Re-Purposing My Self:

A Grounded Theory Study of Young Adults' Experiences of Living with Haemorrhagic Stroke

by

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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 *Doctor of Psychotherapy* (DPsych), 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

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Stroke is typically associated with the elderly population but can occur at any age. Worldwide, the absolute numbers of stroke are on the rise, with a notable increase in strokes among young adults. Despite its prevalence, there is a paucity of research specific to the experiences of young adult haemorrhagic stroke survivors. Typically, research has focused on older adults or on the experiences of those who have suffered an ischaemic stroke. Other research does not differentiate between stroke subtypes, despite the fact that risk factors and clinical recoveries differ between ischaemic and haemorrhagic stroke. This study, therefore, aimed to gain a theoretical and a practical understanding of how haemorrhagic stroke impacts the lives of young adult stroke survivors who are living in the community.

This study used a qualitative approach to address this issue and a Classic Grounded Theory methodology was adopted. Six semi-structured, one-to-one interviews were conducted with young adult haemorrhagic stroke survivors, who were recruited on a volunteer basis. Interviews focused on the experiences of the participants following their stroke. The findings from these interview accounts suggest that the sudden impact of stroke had a profound effect on young adult survivors’ sense of self and on their future life-orientation. Without exception, these young adults engaged in a dynamic, non-linear re-purposing process that spans three phases, namely:- 1) reeling from the shock, 2) living cautiously and 3) reshaping life, enabling them to fit in their world as a stroke survivor. The re-purposing process identified from the data, highlighted some key struggles that the participants experienced while living with haemorrhagic stroke. These key struggles represent areas that psychotherapists might usefully address at different stages in the recovery process. Accessible psychotherapy as part of a wider psychosocial rehabilatiation process, informed by this theoretical framework, could, potentially, assist with the re-purposing process and support the needs of young adult stroke survivors and their families at differing times during their stroke recovery. These study findings, albeit based on a relatively small sample, add new insights into our understanding of the needs and concerns of young adult haemorrhagic stroke survivors. This, combined with the theoretical framework proposed here, has implications for future psychotherapy practice, research and policy – some of which implications are identified.

Chapter 1 – Introduction – Outline of the Study

Background

A stroke is an unpredictable, sudden and devastating event that can be defined as *"rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24h or longer or leading to death with no apparent cause other than of vascular origin"* (Aho et al., 1980, p. 114).

Stroke can be of haemorrhagic and non-haemorrhagic (ischaemic) origin (Paolucci, et al., 2003). The National Institutes of Health (The National Institute of Neurological and Communicative Disorders and Stroke) (1975) provide a cerebrovascular classification tool that enables medical professionals to identify cerebrovascular diseases based on the definitions and diagnostic criteria provided. These classifications continue to be adopted worldwide to identify stroke subtypes and other cerebrovascular diseases. Ischaemic strokes are caused by a reduction of blood supply to the brain and are typically caused by narrowing of a blood vessel in the brain or by a reduction in oxygen supply because of the presence of blood clots that limit oxygen supply to vital brain tissue. Clots can form in the brain itself (thrombosis), or they can form elsewhere in the body and then travel to the brain (embolism). Haemorrhagic stroke (HS), on the other hand, is caused by bursting blood vessels within or on the surface of the brain and can occur either as intracerebral haemorrhage (ICH) or subarachnoid haemorrhage (SAH). Transient ischaemic attack (TIA) is a specific form of ischaemic stroke and is characterised by brief neurological dysfunction that typically resolves fully within 24 hours. The Stroke Association in the UK (2018a) advise TIAs are, however, generally considered to represent a warning sign of increased risk of a more serious ischaemic stroke.

Stroke is the second leading cause of death worldwide (Lozano et al., 2012) and the third-ranked cause of disability-adjusted life years (DALY's) lost (Murray et al., 2012). Stroke is, therefore, considered a global health issue (Feigin et al., 2015). Across a continuum, stroke survivors may experience a range of complex difficulties that may restrict their ability to function independently (Stroke Association, 2018a).

Stroke is typically associated with the elderly population but can occur at any age and the absolute numbers of strokes in adults below the age of 65 years are rising (Krishnamurthi et al., 2013). According to recent research, 31% of the global population below the age of 65 years have experienced a stroke (Feigin et al., 2014). Given improvements in survival rates and in terms of medical treatment, these younger survivors are likely to live longer with stroke-related impairments when compared with older stroke survivors (Ellis, 2010).

While ischaemic strokes are the most frequently occurring stroke type worldwide, in both young and older age groups, the prevalence of HS is on the rise in adults over the age of 75 years and in those under the age of 65 years (Krishnamurthi et al., 2013). HS survivors live with greater impairments when compared with ischaemic stroke survivors (Anderson, Olsen, Dehlendorff & Kammersgaard, 2009; Bhalla, Wang, Rudd & Wolfe, 2013; Kelly et al., 2003), yet studies of ischaemic stroke dominate the research literature. Much of this research is also focused on older adults, likely reflecting the high rate of ischaemic stroke in this age cohort.

Regardless of the cause, stroke typically results in a range of physical, cognitive, psychological and psychosocial impacts. Research about the psychosocial impact and emotional impact of HS is typically included or embedded in studies that examine combined groups of haemorrhagic and ischaemic stroke survivors, with little research focused exclusively on HS. Even fewer studies focus on the impact of HS on young adults.

Although there is a growing understanding of the immediate impacts of stroke, the long-term implications of stroke warrant further research attention (Pollock, George, Fenton and Firkins, 2014). According to Casey, Murphy, Cooney and O’Shea (2008), research about the experiences of stroke from the perspective of stroke survivors can be useful in modifying health systems and in developing future policies to meet the needs of this population. Given the paucity of research on the topic, understanding experiences of young adult HS survivors, in particular, may assist with supporting the well-being in a cohort of individuals who are recognised as being particularly vulnerable.

The Current Study

In this study, the post-stroke experiences of young adult HS survivors are explored, using a Classic Grounded Theory (CGT) methodology (Glaser & Strauss, 1967). Grounded theory aims to generate theories that are grounded in the realities of the social world and are considered useful when little is known about the substantive area under study.

Some early studies defined the upper age limit of young adults as 45 years (Leys et al., 2002; Williams, Garg, Cohen, Fleck & Biller, 1997), which then increased to 50 years (Naess, Nyland, Thomassen, Aarseth & Myhr, 2004; Synhaeve et al., 2014) and subsequently to 55 years (Béjot et al., 2014; Lawrence & Kinn, 2013), likely reflecting increased longevity of adults living with stroke-related impairments as a result of improved general and specific healthcare.

Given these changes to the definition of what constitutes a young adult and, in line with other research on young adults following stroke (Hanney, 2012; Hutton & Ownsworth, 2017; Immenschuh, 2003, Kuluski, Dow, Locock, Lyons & Lasserson, 2014; Leahy, 2010; Roding, Lindstrom, Malm & Ohman, 2003), young adult is, for the purpose of this study, defined as people over the age of eighteen years (the standard definition of an adult) and under the age of 55 years (Moncayo-Gaete, Bogousslavky & Levine, 2017).

Stroke and the impact of stroke in this age group (<55 years) differs from stroke and the impact of stroke in in older adults in at least three ways: -

1) As discussed in Chapter 2, the risk factors associated with stroke differ between young and older adults (O'Donnell et al., 2016). The risk factors pertinent to younger adults can be attributed, largely, to lifestyle rather than medical or genetic factors.
2) Young adults are considered to be at their most productive. Rutten-Jacobs et al., (2011) suggest that young adults are typically more independent than older adults and they are invariably at a stage in life where forming relationships and families, making career choices and engagement in social pursuits are important. Therefore, suffering a stroke at a young age significantly impacts these milestones.
3) Young adults live longer with stroke related impairments when compared with the older population (Ellis, 2010) which may, in turn, cause long-term socio-economic consequences and a high public health impact due to increased direct and indirect costs (Benjamin et al., 2017; Emmett, Wang, McKevitt, Wolfe & Stevens, 2017).

Given the shared characteristics of parental, vocational and social roles, this age group can be considered to represent a relatively homogenous group whose post-stroke trajectory might well differ from that of older adults.

In order to explore this issue, six young adults participated in a one-to-one, face-to-face, semi-structured interview, during which time they were asked to recount their experiences of living with HS. The data obtained in these interviews were analysed by adopting a process of rigorous analytic procedures, associated with CGT, including coding of the data, theoretical sampling and theoretical saturation and the constant comparison analytic method. These procedures guided the analysis process toward the emergent substantive theory.

Thesis Layout

Chapter 2 provides an overview of the key aspects of the relevant literature about stroke, with a particular emphasis on the literature pertinent to young adults and HS. Drawing on literature from stroke and the broader acquired brain injury (ABI) field, the psychotherapeutic approaches adopted currently to address the impacts of stroke are summarised, with a view to highlighting how psychotherapeutic intervention(s) might support this population. This chapter also provides a rationale for the current study, together with detailing the study aims and objectives.

Chapter 3 outlines the methodology and methods adopted in the current study. It discusses aspects of grounded theory and provides a rationale for adopting CGT in this study. The chapter also describes the procedures used throughout the study, specific to data gathering, data analysis, quality and rigour and how the identified ethical considerations of this study were managed.

Chapter 4 outlines the findings of the study. These findings are identified as a main concern, a core category and three major categories that are grounded in the data collected from the young HS survivors' perspectives. The main concern captures the central issue for the participants, and the core category describes the non-linear process of resolving the main concern. The major categories are described as three key phases of this process and highlight how the participants experienced living with HS. Although these phases are conceptualised as general patterns of actions and behaviours across all the data collected, numerous quotations from the participants are included in the chapter to highlight similarities and differences between participants' accounts to elucidate their individual experiences.

Chapter 5 grounds the findings of the study in the extant literature and provides a theoretical understanding of living with HS as a young adult. It incorporates a selection of relevant literature that resonates with the findings. The chapter highlights how this theoretical understanding contributes to the psychotherapy field and proposes a framework to support psychotherapists working therapeutically with this clinical population.

Chapter 6 describes the implications of the study relative to psychotherapy practice, training, and future research. Implications for service planning and policy are also highlighted. The strengths and limitations of the study are considered and how the quality of the study was evaluated, as proposed by Yardley (2000) is discussed.

Chapter 2 – Literature Review – Setting the Scene

Introduction

This chapter provides a review of the stroke literature, with a particular emphasis on the literature pertinent to young adults. The chapter begins with an overview of the epidemiology of stroke and the risk factors for stroke, before moving to discuss what is currently known about the life changes of stroke survivors. An overview is then presented of post-stroke rehabilitation, treatment and intervention, with a particular emphasis on psychotherapy as an intervention post-stroke. Because of the paucity of research on young adult survivors of HS, and given the purpose of this study, the literature review focuses predominantly on these aspects of stroke.

Literature Search

A search of the literature was conducted using PsycINFO, PsycARTICLES, CINAHL Complete, Science Direct and MEDLINE for the terms haemorrhagic stroke, hemorrhagic stroke or stroke together with the terms adults OR young adults. Searches were also conducted using the terms acquired brain injury (ABI) and nontraumatic brain injury AND adults OR young adults. Following this, additional key search terms included experiences OR needs OR rehabilitation OR psychotherapy OR counselling OR counseling. A further search using the same search terms was conducted of specific journals (the Journal of Head Trauma Rehabilitation, the American Stroke Journal and the European Stroke Journal). This body of literature is summarised briefly below. Although the central focus of this research is HS in young adults, some studies related to older adults (>65 years of age), and some studies related to ischaemic stroke research are included in this literature review as some stroke experiences may overlap in younger and older cohorts and across stroke subtypes. Additionally, ABI psychosocial and emotional research is also reviewed briefly as the ABI literature shares many commonalities with the literature specific to stroke. Additional literature and topics were sourced from references identified from the reviewed literature, attendance at conferences and recommendations from colleagues.

