept confidential remains so

Describe any interactions or interventions you made with the client in order to achieve a transition/return back into another social relationship or their environment of care

Signature of the Researcher:

Date:

Appendix R

Brief Discussion of the emerged emic questions.

1. Will SenseCam therapy encourage discussions about recent memories as cued by SenseCam images within social interactions?

1A) Will the images derived from SenseCam cue the person's recent past and be meaningful and enjoyable to the person with dementia?

This issue was set out to explore if the SenseCam images can act as meaningful cues to the recent past of the participants. This issue was explored by observations and diary entries. The SenseCam images did cue the past and participants accessed memories and discussed them in certain conditions. The three case studies allowed more in depth questions regarding the images and their relations to memory to emerge. They include:

- **SenseCam usefulness in stimulating the semantic as well as the episodic memories?**

Initially it was expected that SenseCam would primarily stimulate the episodic memory. However, SenseCam also encouraged some discussions about semantic facts. It seemed impossible to separate the discussions as often they were interchanging between episodic and semantic resources. This is interesting as the theory of identity formation is based mainly on resources in the episodic memory. However, the episodic memories seem inseparable to the semantic memories when reviewing the images.

Accordingly it was also expected that SenseCam will primarily stimulate the recent memory. However, during the second case study SenseCam also encouraged some discussions about distant past memories. It seemed impossible to separate the discussions as often they were interchanging between distant past and recent events. As in dementia each memory type may be impaired at a different level and some people may only wish to review one type (i.e. recent memories) and not the other. Thus, it is of interest to identify which types of images stimulate each memory type and the associated discussion.

- **SenseCam images special cues to access otherwise inaccessible memories?**

During the third case the therapy sessions revealed that without SenseCam images certain events from Dolores life were never recalled by her and often forgotten by instantly. However, they were still accessible in her memories with cues like SenseCam images. The recall of such events was often very surprising to the participant and thus, poses a question if SenseCam has the potential to cue memories, which are otherwise inaccessible?

- **Does reviewing and discussing events represented on SenseCam images formulate new SenseCam memories? New SenseCam memories or usual episodic memories recalled on repeated events reviews?**

Another interesting pattern was observed during the third case where if the same set of SenseCam images were reviewed twice, the narration accompanying them included discussion parts inputted by the researcher at the initial review. The participant would use the exact same wording as the researcher alongside her own parts. She would also recognise objects, which she could not make out at the initial review. It seemed like a learned of narrative rather than the more natural episodic memories recall that comes with the initial review. This poses an issue of SenseCam images review creating new “SenseCam” memories. Making it very hard to differentiate which ones are being recalled at recurring reviews of same sets of images.

1B) Will viewing the images derived from SenseCam encourage rich opinion based discussion?

This issue was set out to explore if SenseCam images are a good discussion starter as well as if they encourage the participants to share their narratives. Initially this was mainly to be explored through observations of the dynamics of the discussions taking place during the sessions. During the three case studies more questions emerged from the data including:

- **Should just meaningful events be recalled?**

The excitement and anticipation of reviewing images from a meaningful event was very evident pattern observed throughout the therapy. The enjoyment associated with viewing images that were significant to the participant was unlike any other excitement present when reviewing the less significant images. This meant the narratives were much more vibrant and lively. Thus, it is relevant to ask if mainly images from meaningful events should be reviewed. This question poses more issues in itself including: how to identify the meaningful events and what if they don't happen too often?

1C) Does viewing the SenseCam images promote interaction between the person with dementia and their relative (carer)?

As this study was initially set out to include participants who have a carer only, it was important to examine what effect the therapy had on their interactions. Mainly to observe if the interactions were present and whether they were negative or positive in nature. Through exploration of the three case studies other questions emerged, even questioning the necessity of the presence of the carer during the sessions.

- **Is the carer's presence beneficial to the therapy sessions? Should the carer be present during the therapy?**

Initially it was hoped SenseCam could act as way of encouraging discussions and interactions among the person with dementia and their carer or relative. The first case study challenged this as the participants coping mechanism laid in the reliance on his carer's memory. Thus Mary's presence during the therapy made it difficult for John to

rely on SenseCam instead of her. It was mutually decided by the carer and the researcher to exclude the carer from therapy sessions. This resulted in John using images as cues to memory and even encouraged the most open discussions and some narratives about the events. This posed a question on the necessity of the carer being present during the therapy.