Stroke – Incidence and Prevalence

Every 2 seconds, someone in the world will experience a stroke (Stroke Association, 2018a). Stroke is considered a global health problem as worldwide, there are approximately 25.7 million stroke survivors, and 113 million DALYs lost to stroke (Feigin et al., 2015). The absolute number of strokes is increasing, as are the survival rates, which, given the impacts of stroke, indicate that stroke survivors are now living longer with post-stroke impairments (Krishnamurthi et al., 2013).

In the US, stroke is the fifth most common cause of death. There are 7.2 million stroke survivors, with 795,000 occurrences of stroke annually – approximately 80% of which are first-time strokes (Benjamin et al., 2017). In Europe, there are approximately 3.7 million stroke survivors (Emmett et al., 2017). Stroke is the fourth most common cause of death in the UK, and there are approximately 1.2 million stroke survivors and 100,000 new stroke cases each year (Stroke Association, 2018a). Here in Ireland, stroke is the third most common acquired disability, with 7,000 new cases hospitalised each year and approximately 30,000 stroke survivors at any given time (National Stroke Audit Rehabilitation Unit, 2016).

Data from the 'Global Burden of Diseases, Injuries and Risk Factors Study 2010' (GBD, 2010) (Krishnamurthi et al., 2013), indicates that the global and regional burden of first-ever ischaemic and haemorrhagic stroke in 21 world regions between 1990-2010 has increased. The study estimated the incidence, mortality, DALYs lost and mortality-to-incidence ratio for ischaemic and HS in high, middle and low-income countries. Stroke incidences have declined, particularly in high-income regions such as Western Europe, North America, Australia and New Zealand. However, the findings indicated that between 1990-2010 the absolute numbers of ischaemic and HS have increased globally by 37% and 47% respectively. Mortality rates for both stroke types increased by 21% and 20% respectively, and DALYs lost increased by 18% and 14% respectively.

On a positive note, the study indicated that the incidence, mortality, DALYs lost and morality-to-ratio incidences related to ischaemic stroke in high-income countries reduced by 13%, 37%, 34% and 21% and the incidence, mortality, DALYs lost and morality-to-incidence ratio incidences related to HS in high-income countries reduced by 19%, 38%, 39% and 27%. Unfortunately, in low and middle-income countries, the incidence of ischaemic stroke increased by 6% and, more significantly, the incidence of HS increased by 22%. The mortality rates, DALYs lost and mortality-to-incidence ratios reduced by 14%, 17% and 16% in ischaemic stroke incidences and the mortality rates, DALYs lost and mortality-to-incidence rations reduced by 23%, 25% and 36% in HS incidences. Risk factors and world regions can account for variations in stroke incidences and are discussed later in the chapter (Feigin et al., 2016). Declines in stroke incidences can be attributed to successful stroke prevention strategies, such as smoking cessation and control of hypertension. The reductions in mortality rates, DALYs lost, and mortality-to-incidence ratios suggest improved healthcare provision globally (Emmett et al., 2017).

Data from the GBD (2010) study indicated that the incidences of stroke increased with age, but the estimates highlighted that, globally, the absolute numbers of both ischaemic stroke and HS increased significantly in adults under 65 years of age. Of particular interest to the current study, the relative frequency of HS to ischaemic strokes in adults under 65 years of age in high-income countries was approximately 1:2. For every two ischaemic strokes, there was one incidence of HS. This contrasts with the relative frequency of ischaemic stroke to HS in older adults – where the ratio is 5:1 for those aged between 65 and 74 years - and is 6.5:1 in those aged over 75 years. In the same younger adult age category, the DALYs lost to HS were almost twice as many as DALYs lost to ischaemic stroke. Thus, although less frequent than ischaemic strokes, HS represent a significant burden. This increase in the relative frequency of HS, absolute numbers of HS and the significant implications associated with DALYs lost due to HS is a cause for concern, particularly in populations aged under 65 years.

Risk Factors for Stroke

As noted above, stroke can present as haemorrhagic or ischaemic (Paolucci, et al., 2003), represent different pathologies and have been associated with different risk factors (O’Donnell et al., 2010). For all stroke types, there are multiple modifiable, and non-modifiable risk factors and these risk factors can be considered triggers for stroke (Boehme, Esenwa & Elkind, 2017).

Determining the risk factors for stroke is important as it can help reduce the burden of stroke. In an attempt to determine the most relevant risk factors for stroke, a two-phase worldwide study (INTERSTROKE study: O’Donnell et al., 2010; O’Donnell et al., 2016) was initiated to identify the global risk factors associated with stroke. Phase one included a case-control study of 3,000 clinical and 3,000 control participants and was conducted across 22 high, middle and low-income countries worldwide (O’Donnell, et al., 2010). The study identified ten significant risk factors for stroke, accounting for nearly 90% of the risk, with each of the ten identified risk factors associated with ischaemic stroke. Table 1 details each of these risk factors, together with the associated odds ratios and population-attributable risks (PAR) for stroke. Notably, just five of the ten risk factors, namely hypertension, smoking, waist-to-hip ratio, diet, and alcohol intake were significant risk factors for ICH.

Table 1: *Risk Factors for Stroke (O'Donnell et al., 2010)*

	Risk Factor	***Odds Ratio (OR) and 99% CI***	***PAR and* 99% CI**
1	History of hypertension*	2·64, 2·26–3·08	34·6%, 30·4–39·1
2	Current smoking*	2·09, 1·75–2·51	18·9%, 15·3–23·1
3	Waist-to-hip ratio*	1·65, 1·36–1·99 for highest *vs* lowest tertile	26·5%, 18·8–36·0
4	Diet risk score*	15·35, 1·11–1·64 for highest *vs* lowest tertile	18·8%, 11·2–29·7
5	Regular physical activity	0·697, 0·53–0·90;	28·5%, 14·5–48·5
6	Diabetes mellitus	1·36,8 1·10–1·68	5·0%, 2·6–9·5
7	Alcohol intake*	1·51, 19·18–1·92 for more than 30 drinks per month or binge drinking	3·8%, 0·9–14·4
8	Psychosocial stress Depression	1·30, 1·06–1·60 1·35, 1·10–1·66	4·6%, 2·1–9·6 5·2%, 2·7–9·8
9	Cardiac causes	2·38, 1·77–3·20	6·7%, 4·8–9·1
10	Ratio of apolipoproteins B to A1	1·89,1·49–2·40 for highest *vs* lowest tertile	24·9%, 15·7–37·1

* significant risk factor for intracerebral haemorrhagic stroke (ICH); CI: confidence intervals; PAR: population-attributable risks

A second phase of the INTERSTROKE study (O'Donnell et al., 2016) was a larger case-control study of 13,447 clinical and 13,472 control participants, conducted across 32 high, middle and low-income countries worldwide. The risk factors for stroke remained consistent with those identified in the earlier study.

As noted above, in the earlier INTERSTROKE study, O'Donnell et al., (2010) highlighted that just five of the ten risk factors for stroke, in general, were significant risk factors for ICH. Of interest, in the updated study, the number of risk factors for ICH increased from five to seven. Regular physical activity, psychosocial factors and cardiac causes now emerged as risk factors and smoking was no longer considered a significant risk factor.

As with the earlier study, O'Donnell et al., (2016) noted some differences in risk factors across different geographical regions. For example, smoking was a dominant risk factor for all strokes globally, but more so in Western Europe, North America, and Australia when compared with Africa. Typically, estimates of smoking are less prevalent in Africa (Ng et al., 2014). This observation of geographical differences was also made in another study from around the same time. Geographical differences in risk factors for stroke were identified by

Feigin et al., (2016), who noted that a diet high in sodium was a risk factor for all strokes in low and middle-income countries and a diet low in vegetables was a risk factor for all strokes in high-income countries. These differences in risk factors and risk factor profiles (hypertension, smoking, diet), environmental and (non)modifiable factors might help explain differences in stroke incidences between different countries and regions. Additionally, differing healthcare services can contribute to these variations (Emmett et al., 2017). Identifying regional variations can tailor stroke prevention interventions to each region, thus, reducing the stroke burden.

Although many of the risk factors for stroke can be considered modifiable risk factors, genetics also play a role and can contribute to the risk of both ischaemic stroke (Markus, 2011) and ICH (Rost, Greenberg & Rosand, 2008). Genetics also play a significant role in the risks for SAH, not covered in the INTERSTROKE studies. As noted in Chapter 1, SAH is a subtype of HS. The frequency of SAH is less common when compared with that of ischaemic stroke and ICH (Feigin, Lawes, Bennett & Anderson, 2003) and this might explain the absence of consideration of the risk factors in those studies. The risk factors associated with SAH are unclear, but systematic reviews identify hypertension, smoking and alcohol intake as the strongest risk factors associated with SAH (Feigin et al., 2005; Teunissen, Rinkel, Algra & van Gijn, 1996) but family history increases the risks of SAH and this risk increases if more than one family member experiences a SAH (Bor et al., 2008).

Congenital predispositions are also risk factors for SAH (National Study of Subarachnoid Haemorrhage, 2006). The presence of aneurysms is a risk factor for SAH as an aneurysm may rupture at any given time (Williams & Brown, 2013). Apart from these non-modifiable risk factors, the three modifiable risk factors for SAH (hypertension, smoking and alcohol intake), overlap with ICH risk factors in the first INTERSTROKE study (O’Donnell et al., 2010) and, with the exception of smoking, overlap with the ICH risk factors in the second INTERSTROKE study (O’Donnell et al., 2016).

Of relevance to this study, O’Donnell et al., (2016) identified not only the ten global risk factors associated with stroke but also the risk factors associated specifically with stroke in younger and older adults. These data are summarised in Table 2.

Table 2: *Risk Factors for Stroke by age group (<55 years and >55 years) (O'Donnell et al., 2016)*

	≤55 years (N=4216)		>55 years (N=9231)	
Risk Factor	***Odds Ratio (OR) and 99% CI***	***PAR and*** 99% CI	***Odds Ratio (OR) and 99% CI***	***PAR and*** 99% CI
History of hypertension or BP of 140/90 mm Hg or higher*	4·51, 3·77–5·41	49·7%, 46.0–53.4	2·55, 2·27–2·85	46·0%, 42·2–49·8
Current smoking	1·66, 1·36–2·02	16·3%, 11·6–22·3	1·70, 1·47–1·97	10·9%, 8·6–13·7
Waist-to-hip ratio*T2 *vs* T1T3 *vs* T1	1·42, 1·15–1·75 1·56, 1·23–1·98	23·5%, 15·2–34·5 T2 + T3 *vs* T1	1·16, 1·01–1·33 1·39, 1·20–1·62	16·0%, 9·7–25·2 T2 + T3 *vs* T1
Diet, mAHEI score*		16·4%, 7·9–30·9 T1 + T2 *vs* T3		26·5%, 20·9–33·0 T1 + T2 *vs* T3
T2 *vs* T1	0·78, 0·64–0·95		0·76, 0·67–0·87	
T3 *vs* T1	0·78, 0·64–0·95		0·56, 0·48–0·64	
Regular physical activity*	0·60, 0·45–0·80	35·3%, 21·0–52·8	0·60, 0·50–0·72	35·9%, 26·4–46·7
Self-reported history of diabetes or HbA1C≥6·5%	1·29, 1·04–1·61	5·6%, 2·5–12·1	1·14, 1·01–1·30	3·6%, 1·4–8·8
Alcohol intake*	1·27, 1·03–1·56 for low to moderate intake 2·20, 1·49–3·23 high or episodic intake	10·9%, 6·1–18·7	1·09, 0·94–1·27 for low to moderate intake 2·14, 1·54–2·96	4·1%, 1·7–9·4
Psychosocial factors*	2·36, 1·60–3·50	22·8%, 14·8–33·3	2·06, 1·59–2·68	15·3%, 10·5–21·8
Cardiac causes*	4·56, 2·81–7·41	4·9%, 3·8–6·3	2·94, 2·45–3·53	10·8%, 9·4–12·4
ApoB/ApoA1 ratio		30·8%, 22·6–40·5 T2 + T3 *vs* T1		25·6%, 20·1–31·9 T2 + T3 *vs* T1
T2 *vs* T1	1·30,1·06–1·60		1·28, 1·13–1·46	
T3 *vs* T1	2·01,1·62–2·49		1·79, 1·56–2·05	
Composite PAR for all ten risk factors		92·2%, 88·8–94·6		90.0%, 87.3–92.1

* significant risk factor for intracerebral haemorrhagic stroke (ICH); T: tertile; CI: confidence intervals; PAR: population-attributable risks

The data indicate that the risk factors for stroke differ, at least to some extent, between the two age groups. By way of example, the odds ratio and PAR associated with hypertension was high in both age groups but hypertension presented as twice the risk in adults under 55 years of age when compared with older adults. Cardiac causes posed a greater risk factor in those aged 55 and below than it did for the older sample (OR: 4.56 –v- 2.94). Diet is a strong risk factor for stroke for adults aged over 55 years but of lesser relevance for the younger group.

Combined, the seven risk factors associated with ICH, in addition to smoking, associated with SAH (Feigin et al., 2005; Teunissen et al., 1996), suggest HS in young adults is largely attributed to lifestyle factors in comparison to the medical and genetic risk factors associated with ischaemic stroke. Therefore, targeted interventions to manage these risk factors, including tailored health, lifestyle and wellbeing programmes, could largely assist with reducing the HS burden and improving stroke prevention in this specific population.

Impact of Stroke

The impact of stroke is devastating to the individual and their family. Stroke survivors typically experience a range of multifaceted difficulties that may impact on their ability to function independently (Stroke Association, 2018a). Such difficulties include physical and cognitive impairment as well as psychosocial and emotional challenges, which are discussed later in the chapter. These difficulties can impact family members - who often take on long-term, or for an extended period of time, caregiving roles to support stroke survivors in their homes and in their communities, which can impact their well-being (Lawrence & Kinn, 2013; 2006; Smith, Lawrence, Kerr, Langhorne & Lees, 2004) and their own economic status (Di Carlo, 2009).

Additionally, the burden of stroke impacts on a wider societal and economic level. In the US, cardiovascular diseases and stroke accounted for 14% of the total health expenditure between 2012 and 2013, which was more than any other diagnostic group. The annual direct costs associated with stroke, for example, hospital fees, medical fees, consultant costs, medication and home help, for the same year were $189.7 billion. The indirect costs (productivity losses) were $126.4 billion (Benjamin et al., 2017). Collectively, the direct and indirect costs associated with stroke in Europe are estimated at €45 billion annually (European Heart Network, 2017). The direct healthcare costs are estimated to be €20 billion annually, representing 44% of the total costs associated with stroke. The annual indirect costs associated with informal caregiving are estimated at €15.9 billion annually (35% of stroke-related costs), loss of productivity caused by death is estimated at €5.4 billion annually (12% of stroke-related costs) and productivity losses associated with disability are estimated at €4 million (9% of stroke-related costs).

The Burden of Stroke in Europe Report (Emmett et al., 2017), which was presented to the EU Parliament, highlighted that the absolute numbers of stroke are rising due to an ageing population and between 2015 and 2035, the number of strokes occurring in Europe is set to rise by 34%. Over the same period, the number of stroke survivors will increase by 25% from 3,718,785 to 4,631,050. Projected estimates suggest DALYs lost to stroke will rise and are set to increase by approximately 41% to a total of 861,878 in 2035. The report also identified the broad categories of difficulties regarding stroke care including lack of awareness of risk factors and stroke symptoms, difficulties accessing rehabilitation and follow-up reviews and lack of robust stroke research.

Feigin and colleagues (2014) speculate that should global trends of stroke incidence, mortality rates and DALYs continue, then, by 2030, the global burden of stroke will increase significantly. As stroke numbers are rising, a greater focus on healthcare and resources is needed to reduce the economic impact of stroke (Di Carlo, 2009). This is of growing concern for our young adults, who are, given current trends and the nature of the modifiable risk factors associated with stroke (O'Donnell, 2010; 2016), increasingly likely to experience a stroke (Krishnamurthi et al., 2013).

Clinical Symptoms – Physical and Cognitive

Stroke survivors, regardless of age, can experience persistent physical disabilities that can affect independent functioning (Stroke Association, 2018b). Hemiparesis, i.e. partial weakness down one side of the body, can be a consequence of stroke and can cause balance difficulties (Dickstein & Abulaffio, 2000) that can affect activities of daily living (ADLs) (Laufer, Sivan, Schwarzmann & Sprecher, 2003) and increase the risk of falls after stroke (Weerdesteyn, de Niet, van Duijnhoven & Geurts, 2008). Hemiplegia, i.e. paralysis down one side of the body, has resulted in stroke survivors losing independence in personal care tasks and ADLs (Lai, Studenski, Duncan & Perera, 2002) and can impact sexual relationships (Chambon, 2011).

A systematic review identifying the incidence of dysphagia, that is, swallowing difficulties, indicate that dysphagia can occur after stroke and can increase the risk of pulmonary complications (Martino et al., 2005) which can increase the risk of mortality and affect quality of life (QoL) (Gonzalez-Fernandez, Ottenstein, Atanelov & Asare, 2013). Sensory impairments are common after stroke and are associated with poor outcomes, typically regarding motor function and QoL (Sullivan & Hedman, 2008).

Cognitive impairment, both short and long-term, is a typical complaint from stroke survivors (Pyun et al., 2009) and can significantly impact ADLs (Jaillard, Naegele, Trabucco-Miguel & LeBas, 2009). Cognitive functioning relates to ones' ability to manipulate information in the world and relies on several functions, for example, memory, attention, information processing, executive functioning and language (Nilsen et al., 2015). The site of the stroke and the severity of the stroke can affect cognitive impairments after stroke (Chaudhari et al., 2014).

Cognitive impairment is not restricted to one deficit in one domain but can present as multiple deficits across multiple domains (Jokinen et al., 2015). Studies have corroborated this and identified multiple post-stroke cognitive impairments across all age groups and stroke subtypes including visuo-executive dysfunction (Delavaran et al., 2017), memory, executive functioning, attention, reasoning, language and problem-solving, (Oh, Park & Seo, 2018). Additionally, there is an increased risk of post-stroke dementia across all strokes (Pendlebury & Rothwell, 2009) and a recent nationwide population-based Danish study of 215,118 clinical and 1,075,588 controls identified that the risk of dementia was more prevalent in HS survivors when compared with ischaemic stroke survivors, and even more concerning, in HS survivors under the age of 65 (Corraini et al., 2017).

Communication difficulties are a common consequence of stroke (Borthwick, 2012). Communication disorders such as aphasia, difficulty with processing and formulating speech and dysarthria, resulting from weak muscles in the speech tract, can cause social isolation (Brady, Clark, Dickson, Paton & Barbour, 2011) and can affect stroke survivors' QoL (El Hachioui et al., 2013). As noted by Hilari (2011), stroke survivors living with aphasia participate less in ADLs and experience psychological distress when compared with individuals who do not have aphasia.

The cognitive impairments noted can be described as invisible difficulties that can create a lack of understanding among stroke survivors and others (Balasooriya-Smeekens, Bateman, Mant & De Simon, 2016). Long-term cognitive impairments can lead to increased dependency needs and greater economic burden on health and rehabilitative services (Jokinen et al., 2015; Zinn et al., 2004).

Post-stroke fatigue (PSF) is a common complaint of stroke survivors, regardless of age and stroke subtype and can persist long-term (Christensen et al., 2008; Duncan, Wu & Mead, 2017; Elf, Eriksson, Johansson, von Koch & Ytterberg, 2016; Lerdal et al., 2009; Maaijwee et al., 2015; Moran et al., 2013). PSF is described as *"…a feeling of early exhaustion with weariness, lack of energy and aversion to effort that develops during physical or mental activity and is usually not ameliorated by rest"* (Staub & Bogousslavsky, 2001, p. 75). Clinically, symptoms of PSF are often underestimated. However, PSF can have an impact on stroke survivors' ability to participate in ADL's, such as returning to work - which can negatively impact stroke survivors' QoL (Glader, Stegmayr & Asplund, 2002). In the context of the current study, PSF in young adults can interfere with the personal, vocational and social aspects of life and can cause emotional distress with survivors feeling misunderstood by others (Carlsson et al., 2004; Roding et al., 2003).

Schepers et al., (2006) examined the course of fatigue in survivors in their first year following stroke. In their study, 167 Danish stroke survivors who experienced a supratentorial stroke reported increased fatigue as they attempted to resume vocational and social roles. Post-stroke fatigue was also considerably greater among survivors who were experiencing depressive symptoms and ill health. Older females were more inclined to experience post-stroke fatigue but the influence of other variables such as physicality, sleep disturbances and medication use were not examined as part of the the study.

A meta-synthesis review of qualitative research exploring PSF from stroke survivors' (n=229, of all ages) experiences identified twelve American and European studies pertinent to this issue between 2002-2012 (Eilertsen, Ormstad & Kirkevold, 2013). The review identified five core characteristics that were associated with PSF, regardless of context. These were: lack of energy to perform activities, being easily tired by activity, an abnormal need for rest or sleep, unpredictable feelings of fatigue without explanation and increased sensitivity to stress. Two additional characteristics were identified and related to how stroke survivors manage fatigue. Fatigue management was less challenging if stroke survivors received support from significant others when adopting stratgeis to reduce fatigue including rest, altering priorities, finding new meaningful activities and decreasing activities. If fatigue symptoms remained unacknowledged by significant others, the stroke survivors experienced higher levels of emotional distress including frustration, anger and guilt. Collectively, these core characteristics highlight how PSF influences survivors' life experiences post-stroke and highlights a pivotal invisible difficulty associated with stroke. A limitation of this review is the lack of contextual detail included in the studies. For example, age, gender stroke sub-type and social and ethnic background information was not provided, all of which can influence PSF. Additionally, the limited number of studies in this meta-synthesis suggest this PSF characteristics model should be treated as a preliminary model and further research into PSF is needed.

A more recent and larger systematic review of PSF included 98 qualitative studies carried out internationally between 1999 and 2015 (Ponchel, Bombois, Bordet & Henon, 2015). Of these 98 studies, only two had been identified in the Eilertsen et al., (2013) review. In addition, a number of studies identified in the first review were not identified in the latter, raising questions about the adequacy of the search strategy adopted in both reviews. Notwithstanding this issue, Ponchel et al's review reflected the findings from Schepers et al., (2006) whereby older females were most impacted by PSF. The review also highlighted that PSF, caused by multiple factors, is a common, debilitating consequence of stroke. Of interest, sociodemographic and neurological factors were deemed not to have a direct impact on PSF. In contrast, lifestyle factors and cognitive impairment were considered important factors that influenced PSF.

Taken together, the findings from the literature indicate that the burden associated with 'invisible' impairments following stroke is unpredictable and individual. These impairments are persistent issues that impact upon participation in ADL's and influence QoL, particularly for young adult stroke survivors, and this warrants greater attention from the medical professionals and rehabilitation and community services.

Psychosocial and Emotional Difficulties

The experience of having a stroke goes beyond the physical and cognitive impacts on the individual. A review of the literature pertinent to the psychosocial and emotional sequelae of stroke reveals a range of multi-layered and complex issues that impact on the stroke survivor, their family and, in a broader context, society.

In 2009, a Swedish national survey was conducted investigating the perceived physical and cognitive impact of stroke in adults aged between 18-55 years (Roding, Glader, Malm, Eriksson, Linsstrom, 2009). In total, 1,068 respondents participated in the study and these individuals were between eight and 36 months post-stroke. The mean age of the respondents was 48 years. Of these, 82% (n=706) suffered an ischaemic stroke, 15% (n=132) suffered an ICH and 3% (n=29) indicated an unspecified stroke. The most commonly reported difficulties were physical (reduced participation in personal ADL's, balance, speech, headaches, pain and visual impairment). 60% (n=641) reported cognitive difficulties (concentration difficulties, difficulties completing tasks, navigating crowded environments and managing social interactions). Fatigue was also identified as an issue for the respondents.