- **Can the carer replace the therapist and under what conditions?**

During the third case the sessions involving the carer seemed to work exceptionally well and bring much joy and laughter to the sessions. At times it felt like the therapists' presence was unnecessary. Possible issue is whether the carer can potentially replace the therapist perhaps in the form of maintenance sessions.

2. Will SenseCam use within CST framework work as an intervention aimed at identity maintenance in early stage dementia.

The intervention was designed to provide resources in memory, communication and interaction with an aim to help the person with dementia maintain their identity. While it is important to explore each one of these resources separately as demonstrated above, the overarching question was also explored in detail in the discussion chapter.

3. Why and How to use SenseCam within Cognitive Stimulation Therapy framework as an intervention for Early-Stage Dementia?

This is the first of the issue questions concerning any aspect of delivering the therapy. Initially it was anticipated mainly the frameworks and functional aspects of the delivery of the therapy will need to be explored and clarified. However, as the case studies were explored a number of new emic questions emerged. These included:

- **Is early dementia stage enough of a criterion to determine the suitability of the person to participate in the therapy?**

The first case offered some insight into the criteria of people with dementia the therapy may be suitable for. Initially it was expected that a diagnosis of early stage dementia would be enough to determine such suitability. However, John's case illustrated that despite his early stage dementia confirmed by several psychometric measures his episodic memory of recent events was severely impaired. The impairment seemed too severe for John to gain the maximum potential benefits from the therapy. Suggesting that in the future cases a different manner of establishing the suitability may have to be deployed. The focus may need to lay more on the memory alone rather than an overall dementia stage. Therefore, in the following two cases participants with early stage dementia were still recruited, however their recent memory and ability to recall recent events was taken into consideration. This posed a question on the matter of what should be the participant's profile suitable for the therapy.

- **Is the SenseCam technology too confusing for someone with severe recent memory impairment?**

This question integrates with the first one as it refers to the participant profile. The case of John also highlighted that SenseCam and images were confusing to John because of his severe recent memory impairment, as he could not maintain memory of wearing SenseCam or what it does.

- **Should feedback at midpoint of the therapy be part of the frameworks of the therapy?**

During the first case the carer expressed need for some feedback on any benefits or improvements in her husband the person with dementia midway through the therapy. This need for feedback was explored further in the other two cases.

- **How ethical is it to discuss private details of participants as revealed by SenseCam – that may not otherwise be revealed?**

It was observed during the second case that many personal details were revealed as SenseCam captured them. Before any of the details were discussed a trusting relationship was formed between the participants and me as the therapist. They were very comfortable talking about the intimate aspects of their lives, however they may have never mentioned some of them without SenseCam images revealing them and acting as cues to such discussions. Thus, it may be disputed how ethical is it to discuss such details or under what circumstances is it acceptable to do so.

Participants are already made aware of the possibility of such details being revealed in the plain language statement. Nevertheless, the potential therapists should also be aware that such revelations take place and that discussions should only take place after a trusting, therapeutic relationship is made between them and the participants.

- **Does using SenseCam conflict or complement any existing coping mechanisms to memory impairments?**

When designing the SenseCam therapy many aspects of dementia were taken into consideration. However, some unforeseen aspects were impossible to predict including existing coping mechanisms people with dementia form to deal with their memory impairments. The last case revealed how SenseCam can conflict with such mechanism but can also work to enhance it. Working against a coping mechanism has shown to be the least beneficial or stimulating.

- **Should the SenseCam be worn by the carer also? With clear instructions like “try to sit across the person with memory problems”**

During the first case an enjoyment in the participant when viewing self-portrait images was observed. He was able to associate these images with himself and they often encouraged discussions. John’s memory was too impaired to associate other images with himself or with his recent past. It may be worth exploring if similar enjoyment was present in other participants with less severe impairment of recent memory.

4. **Will SenseCam uses within CST frameworks provide any other benefits to the people with early stage dementia?**

Initially it was planned to obtain the insight into this from different data sources. However, as the case studies were explored it came to light participants did find the therapy beneficial but were unable to explain their reasoning. A new issue emerged to examine if a specific part of the therapy can be identified as most beneficial to the participant? It may be that the therapy is only beneficial when administered as a whole including the social interaction, the discussions, the therapeutic relationship with the therapist and the cues to memory provided by the SenseCam images. Another issue, which was observed, was that the participants reported some anxiety when the therapy was nearing completion. It is important to be aware of such occurrence in order to know how to deal with it.