A UK-based Stroke Survivors Needs Survey (McKevitt et al., 2010) was conducted in London and Oxford, to ascertain the long-term needs of stroke survivors. A total of 799 respondents took part in the study of which 30% (n=240) were under 65 years of age. The length of time since the stroke onset ranged from one to over five years. Emotional difficulties, fatigue and concentration difficulties were the most frequently reported difficulties associated with stroke. In terms of occupational status, 52% (n=415) of the respondents had not returned to work and, as a result, a significant number of experienced financial difficulties (n=344: 43%). Regarding expenses, 31% (n=248) confirmed that their expenses increased following a stroke. A total of 42% (n=336) confirmed that the stroke significantly impacted their spousal relationship and 26% (n=208) confirmed their social relationships were negatively affected.

As found in the previous surveys, results from a nationwide Irish study, which investigated the experiences and long-term needs of community-dwelling stroke survivors, identified similar difficulties, despite the smaller sample of respondents. A total of 196 respondents, aged between 24-89 years (mean age – 61.9 years) participated in the study (Walsh et al., 2013). The average length of time since the stroke onset was 28 months (ranged between three months and nineteen years). The respondents identified physical difficulties (mobility and arm dysfunction), cognitive difficulties (concentration), fatigue and emotional difficulties as the most common consequences post-stroke. Personal ADLs were impacted for 52% (n=101) of the respondents, and 66% (n=130) identified that they now required support in completing household tasks, such as cooking, cleaning and shopping. Regarding relationships, 42% confirmed the stroke significantly impacted their spousal relationship. However, 40% also acknowledged support from family and friends aided the recovery process. In terms of impacts, 40% had not returned to driving, 60% confirmed their leisure activities significantly changed and half of these respondents (n=60) confirmed that the stroke had a negative impact on their social life. Of note, 103 of the respondents were under

66 years of age at the time of study and 77% of them (n=79) had not yet returned to work. Regarding finances, 57% confirmed that their finances were negatively impacted as a result of a stroke as their salary decreased due to inability to resume employment and an increase in their ongoing post-stroke expenses. This Irish study also identified supports required to assist stroke survivors in their recovery. In relation to needs, 20% (n=41) of the respondents confirmed the need for specific stroke-related supports, such as physiotherapy, cognitive rehabilitation and regular follow-ups.

Taken together, these three surveys highlight similar psychosocial difficulties across all ages and stroke sub-types. These surveys, from stroke survivors' perspectives, highlighted that stroke survivors experienced persistent physical, cognitive, psychosocial and emotional difficulties that extended beyond the short-term. These difficulties impacted both the individual, their family. Additionally, the economic burden of life after stroke was significant.

It is plausible to assume that surveys in stroke research were and continue to be an essential forum to identify post-stroke needs from survivors' persepectives. These surveys were not, however, validated instruments but were, rather, developed specifically for these studies. They typically included pre-determined questions about health, everyday living, work and leisure, relationships and finances and may not have necessarily explored the concerns of the target audience or captured changes over time or the processes the stroke surivors engaged in. Roding et al's. (2009) survey was even more limited, surveying respondents only in the areas of physical and cognitive function. This survey did, however, focus exclusively on stroke survivors between the ages 18-55 years, which is of direct relevance to the current study.

According to Barclay and Tate (2014) however, stroke survivors' responses can change over time, likely reflecting changes in life priorities at different times in survivors' individual recovery process. These needs however, may not be altogether related to stroke but also additional life circumstances. Also, capturing in-depth experiences, which contribute to survivors identifying their post-stroke needs, is not captured in detail in surveys, i.e. the processes by which stroke survivors engaged in as part of their recovery.

The adoption of qualitative methodologies invites stroke survivors to discuss more fully their stroke experiences / stroke issues. Up to two years post-stroke, qualitiative reseachers have captured a number of issues that have arisen from the perspective of the stroke survivors.Not unexpectedly, one of the most recurring themes in the stroke literature, particularly the qualitative stroke literature, is the loss of identity / self due to the consequences of stroke, regardless of time since stroke onset, age, gender or stroke subtype. This can create uncertainty about the future (Carlsson et al., 2009; Hjelmblink & Holmstrom, 2006) and the implications of such a loss can be long-term (Ellis-Hill & Horn, 2000).

To elicit the experience of stroke survivors at ten months post-stroke, Pound, Gompertz and Ebrahim (1998) explored the experiences of 21 men and 19 women between the ages of 40-87 years (mean age 71 years) from the east end of London, UK using depth interviews. These interviews enabled the participants to have more autonomy during the interview process. In this phenomenological study, the participants all reported a loss of valued roles including roles within and out of the home. Difficulties with personal ADL's and communication and memory impairments contributed to feelings of living in an altered body and ultimately impacted the survivors' sense of self. The sample was not overly large but did give an indication of the difficulties experienced by community-dwelling stroke survivors during the first year post-stroke. The sample was, however, primarily comprised of older stroke survivors (>70 years) who were considered to be more impacted by their strokes than others. Additionally, the stroke subtype was not identified so it is not possible to identify any stroke subtype differences.

These findings by Pound et al., (1998) are reflected in other short-term phenomenological studies (Eilertsen, Kirkevold & Bjork, 2010; Hawkins et al., 2017; Kirkevold, 2002; Pallesen, 2014). To explore the illness trajectory during the first year post stroke, Kirkevold (2002) adopted a repeated in-depth interview with nine Norwegian community-dwelling stroke survivors (six men and three women). The ages ranged from 40-83 years with a mean age of 67.8 years, and all participants undertook repeated in-depth semi-structured interviews during their first year post-stroke. The stroke subtype was not specified, although the author did identify the laterality of the stroke in eight participants and she identified that for the ninth participant the stroke occurred in a posterior skull location. The study revealed that the adjustment process during the first year after stroke is gradual and it occurs in phases. Kirkevold identified four phases associated with the trajectory of stroke namely; 1) trajectory onset – one to seven days, 2) initial rehabilitation – one to eight weeks, 3) continued rehabilitation – two to six months, and 4) semi-stable – six to twelve months. The participants experienced uncertainty and frustration while adjusting to their stroke-related difficulties and this later subsided with an increased understanding of stroke. Of interest, the study identified that the stroke was not initially experienced as a crisis event until the latter phases as the participants' lives and the participants' sense of self changed significantly during this time. These findings suggest the stroke recovery process is a linear, time-limited process. Although the repeated interviewing approach enabled Kirkevold to gain in-depth knowledge of the recovery process during the first year post-stroke, the sample cannot be considered representative. The sample was recruited from two medical and rehabilitation centres in Norway. All patients availed of rehabilitation services and, as such, the findings cannot be generalised to survivors who did not receive post-stroke rehabilitation.

Eilertsen, Kirkevold & Bjork (2010) conducted a phenomenological study, adopting multiple (12-14) semi-structured interviews with six Norwegian older female stroke survivors (aged between 68-83 years, mean age – 74.3 years) living in the community. Their aim was to explore their post-stroke experiences and their recovery process within the first two years of the stroke onset. The sample comprised of ischaemic stroke survivors only but identified four phases of a stroke trajectory over a two-year period from the stroke onset. For example, Phase 1) focusing on bodily changes within two months from the stroke onset, Phase 2) focusing on activities of daily living between two and six months, Phase 3) self-understanding between six and twelve months and Phase 4) going on with life between 12 and 24 months. The study identified the stroke recovery as an evolving, emotional process filled with worry, uncertainty and adjustment. The loss was experienced primarily in the latter phases, and the survivors required practical and emotional support to cope with the changes associated with the self. Similar to Kirkevold (2002), these findings suggest the recovery process is linear and time limited. However, despite this study comprising of a relatively small sample, the multiple interviews adopted with each participant generated in-depth and detailed knowledge of their recovery processes during the first two years post-stroke. Of note, the sample did not include stroke survivors who experienced a severe stroke and, as such, the findings of the study are not generaliseable to the wider older female stroke population. Further research with this specific population could identify the needs of the older female stroke survivor.

A Danish phenomenological study set out to identify how stroke survivors viewed themselves after stroke, how they perceived their disability and how they managed at follow up - five years after the event (Pallesen, 2014). The study included fifteen ischaemic and HS survivors; ten of whom were men and five who were female. The age range was 42-84 years (mean age – 62 years). The data identified three themes, 1) bodily experiences, 2) coping and 3) an altered life. These themes encapsulated a continuous process of change. The survivors felt vulnerable in their bodies, which they perceived to have aged prematurely. They experienced reduced functionality, which significantly impacted their identity. Internal and external resources such as perseverance, stubbornness and family support aided the recovery process. As the study included survivors who experienced mild-severe strokes, the study illuminated that identity changes post-stroke is a long-term dynamic process, regardless of stroke subtype and stroke severity. The authors identified that some participants had severe cognitive difficulties that affected their recall of events. To compensate for this, participants' carers provided an account of the events and, as such, the analysis cannot be considered to be a precise application of the phenomenological study. Despite this criticism, the study does serve to encourage other researchers to look at tailoring research to suit the needs of stroke survivors, particularly those who experience severe stroke impacts.

Hawkins et al. (2017) conducted a grounded theory study adopting in-depth interviews, solicited diaries and network mapping, to explore the long-term trajectory of stroke. The study sample included 22 community-dwelling stroke survivors (n=14 males; n=8 females), aged between 50-89 years, and twelve carers. The stroke subtype was not specified and the average length of time from the stroke onset was fifteen months (ranged between fourteen and 24 months). The UK study identified four phases of the trajectory of stroke namely, 1) meaningful recovery, 2) cycles of meaningful recovery, 3) ongoing disruption and 4) gradual, ongoing decline. The study highlighted the recovery process as a continuous process that was shaped by the participants' evolving sense of self post-stroke. The meaning of stroke at their time of life also shaped the participants' sense of self. Feelings of loss persisted as the participants forged meaningful relationships and roles while they simultaneously learned to manage their difficulties. Similar to Pound et al., (1998), this study identified that the stroke survivors who were experiencing an ongoing decline did not relate this decline specifically to the stroke. They acknowledged that other lifestyle factors may influence the decline. Within the context of their study, it is certainly possible that the ageing process itself might have an impact of the survivors' health. Eighteen of the participants were over the age of 60 years.

There are a number of methodological strengths to Hawkins et al.'s (2017) study. The authors provided a sound application of grounded theory and adopted multiple approaches to gather as much information as possible. Another strength of the study is the inclusion of the carers in the research. This enabled the authors to generate a theory that was grounded in both the survivors' and the carers' perspective. This is encouraging as Hawkins et al. acknowledged that the stroke not only impacts the survivor but also the people involved in their lives post-stroke. A limitation of the study was that mood was not explored in-depth with the participants. Pan, Song, Lee & Kwok (2008) identified that mood significantly impacted older stroke survivors QoL more so than did the ability to carry out ADLs or the severity of the survivors' limitations. As mood can impact and influence the recovery process, additional research exploring this topic is warranted.

Collectively, these studies highlight a number of difficulties community-dwelling stroke survivors experience in the short and medium-term following stroke. Similar findings have been identified in other studies that explore the long-term impacts on community-dwelling stroke survivors.

In a UK study, Murray and Harrison (2004) explored the lived experiences of ten stroke survivors (four males and six females) aged between 38 and 81 years (mean age – 48.8 years) who were over two years post-stroke. The average length of time since the stroke onset was nine years (between four and twenty years). The stroke subtype was not specified. This phenomenological study adopted semi-structured interviews with five participants and email interviews with a further five participants. The use of email interviews has been found useful in including persons with disabilities in research, particular when discussing sensitive or personal topics (Murray and Sixsmith, 1998). However, this method of data collection did not create the same opportunities for observation and non-verbal communication that would have been facilitated in the face-to-face interviews. Nevertheless, from the ten participants, themes of disrupted embodiment and loss of self, emotional difficulties, difficulties with both gendered and sexual relationships and social interaction challenges were identified. The participants reported difficulties with physically adapting to the stroke and re-engaging in pre-stroke activities and skills that were subsequently lost. This affected the stroke survivors' sense of identity and there were profound feelings of loss associated with the stroke impacts while trying to navigate between their pre and post-stroke lives.

To understand what aids the stroke recovery process, Ahuja et al. (2013) explored the experiences of stroke survivors living in the South Island of New Zealand. For the purpose of their study, eleven participants, ten men and one woman aged between 49-72 years (mean age – 58.9 years), were interviewed. This study adopted a general inductive method of analysis and identified the recovery process as a long-term individualised process of self-exploration that is personal and varied. The participants identified social support, goal setting, accepting their new-found limitations and adopting coping strategies as factors that aided their recovery journey to finding a new self. As this study focused primarily on men, the extent to which the study findings apply to women is unclear and the study did not specify the length of time since the stroke. Additionally, as the study did not specify the stroke subtype, the extent to which findings can be applied to both ischaemic and HS stroke is not clear. The length of time since the stroke onset was not provided thus restricting the clinical implication for their proposed recovery phases. However, this sample was comprised of survivors of diverse ethnic groups who experienced a mild-severe stroke. As a result, the findings can be generalised to the wider stroke population in the South Island of New Zealand. Given the ethnic diversities between the North and South Island, the generalisability of the findings to the North island warrant further research.

Arntzen, Borg and Hamran (2015) explored the long-term trajectory of stroke using a longitudinal qualitative design. Nine stroke survivors (six men and three women) aged between 39-66 years (average age – 56.55 years) and thirteen carers took part in this study. The stroke subtype was not specified, but the authors identified the laterality of the strokes. Six had a right hemisphere stroke, and three had a left hemisphere stroke. The average length of time since the stroke was approximately six years (between six months and twelve years). This Norwegian study identified three phases related to the stroke trajectory; 1) modified habitual body, 2) repositioned participation in everyday contexts and 3) transformed sense of self. The study identified that post-stroke changes significantly impacted stroke survivors' bodies, their ability to participate in ADLs' and their sense of self which persisted over an extended period of time. This exploration of self was influenced by setbacks and facing new challenges, indicating a non-linear post-stroke recovery process. Pallesen (2014) and Hawkins et al., (2017) reflects these findings, which contradicts the earlier Norwegian works of Kirkevold (2002) and Eilertsen et al., (2010), indicating a greater understanding of stroke recovery and stroke recovery in the long-term.

Erikson et al. (2016) presented the findings of a qualitative longitudinal study of eleven Swedish stroke survivors aged between 50-67 years. In their study, which used a phenomenological approach, they looked at the impact of stroke on everyday life between eleven and thirteen years after a stroke. This study was a sub study of a larger ABI study. Their data revealed ongoing, long-term implications of stroke including loss of previous life, struggling to reclaim former existence and finding meaning in a new, different world. Based on their data, they concluded that the major challenge for these survivors was finding a new self while experiencing persistent physical impacts which prevented them from engaging fully in their pre-stroke lives or engaging in meaningful activities post-stroke. The subtype of stroke was not indicated, however, so it is not possible to determine whether between-group differences exist.

Nasr, Mawson, Wright, Parker and Mountain (2016) adopted a narrative inquiry with five stroke survivors and three carers in the UK, to explore their post-stroke experiences. This methodological approach was a refreshing change from the previous phenomenological and grounded theory approaches in that the narrative inquiry enabled the interviewers to facilitate a more holistic approach in gaining a greater understanding of survivors' post-stroke experiences. Narrative inquiry was successfully applied to the stroke population previously and invited stroke survivors to engage in a story-telling process about their lives (Van der Riet, Dedkhard & Srithong, 2012). The data identified that the survivors' experiences were rooted in the reinterpretation of life based on their new situation. The survivors' identities and roles significantly changed as did their relationships with others and these changes were based on the changes associated with their bodies post-stroke. The gender, age and stroke subtype were not, however, specified in the study. This reflects similar findings of Arntzen et al., 2015, Erikson et al., (2016), Murray and Harrisson (2004) and Pound et al., (1998), indicating that persistent physical impacts of stroke and lack of meaningful activities directly influence the sense of self and identity in the short, medium and long term for stroke survivors. The findings are based on a small sample size but a narrative inquiry was adopted in this study to gain further understanding of the lived experience and not for generalisability of findings.

Collectively, the studies reviewed here provides a synthesis of international data from multiple sources. The qualitative methodology provides an opportunity to review the in-depth factors related to the experiences post-stroke from the survivors themselves. Included studies represent community-dwelling stroke survivors short, medium and long-term experiences of living with a stroke. The studies include participants from a variety of age categories and stroke subtypes which has improved the transferability of findings to community settings. There are some limitations already identified. The most recurring limitation in studies was the lack of clarity regarding the sample. The stroke sub-type was not identified in six studies (Pound et al., 1998, Hawkins et al., 2017; Murray & Harrisson, 2004; Ahuja et al., 2013; Erikson et al., 2016 & Nasr et al., 2016). One study included ischaemic stroke survivors only (Eilertsen et al., 2010) and one study included a mixed ischaemic and HS sample (Pallesen, 2014). Two studies identified the laterality of the stroke (Arntzen et al., 2015; Kirkevold, 2002). Additionally, there was a lack of contextual detail in one study (Naser et al., 2016) and the mixed ages in all the studies suggest the experiences reflected in the findings are an under-representation of the experience of stroke from survivors' perspectives. While the methodological approaches undertaken appear sound, reference to reflexivity (an important aspect of qualitative research) was only identified in one study (Hawkins et al., 2017). However, the overall findings from the studies draws on a broad range of detailed stroke survivors' experiences and provided a reality that is adult stroke survivors experience a profound change in their sense of self that requires a continuous process, over time, of adaptation, adjustment and transformation.

In the context of the current study, the extent to which these issues are particularly pertinent for younger adults has not yet been fully addressed, nor has the issue of whether HS presents specific additional challenges. Therefore, it is not possible to determine whether young adults differed in any way from older adults or if there were significant impacts associated with HS. Thus, the initial motivation for this study. Table 3 below summarises the relatively sparse literature that addresses the impact of stroke on young adults specifically, highlighting further the lack of research on young adults who have experienced a HS.

Table 3: *Qualitative research studies undertaken specifically with young adult stroke survivors*

Year	Authors	Country of Study	Participant Current Age (yrs)	Sample Size	Gender	Stroke Subtype	Time since stroke (yrs)	Research Method	Key Research Aim	Main Findings
2003	Immenschuh	Germany	18-51 (mean age=35)	11	M (n=6) F (n=5)	Ischaemic	1	Interpretive Phenomenological Analysis	To develop an understanding of the experiences of having an IS from the perspective of those under 55years	Young adult stroke survivors experience an interruption of self after an event typically associated with the elderly. The stroke disrupted two main areas – time and being normal. Difficulties with vocational and social roles in addition to the uncertainty of experiencing a further stroke were difficult and lonely challenges to overcome. The stroke was considered a turning point as participants perspectives and tendencies shifted at 3,6, and 12 months post stroke. Managing the disruption of the stroke and accepting themselves as post-stroke was highly individual.
2003	Roding et al.	Sweden	37-54 (mean age=43.2)	5	M (n=3) F (n=2)	N=3 left hemisphere lesion N=2 right hemisphere lesion	1-1.5	Thematised in-depth interviews using the constant comparison method	To describe and analyse how younger stroke patients had experienced rehabilitation and the time after stroke and to develop a hypothesis about their life situation	The participants felt frustrated and invisible after the stroke. Fatigue caused difficulties with returning to work and family/social relationships. Gendered roles such as females as homemakers and males as providing financial stability were problematic post-stroke. Rehabilitative services were not age-adapted and did not meet the participants' needs, citing a lack of information and age-related interventions as sources of frustration. Age and gender have an impact on rehabilitation outcomes. Issues pertinent to young adults specifically, after stroke, can be detected earlier with the development of appropriate instruments for these issues.
2005	Stone	Scotland,	19-57	22	F	Haemorrhagic	3-34	Constant Comparison Method	To discover the meaning(s)	The participants were shocked as

Year	Authors	Country of Study	Participant Current Age (yrs)	Sample Size	Gender	Stroke Subtype	Time since stroke (yrs)	Research Method	Key Research Aim	Main Findings
		England, United States, Canada	(mean age=41)						that survivors attach to their stroke experiences and understanding this within the context of their lives, and to discover the extent to which there are commonalities and differences regarding experiences and issues of concern	they experienced a stroke, which they typically associated with the elderly. Others not recognising their disabilities was a source of frustration for the participants. Participants justified or concealed their difficulties from others and others expectations of them were unrealistic, due to others not recognising the invisible difficulties. As a result, the participants limited their social experiences. Rehabilitation services must take into account that young female stroke survivors are negotiating their everyday lives in a social context and stroke survivors should be counselled on what to expect to improve their QoL.
2010	Leahy	Ireland	20-48 (mean age=34.4)	12	F	Not specified	7 mths-3.3	Interpretive Phenomenological Analysis	To explore the experiences and psychosocial impacts of stroke in young women	Four super-ordinate themes emerged from the data 1) stroke as a disease of the elderly, 2) post-stroke selves, 3) a desire for peer support and 4) the impact of stroke on relationships. Getting a stroke diagnosis was difficult due to their young age. The participants were shocked at a stroke diagnosis, an illness typically associated with the elderly. The participants felt isolated in their stroke recovery, particularly living with an older person’s illness and desired the support of others in similar situations. Significant social support was needed which was, at times, suffocating. The stroke positively and negatively impacted familial and social relationships. Age-adapted facilities, service and advice was recommended to support the needs of young adult stroke survivors.
2012	Hanney	Ireland	30-49	11	M (n=2)	Not specified	1.5 (mean)	Interpretive Phenomenological	To explore the experience	Four super-ordinate themes were

Year	Authors	Country of Study	Participant Current Age (yrs)	Sample Size	Gender	Stroke Subtype	Time since stroke (yrs)	Research Method	Key Research Aim	Main Findings
			(mean age=41)	(+4 spouses, mean age 43yrs)	F (n=9) M (n=4)			Analysis	and psychosocial impacts of stroke amongst young adults and the impact it has on spouses of stroke survivors.	identified as 1) sudden and unexplained - will it happen again? 2) changes in daily life, 3) trying to get better and 4) relationship changes. Frustration, distress and fatigue were common emotional difficulties recounted by the survivors. Persistent cognitive impairments prevented them from participating in ADL's. Familial, vocational and social roles and responsibilities significantly changed which caused anxiety. The positive implications of stroke included improved spousal relationships and reappraisal of life priorities. Spouses experienced loss and change associated with taking on a carer role. These relationships later evolved and were more positive when the stroke symptoms resolved somewhat. Greater recognition of cognitive impairments from rehabilitation staff was recommended as was education and formal counselling to reduce anxiety. Practical and emotional support for spouses was suggested.
2014	Kuluski et al.	United Kingdom	23-55 (mean age=46.5)	17	M (n=6) F (n=11)	Ischaemic /Haemorrhagic /Transient Ischaemic Attack	1-12	Directed Content Analysis	To understand the impact of stroke on young survivors in addition to how they cope with the changes.	Two themes that emerged from the findings were 1) an altered self and 2) an adapted self. The impact of stroke significantly disrupted young adults' life trajectory. They experienced a loss of identity, family disruption and / or loss of valued roles. Persistent stroke symptoms impacted ADL's. This was a source of frustration and lead to low motivation, low patients and confidence resuming ADL's. Future plans became uncertain. Family, friends, peer support groups and employers were considered beneficial in

Year	Authors	Country of Study	Participant Current Age (yrs)	Sample Size	Gender	Stroke Subtype	Time since stroke (yrs)	Research Method	Key Research Aim	Main Findings
										adapting the self post-stroke. Aiding the recovery process. Re-establishing roles in the home, workplace and community were common in restoring normality post stroke. A holistic model of rehabilitation was recommended to support stroke survivors to regain capacity for ADL's and address the emotional impact of stroke, restore wellness and reduce the family burden associated with stroke.
2017	Hutton & Ownsworth	Australia	26-70 (mean age=47.2) *P's experienced their stroke before 55 years	10	M (n=3) F (n=7)	Ischaemic /Haemorrhagic	6 mths-31	Phenomenological Approach Idiographic and Nomothetic Analysis	To explore the experience of sense of self and continuity in younger adults after stroke.	Two super-ordinate themes were identified; 1) the centrality of stroke and 2) the impact of stroke on self. The connection between the centrality of self and impact of self was individual and influenced by time, the severity of the impairments, stroke recurrence, life stressors and engaging in activities or life contexts. These young adults could simultaneously experience a continuation of self without significant disruption, an interruption of self and a growth of self. Some participants experienced a continuation of self, by learning to adapt to their changing situations and integrate the stroke in to their life stories. Others felt their self was 'interrupted' and referred to physical, psychological and vocational/ social losses. Psychological support was recommended to support young adults to make sense of their stroke experiences and integrate these experiences into their life story, thus strengthening their self-coherence.

As seen in this table, a number of qualitative studies explored the experiences and needs of young adult stroke survivors.

Immenschuh (2003) aimed to develop an understanding of the experience of ischaemic stroke from the perspectives of young adults (<55years). Six male and five female survivors, with an average age of 35years (18-51 years range), participated in the study. All participants suffered an ischaemic stroke between January 2000 and March 2001. Interviews were conducted with each participant at three, six and twelve months after their stroke and were analysed using IPA. The findings suggest that the stroke interrupted the participants' sense of time and their sense of self as being normal. The participants struggled with the interruption to their self as they experienced an event that they typically associated with the elderly. The stroke caused the young adults to break from the normality of life. The recovery trajectory depicted in the study suggests the participants tried to return to their pre-stroke lives at three months post-stroke. At six months post-stroke, the participants focused on their current challenges and incorporated their insights of their limitations into their post-stroke lives and at twelve months post-stroke, the participants were ready to look to the future. Some post-stroke difficulties such as managing work environments, fear of a second stroke and the desire to be treated as 'normal' were difficult and lonely for the participants. The stroke was, however, considered a turning point as there was a tendency to shift perspectives and rethink priorities. Resuming valued roles, particularly vocational roles, were considered important to the participants as they wanted to be treated as being normal and not as someone who experienced a stroke. Immenschuh suggests the disruption caused by the stroke, how it was managed and how the participants accepted themselves as post-stroke was highly individual during the first year since the stroke onset. She recommended that individualised and sensitive assessment of needs and planning of services to support young adults come to terms with their stroke was needed.

The longitudinal design and homogenous group of ischaemic stroke survivors in Immenschuh's (2001) study clearly demonstrated the peaks and troughs young adult stroke survivors experienced within the first year post-stroke. The application of IPA was considered to be that of quality and rigour that produced credible findings pertient to this specific cohort. The author was reflexive in her approach and acknowledged how she, as insider researcher, impacted the study. However, a limitation of this study is that of sample bias. The participants were recruited from a specialist stroke unit in Germany and young post-stroke adults who were not admitted to this unit were excluded. Bishop and Bushnell

(2017) acknowledge that rehabilitation supports stroke survivors to manage their new-found challenges post-stroke. Therefore, individuals who participate in rehabilitation, as was the case in Immenschuh's (2001) study, have received some supports to manage the stroke impacts. The impact of this support is, at least to some extent, identifiable in the study. For example, at six months post-stroke, the participants focused on resuming pre-valued roles, a position often not reached by those who do not have the benefit of rehabilitation.

Roding et al., (2003) set out to describe and analyse the experiences of the rehabilitation process in younger stroke survivors. Additionally, the study set out to develop a hypothesis about these young adult stroke survivors' life situations. Five participants, three male and two female, aged between 37 and 54 years (mean age 43.2 years), each of whom had experienced a stroke, participated in the study. The length of time since the stroke onset was twelve to eighteen months but other than specifying the laterality of the stroke (left or right hemisphere), no further detail of stroke type was provided. In-depth interviews were analysed using the constant comparison method. The core category was identified as 'frustration' and encapsulated how the stroke impacted the participants' everyday lives. Fatigue was the most common difficulty post-stroke and significantly impacted all aspects of the participants' lives (familial, vocational and social). The data revealed that the participants experienced difficulties with their ADL's. Difficulties maintaining gendered roles added a source of frustration - the female participants spoke about the difficulties with expectations of their roles that they encountered in the home and the male participants spoke about the difficulties managing the financial stability of the home. During the rehabilitation process, the participants felt isolated. All the participants expressed that the rehabilitation process was below par and that their age-adapted needs were not met nor understood. They reported they did not receive age-adapted information and they felt distant from older stroke survivors during the rehabilitation process. This caused them to feel invisible and added to their frustration. Ongoing difficulties, hypothesised by the authors to be of a cognitive nature, were invisible and added to the frustration for the participants. The participants reported that talking with others of similar ages could have reduced the feeling of isolation. Age-adapted rehabilitation was recommended by the study authors to meet the needs of this population. The authors hypothesised that age and gender have an impact on the outcomes of current rehabilitation programmes and young adult stroke survivors' difficulties can be detected early on by developing appropriate instruments specifically for young adult issues that arise after stroke. The application of grounded theory is not wholly explicit in the study. The identification of a core category is based on *"thematised in-depth interviews"* (p. 868) yet the application of the systematic procedures associated with grounded theory are not identified. The constant comparison analytic method (Glaser & Strauss, 1967) is identified in the study. The authors do not, however, identify a theory generated in their substantive area, suggesting this study is more a thematic analysis rather than a grounded theory study. Further research with a larger sample and a comprehensive application of the grounded theory methodology would be beneficial in this substantive area. The findings of this study do, however, reflect those of Kirkevold (2002), whereby, during the first year following stroke, survivors' often felt frustrated during the rehabilitation process.

Stone (2005) explored the experiences of young female HS survivors. The goals of Stone's (2005) qualitative study were to: -

1) Discover the meaning of the participants' stroke experiences within the context of their own lives.
2) Discover the commonalities and differences in the participants' experiences and their concerns.

The inclusion criteria consisted of females who experienced a HS before 50 years of age, had experienced their stroke a minimum of two years before participating in the study, and were living with residual, invisible stroke difficulties. For the purpose of her study, invisible stroke difficulties took the form of subtle cognitive difficulties, persistent fatigue and / or one-sided weakness. Convenience and purposive sampling methods were adopted, and 22 women, living in the community, from Scotland, England, the US and Canada took part in the study. The mean age of the women was 41 years (ranged between 19 and 57 years). The mean age at stroke onset was 30.8 years (ranged between eight and 49 years) and the length of time since the stroke varied from three to 34 years. As reported, these young participants were shocked that they experienced a stroke, which they typically associated with the elderly. All the participants encountered difficulties with others not recognising their disabilities, and most of the participants felt the need to balance the issues of justifying themselves to others or concealing their difficulties from others. Most of the participants were frustrated as they felt their difficulties were misunderstood by others who, because the residual difficulties were not clearly visible, did not perceive the survivors to have ongoing difficulties. This affected their expectations of the stroke survivors. Additionally, some participants limited their social experiences because of their ongoing problems and the reaction of others. As noted by Stone (2005), their concern about the reaction of others is understandable, and she attributes this to the fact that women are traditionally socialised to be *"attentive to the opinion of others, especially regarding their appearance."* (p. 302). Stone (2005) recommended that rehabilitative services must take into account the fact that post-stroke survivors must deal with *"negotiating their everyday lives within a social context that they are ill prepared to deal with"* (p. 293) and she recommends that stroke survivors should be counselled about what to expect and what they ought to do to ensure a good QoL in the community.

Similar to Immenschuh (2003) study, this study's strength is the longitudinal design and the study of a homogenous group. In the context of this current study, Stone's study focused solely on survivors of HS. In examining the results of the Stone's (2005) study, it is important to recognise that the study included five participants who experienced childhood strokes (<18 years of age at stroke onset). The presentation of stroke in children is starkly different when compared with older adults (Roach et al., 2008) and the recovery in children when compared with adults may differ (Kim, Han & Kim, 2009). Additionally, the inclusion criteria specifically included participants with invisible disabilities, suggests a possible bias in favour of exploring these particular impairments with young female HS survivors.

In an Irish context, Leahy (2010) explored the subjective accounts of young adults' experiences of stroke, focusing on self-concept, emotional experience, interactions with others and adjustment over time to increase understanding of psychological and social needs of this cohort within a medical setting and the wider community. Purposive sampling was adopted, and the participants were recruited through the William Strokes Unit, the Stroke Service of the Adelaide and Meath Hospital, Tallaght, Dublin, Ireland. Patients residing in Southwest and South-Central Dublin attend this unit. Twelve females, presumably living in Dublin, with a mild-moderate stroke of unspecified type were included in the study. One male survivor also participated in the study, but his data were excluded from the data analysis phase so that a homogenous group of female stroke survivors was used. The participants mean age was 34.4 years and the length of time since the stroke onset was between seven months and 39 months. An Interpretative Phenomenological Analysis (IPA) approach was adopted, and four super-ordinate themes emerged from the data 1) stroke as a disease of the elderly, 2) post-stroke selves, 3) a desire for peer support and 4) the impact of stroke on relationships. As reported by Leahy (2010), diagnosing the stroke was difficult for the medical professionals as the participants minimised their symptoms and, at times, the medical professionals deliberated over a stroke diagnosis in such young adults. According to the study findings, the participants were, like those in Immenschuh (2003) and Stone's (2005) studies, shocked at a stroke diagnosis and had difficulty coming to terms with their stroke, an illness they typically associated with the elderly. Some of the participants were reported to have felt they aged prematurely. According to Leahy, the participants mourned their pre-stroke selves as they attempted to adapt to their current physical and emotional self post-stroke. They felt isolated in their stroke recovery due to living with an older person's illness, and they reported a desire to speak with others in similar situations, a feature also reported by (Roding et al., 2003). As in the Roding et al. (2003) study, participants in this study reported that there was a lack of age-related information. As reported by Leahy, the participants needed considerable social support post-stroke which was, at times, suffocating. The stroke resulted in both positive and negative impacts on familial and social relationships. The findings from this study suggest that young adults have specific needs that warrant attention in age-appropriate and age-adapted facilities. Such facilities should, according to Leahy include age-adapted services and advice, a similar recommendation to that of Roding et al.'s, (2003) study.

Survivors with severe communication deficits were excluded from Leahy's study limiting ability to generalise the findings to the general young adult stroke population. While the study aligns itself with Roding et al., (2003) in that gender impacts young adults' QoL, this claim warrants further investigation with the possible inclusion of male stroke survivors. Lastly, although the aim of the study was to explore the psychosocial consequences of stroke, the interview schedule adopted for the purpose of the study included twelve questions, some of which might be considered leading. For example, "*How did you cope emotionally after your stroke?*" (p. 122) suggests a researcher bias and as such the findings should be considered preliminary until further research with females is conducted within an Irish context.

In a second Irish study, Hanney (2012) set out to explore the subjective accounts of young adults' experience of stroke focusing particularly on self-identity, emotional experience and the impact of stroke on spousal and partner relationships. Additionally, the study set out to explore the subjective accounts of spouses of stroke survivors and the impact the stroke had on their lives and the relationship dynamics. Purposive sampling was adopted, and the participants were recruited, like those in the Leahy (2010) study, through the William Strokes Unit, the Stroke Service of the Adelaide and Meath Hospital, Tallaght, Dublin, Ireland. For the purpose of this study, fifteen participants were recruited - eleven community-dwelling young adult stroke survivors (nine female and two male) and four spouses (all male). The average age of the stroke survivors at the time of the interview was 41 years (ranged between

30 and 49 years) and the length of time since the stroke onset was seventeen months. Like Leahy (2010), the nature of the stroke was not specified. Semi-structured interviews were adopted and the stroke survivors and their spouses were interviewed, and their data analysed separately. As with the Leahy (2010) study, an IPA approach was adopted, and four super-ordinate themes were identified as 1) sudden and unexplained - will it happen again? 2) changes in daily life, 3) trying to get better and 4) relationship changes. Fear of experiencing a second stroke caused some participants to disengage in activities including driving, employment, travelling and leisure activities. Participants also attempted to avoid unknown situations or people as they were conscious of their stroke impairments. They were fearful of being stigmatised and treated differently. As reported in other studies, the participants experienced a sense of loss, frustration, distress and fatigue. Persistent stroke impairments such as difficulties with attention, memory and speech prevented them from participating in ADL's. In the stroke survivors, these residual difficulties evoked feelings of being different - they felt different when compared with their pre-stroke selves, their peers and in their social contexts. Familial, vocational and social roles and responsibilities significantly changed, typically associated with cognitive impairments and were a source of anxiety for the participants. As was the case in the Leahy (2010) study, stroke survivors reported both positive and negative impacts of stroke. The positive impacts included improved spousal relationships and re-appraisal of life priorities to make positive lifestyle changes.

In contrast to the stroke survivors, the spouses reported having experienced loss and change in their relationships with the stroke survivors. This change was, as reported by the spouses, often of a negative nature. As reported by Hanney (2012), the spouses were uncertain about the future as recovery plateaued and the loss of certain aspects of their partner became evident. Spousal roles changed into that of carer roles, which required adjustments. These roles later evolved as the stroke symptoms reduced and the spouses reported a positive change in their relationship with the stroke survivor.

Overall, this study illuminates the need for greater recognition of the impact of stroke from rehabilitation staff to support stroke survivors to deal with their impairments (including cognitive difficulties) in everyday life. Hanney recommended education on stroke recurrence and formal counselling to help stroke survivors manage anxiety. He also identified that practical and emotional support for spouses is needed. This study extends Leahy's (2010) study and included both young male and female stroke survivors and their partners. However, the methodology and recruitment strategy were the same and, not unexpectedly, the themes identified map closely onto those identified by Leahy (2010). Additional qualitative research from stroke survivors' perspectives within an Irish context may assist with grounding these findings in Ireland.

Kuluski et al., (2014) aimed to understand the impact of stroke on young survivors to learn how they cope with the changes. Seventeen community-dwelling young adults (n=11 female and n=6 male) with a mean age of 46.5years (ranged between 23 and 55 years) participated in the study. The average age at the stroke onset was 38.5 years (ranged between 21 and 53 years), and one female participant experienced a second stroke 20 years later. The sample comprised of mixed stroke subtypes; ischaemic stroke, HS and TIAs. Two themes emerged from the directed content analysis, namely 1) an altered self and 2) an adapted self. Based on their data, Kuluski et al. demonstrated that the participants were shocked to learn they suffered a stroke and experienced loss of identity, family disruption and / or loss of valued roles post-stroke. As noted by others, persistent stroke impairments disrupted the survivors' personal and work lives. Lack of motivation, lack of patience, reduced confidence and increased frustration were common as the participants struggled to resume ADL's. Roles within the family home changed, which caused disruptions such as the need for spouses to take time off work. According to the findings, some participants were advised to put future plans such as childbearing on hold, at least for a time, and, for many, the quality of relationships into the future was uncertain.

For some of the participants, disruptions to employment had significant financial implications, in addition to the loss of self that arose from not partaking in valued social and occupational roles. According to the study participants, family, friends, peer-support groups and employers were considered beneficial in adapting their sense of self. Re-establishing roles in the home, workplace and community were common practices to restore normality. Some participants were grateful to be alive and were grateful to have been afforded the opportunity to continue with life, but they would move back and forth between grieving for their pre-stroke lives and seeking to move forward with their post-stroke life. As might be expected, there are some methodological concerns related to this study. The interviews were conducted by three interviewers. Although experienced, multiple interviewers can create variations within the findings as interviewers may ask different probing questions and approach the analysis differently. Variations in interviews and analysis of different interviewers has since been identified in another qualitative stroke study that used an interprofessional approach (Danzl, Hunter & Harrison, 2017). Nevertheless, based on the findings of the study, Kuluski et al. recommended a holistic model of rehabilitation to support young adults stroke survivors to regain the capacity to partake in ADL's and support them and their families to cope with the implications of stroke and minimise the burden experienced by all. This is reflected in previous studies (Roding et al., 2003; Hanney, 2012 & Leahy, 2010).

More recently, and as the current study was under way, Hutton and Ownsworth (2017) aimed to explore the experience of a sense of self and continuity of self in younger community-dwelling adults after stroke. Through the use of semi-structured interviews, the researchers set out to determine what impact stroke has on young adults living in Queensland, Australia. Purposive sampling was adopted, and the participants were recruited from stroke support services and groups. In addition to an interview, all participants also underwent a cognitive assessment to assess the adequacy of their English language skills and to provide a global index of their cognitive status. Three males and seven females aged between 26 and 70 years participated in the study. The average age at the stroke onset was, however, 37.6 years (ranged between 20 and 55 years). Thus, all participants suffered a stroke while a young adult (i.e. <55 years). The mean length of time since the stroke was 10.25 years (ranged from six months to 31years). The study sample comprised of individuals who suffered either an ischaemic stroke (n=7: albeit one participant suffered three separate ischaemic strokes) or a HS (n=3). The phenomenological approach towards analysis identified two super-ordinate themes related to young adult stroke survivors' experience of the self and continuity of self namely; 1) the centrality of stroke and 2) impacts of a stroke on self. Of interest, stroke was more prominent in some participants' life stories than others. The centrality of stroke was lower for the participants who experienced a fast recovery with minimal long-term implications of the stroke when compared with participants who experienced the stroke as a major disruptor that caused uncertainty about their future.

According to the authors, these young adults could simultaneously experience a continuation of self without significant disruption, interruption of self and growth of self. The participants noted some aspects of their selves remained unchanged post-stroke while other aspects of self were interrupted. To maintain a sense of continuity, they called upon or drew upon, their internal resources, e.g. determination, to ensure that the stroke impacted to the least extent possible. Some participants had learned to adapt to their changing situations and had integrated the stroke into their life stories. Others, however, continued to describe aspects of themselves as 'interrupted'. This was viewed in a negative context by the participants who referred to their losses in physical, psychological and vocational/social domains. In line with other literature, many of the participants identified the stroke experience as positive, noting positive personality changes and the fact that they had re-appraised their life priorities. Overall, the connection between the centrality of self and the impact of the stroke was individual and was influenced by factors such as time since stroke, the severity of the impairments, stroke recurrence, life stressors and engaging in specific activities or life contexts. In recognition of the impact of stroke on a sense of self, the authors recommended that psychological support is provided to support young adults to regain their self-coherence by making sense of their stroke experiences and integrating these experiences into their life story. The strength of this study lies in the retrospective accounts of stroke survivors. This enabled the authors to capture the processes that evolved pertinent to the centrality of self over time for this young adult population. Additionally, there was a clear application of the IPA approach outlined in the study, including the inclusion of a reflexive journal suggesting a rigourous IPA study.

These seven studies have both strengths and limitations but, ultimately, they allow a synthesis of data from multiple international sources. Additionally, two of these studies were conducted withn an Irish context, which is of direct relevance to this current study. The qualitative methodology adopted in these studies captured the in-depth experiences specific to young adult stroke survivors thereby addressing a void in the literature. Taken together, these seven studies demonstrate the profound impact the stroke had on sense of self in young adults. Their personal, professional and social lives were all imapcted to varying degrees and a number of recommendations were provided by the authors, particulalry the development of age-adapted facilities for young adult stroke survivors.

Additionally, the methodological quality and rigour of each study and the findings of the studies were considered. Recurring issues regarding samples continued to limit the findings of some of the studies. With the exception of the study conducted by Stone (2005), who focused on female HS survivors, the other studies either included both ischaemic and HS (Hutton & Ownsworth, 2017; Kuluski et al., 2014) or did not specify the stroke subtype. As a result, for the purpose of this current study, it is not possible to determine whether HS survivors have post-stroke needs that differ from those of ischaemic stroke. What is clear, however, is that the sense of self is impacted by stroke and it is also clear that following a stroke, young adults experience a range of psychosocial and emotional difficulties.

Reflecting the studies discussed earlier in this chapter, the loss of self is the single most profound impact stroke survivors continue to struggle with. In the ABI literature, loss of sense of self, therefore not unexpectedly, is associated with exacerbated emotional distress including depression, anxiety, anger and grief (Klonoff, 2010; Cicerone, 1989). Given the plethora of physical, cognitive, psychosocial and emotional sequalae that arise in the aftermath of stroke and the prevalent issue of loss of sense of self associated with stroke, it is not surprising that there is a high prevalence of emotional difficulties in stroke survivors (Murray et al., 2003). Collectively, the studies discussed in this chapter, and those focusing on young adults, in particular, have identified feelings of frustration, grief and loss, loneliness and worry, fear and uncertainty following a stroke. As discussed in this chapter, coping with these sudden difficulties can be challenging as survivors gradually come to terms with what happened to them, their new-found limitations and changes to their personal and work life. According to a recent systematic review of 51 international studies (Hackett, Yapa, Parag & Anderson, 2005), post-stroke depression (PSD) is the most common neuropsychiatric consequence of stroke, regardless of the cause of stroke. Risk factors contributing to PSD include stroke survivors who perceive themselves to have a lower level of autonomy or who experience communication difficulties (Thomas & Lincoln, 2006). In their review, Hackett et al., (2005) identified a pooled-estimate of PSD in 33% of adult stroke survivors up to five years post-stroke. Typically, one in three adult stroke survivors will experience PSD in the acute, medium and / or long-term. This review included population-based, hospital-based and rehabilitation-based non-experimental studies as well as some studies published by the team of researchers from the Department of Psychiatry, University of Iowa, College of Medicine, Iowa (i.e. the IOWA group). All studies were conducted between 1977 and 2002. A total of 25,670 participants were included in the 51 papers included in the review. These studies included mixed-stroke samples of both ischaemic and HS – although one population-based study excluded SAH survivors. According to the review authors, this rate of PSD, at 33%, is, however, likely an underestimation given the heterogeneity of the studies, for example, varied stroke subtypes and patient characteristics, and variations in the methods of assessing PSD.

Hackett and Pickles (2014) updated the earlier Hackett et al. (2005) systematic review. 28 new studies were identified, and upon review of the studies included in the 2005 review, seventeen were now excluded due to not meeting the new inclusion criteria, e.g. upper-age limit restrictions, recruitment timing, location, disability and lesion location. The updated review, therefore, included 61 population-based, hospital-based and rehabilitation-based studies. A total of 25,488 stroke survivors across the studies included in the review. When compared with the earlier review, similar results were obtained regarding the rate of PSD. On this occasion, the data revealed that depression is present in 31% of stroke survivors at any time within the first five years post stroke. Between one and five years post stroke, PSD was prevalent in 25% of the stroke population and was observed in 23% at five years after a stroke. Of potential relevance, a substantial proportion of these studies excluded individuals who experienced HS, focusing only on those who had experienced an ischaemic stroke.

Post-stroke anxiety (PSA) is also a frequent neuropsychiatric consequence of stroke. Although under-researched when compared with PSD, a recent systematic review by Burton et al., (2013) identified 44 international studies conducted between 1984 and 2010 related to the frequency of PSA. These studies covered strokes in adults with a mean age of between 51 and 76 years, depending on the study. Based on this review, the pooled estimate of the prevalence of PSA is 25% at any time. Specifically, PSA is prevalent in 20% of the stroke population within one month of the stroke, in 27% between one and five months and in 24% at six months or longer.

PSD and PSA are both known to have an adverse effect on functional outcomes (Kutlubaev & Hackett, 2014; Bertisch et al., 2013). Bertisch et al.'s (2013) recent study on ABI survivors (35% of whom were stroke survivors) suggests that anxiety negatively affects functional impairment within the first year of onset. In their study of 54 survivors, examining the effect of cognitive impairment and anxiety on functional status, anxiety predicted a significant proportion of the variance in both affective/behavioural and cognitive functioning. Given these findings and given that a substantial proportion of stroke survivors experience PSD, PSA or both, each of which affect the functional outcomes, it is reasonable to expect that the long-term emotional impact of stroke warrants greater attention from medical, rehabilitative and community services to reduce, where possible, the burden associated with these difficulties. The next section of this chapter focuses on aspects of post-stroke rehabilitation, treatment and intervention, with a specific emphasis on the role of psychotherapy. In doing this, the paucity of psychotherapeutic services becomes apparent.

Post-Stroke Rehabilitation, Treatment and Intervention: The Role of Psychotherapy

As noted by Bishop and Bushnell (2017), rehabilitation services can support stroke survivors to learn to manage their new-found challenges. These services should, however, as noted above, be tailored to the specific needs of the individual.

Notably, clinical recovery differs between ischaemic and HS (Saulle & Schambra, 2016; Schepers et al., 2008), which could, at least potentially, influence the rehabilitation process. As noted earlier, HS typically causes greater damage than ischaemic stroke (Anderson et al., 2009; Bhalla et al., Kelly et al., 2003) and mortality and morbidity rates are significantly higher in HS when compared with ischaemic strokes (Anderson et al., 2009; Gonzalez-Perez, Gaist, McFeat & Garcia-Rodriguez, 2013). As a consequence, the needs of HS survivors are, almost certainly, different from those of ischaemic stroke survivors.

A relatively recent Dutch study investigating the differences between ischaemic stroke and ICH recoveries during the first-year post-stroke in an inpatient rehabilitation setting indicated that recovery trajectories differ based on stroke type (Schepers et al., 2008). The study investigated a large number of stroke survivors (n=229 ischaemic; n=45 ICH) with mean ages of 57.5 years and 56 years respectively. The study confirmed that a slow, gradual and sustained recovery was evident in ischaemic stroke survivors, lasting for approximately 26 weeks. In contrast, a spontaneous rapid, albeit incomplete, recovery was evident in ICH patients, which occurred over a period of approximately ten weeks. Given their restricted recovery window, this study shows the importance of early rehabilitation to support stroke survivors, particularly those who have an ICH. This study did not, however, include patients with SAH, which might influence further the timing of the recovery trajectory.

In a large population-based study in London, England, ICH stroke survivors typically sustained poorer long-term outcomes associated with ADLs when compared with ischaemic stroke, certainly during the first five years after the stroke onset (Bhalla et al., 2013). Of 3,730 patient records reviewed, 3,177 records were of patients who were ischaemic stroke survivors, and 533 were ICH survivors. The mean age at the time of stroke was 71 years and 66.4 years respectively. Similar to the Schepers et al. (2008) study, a notable surge in recovery was observed in ICH survivors in the first three months post-stroke. This recovery plateaued, however, between three months and five years, with many individuals having ongoing residual symptoms. There were no obvious differences in outcomes between ischaemic stroke survivors and ICH survivors more than five years post-stroke onset. The authors highlighted that the differences in recovery patterns of different stroke types could help to effectively allocate rehabilitation services to those who may benefit. They are also in favour of the development of long-term management strategies to address the impacts of stroke, particularly in ICH survivors.

In a case-control study of ICH (n=135) and ischaemic stroke survivors (n=135), ICH survivors typically recovered more quickly than did ischaemic stroke survivors (Paloucci et al., 2003), possibly reflecting the resolution of the haematoma. Recovery is, however, often incomplete – for both ICH and ischaemic stroke survivors. Of note is the fact that ICH survivors have greater functional recoveries after rehabilitation than do those who sustain ischaemic stroke (Kelly, et al., 2003) and this might, at least in part, explain some of the findings of faster recovery by ICH patients noted by Paloucci et al. (2003), who examined the recovery trajectory of those attending an inpatient rehabilitation unit.

Regarding treatment for anxiety and depression, both of which are recognised as impacting negatively on individuals post-stroke, PSD and PSA are treated primarily using pharmacological interventions (Knapp et al., 2017; Paolucci, 2008). In a systematic review of 21 studies examining the pharmacological treatment of PSD (Wannagat, Zielasek & Gabel, 2018), the literature related predominantly to adults over the age of 55 years. In general terms, participants received some benefit from drug treatment, with some reductions in PSD symptoms. However, as noted by Salter, Foley, Zhu, Jutai & Teasell (2013), optimum timing of drug treatment and appropriate selection of those who might benefit most from drug treatments warrant further attention.

Anderson et al., (1994) suggested that pharmacotherapy interventions immediately after stroke can prevent the development of PSD. In a similar vein, Palomaki and colleagues (1999) suggested that early pharmacological treatment and rehabilitation are efficacious at preventing PSD. Notably, Robinson et al., (2008) indicated that pharmacotherapy interventions were more effective than psychotherapy for the treatment of PSD but acknowledged that psychotherapy was marginally more effective when compared with a placebo in reducing PSD symptoms.

A 2004 systematic review identified no available data pertinent to psychotherapy in the treatment of PSD (Hackett et al., 2005). All trials related to pharmacological interventions. A follow-up review of interventions adopted to reduce depressive disorders after stroke identified four trials relating to psychotherapy that proved efficacious in reducing psychological distress in strokes of all ages. However, there was no statistically significant improvement in ADL's or social integration (Hackett et al., 2008). These four intervention trials conducted between 2004 and 2008 are encouraging, indicating that the gap in the stroke and psychotherapy literature is now being addressed, albeit slowly. Despite the lack of psychotherapy with stroke survivors identified in these systematic reviews, Hackett et al. (2008) recommended psychotherapy soon after the stroke onset to prevent the onset of mood disorders and improve wellbeing, cognitive functioning and potentially physical functioning.

A very recent systematic review of psychotherapy interventions to treat PSD identified 21 qualitative studies pertinent to psychotherapy for PSD - all published between 2002-2015 (Hadidi, Roberta & Lindquist, 2017). Psychotherapy treatments included CBT, ecosystem-focused therapy, life review therapy, problem-solving therapy, motivational interviewing and complementary therapies including meridian acupressure, repetitive transcranial magnetic stimulation, music therapy, exercise, light therapy and robotic-assisted neurorehabilitation. Sample sizes ranged from four to 411 individuals and the time since stroke ranged from two days to five years. The review indicated that problem-solving therapy, motivational interviewing and complementary therapies were somewhat effective in reducing PSD. However, the results were not statistically significant, possibly due to small sample sizes and issues with study design. A recent systematic review looking at the treatments for anxiety post-stroke identified three randomised control trials suitable for inclusion; two Chinese studies that were conducted in 2005 and one UK study conducted in 2016 (Kanpp et al., 2017). In total, 196 stroke survivors were included across the three studies in the review (mean age – 62.9 years). All three trials included ischaemic, and ICH survivors but SAH survivors were excluded. Two of the three studies indicated anxiety symptoms reduced with pharmacological treatment, although one study did include psychotherapy alongside the pharmacologic treatment. The remaining study indicated that stroke survivors were less anxious three months after regularly listening to a relaxation CD. Overall, this review indicated the paucity of research in the area of PSA and also in psychotherapy as a treatment for PSA.

Taken together, the research about post-stroke anxiety and depression reveals that there is a dearth of psychotherapeutic literature aimed at supporting individuals faced with the challenges that arise from a stroke. The more general ABI literature can, however, help identify the potential benefits of psychotherapy for the stroke population. It is well recognised that psychotherapy can support individuals with brain injury to explore the psychosocial and emotional challenges associated with loss and trauma, adapting to life-altering situations and developing new ways of coping (Cicerone, 1989; Klonoff, 2010; Ruff, 2013). Psychotherapy can support ABI survivors to regain their sense of self and create a meaningful life after brain injury (Prigatano, 1999) and can empower ABI survivors to regain a sense of control of their lives ultimately reducing feelings of emotional distress that is central to healing existential angst (Patterson & Staton, 2009). Additionally, psychotherapy can support stroke survivors to normalise their situation (Alvarez, 1997). Although under-researched, brain functioning improvements have been identified in individuals with psychiatric disorders who have received psychotherapy (Barsaglini et al., 2014; Linden, 2006; Roffman et al., 2005). Therefore, it seems reasonable to suggest that young adult HS survivors engaging in psychotherapy may have similar benefits.

Ward and Hogan (2015) suggest that the psychotherapy literature for ABI is limited, given the individualised nature of the psychotherapeutic process post-ABI. Block and West (2013) suggest that the prevalence of neurological difficulties in the ABI population makes psychotherapy a more complex process when compared with the general population as the brain functions differently. Williams and Evans (2003) suggest that these complexities should not impede effective interventions with this population and Gideon (2009) recommends that identifying effective therapeutic interventions is critical to the advancement of psychotherapy for the ABI population. The next section of this chapter provides an overview of the specific psychotherapeutic interventions that have been adopted with the ABI population to support ABI survivors to adapt to their new situation. By extension, these interventions could be applied to the stroke population, and of particular relevance to this study, to the young adult stroke population.

Successful stroke recovery and reintegration to the community is dependent on functional and emotional support, which is largely provided by families (Palmer & Glass, 2003). Family members play a significant role in the recovery process, and the responsiveness of family members can influence the rehabilitation process (Lawrence & Kinn, 2013). Backhaus, Ibarra, Klyce, Trexler and Malec (2010) and Stejskal (2012) suggests that family intervention that includes psychoeducation, skills-building and emotional support, can support families to cope with the long-term implications of ABI, and by extension, stroke.

Hofer et al., (2010) examined the efficacy of psychotherapy interventions for adjustment difficulties post-ABI. Interventions included emotion-focused techniques and coping skills training over 23 sessions for twelve to eighteen months with eleven participants. Although the study sample was mixed (four HS survivors, three ischaemic stroke survivors and four TBI survivors), the interventions were individually adapted and tailored to the individual needs of the participants. The study concluded that these psychotherapeutic interventions reduced anxiety and depressive symptoms and increased coping skills and goal attainment post-ABI.

Cognitive-behavioural Therapy (CBT) has been considered useful with TBI survivors (Ponsford, 2013) and can fit the needs of stroke survivors experiencing PSD (Broomfield et al., 2011). The orientation of CBT is the 'here and now', which fits with the needs of stroke survivors', as they face many challenges in their new life situation (Broomfield et al., 2011). Bradbury et al. (2008) suggest adopting a CBT approach with ABI is favourable because it is goal focused, directive, can address multiple issues of brain injury and can be adapted to meet the needs of cognitively impaired clients. Modified CBT to support post-stroke cognitive deficits has shown a reduction in anxiety symptoms, in two stroke survivors, which were maintained at three-month follow-up (Kneebone & Jeffries, 2013).

Brief psychotherapy (six sessions) has shown improvements in self-esteem and identity post-ABI (Vickery et al., 2006) and reduction in depressive and anxiety symptoms post stroke (Peng et al., 2015). Ownsworth and McFarland (2004) propose that group interventions, post-ABI, are effective in improving self-awareness, psychosocial functioning and problem-solving abilities. Chow (2015) suggests narrative therapy reduces emotional distress and gently supports ABI survivors to create new narratives and identities post-ABI.

Integrating cognitive and emotional interventions such as memory training, attention training and psychoeducation have proven effective in reducing emotional distress in the ABI population (Mateer, Sira & O'Connell, 2005). Cognitive interventions can address functional limitations and are designed to reduce feelings of helplessness associated with emotional distress in those who experience psychological trauma (Eagle, 2000). Psychoeducation aims to normalise feelings regarding trauma and anxiety and psychoeducation regarding the impact of brain injury, and common factors can be beneficial to create links between the traumatic event and symptoms experienced (Folzer, 2001).

Despite recognition of the benefits of psychotherapy, the emotional impact of brain injury, however, remains under-treated, particularly with young adult stroke survivors, as evident in the studies discussed earlier in this chapter. Given the known benefits of psychotherapy, incorporating psychotherapy into the rehabilitation process may reduce the burden associated with stroke.

These studies indicate that a diverse range of therapeutic approaches can be successfully applied to the ABI population and, by extension, to the stroke population. However, to ensure that the most adequate and appropriate approaches are adopted, it is critical that practitioners and those best placed to offer are fully aware of the needs of those to whom the interventions are to be offered.

Study Rationale, Aims and Objectives

The qualitative studies highlighted in Table 4, explore the subjective experiences of young adult stroke survivors. The studies showcase the wide, and varied impact of stroke and the demanding journeys the young stroke survivors embarked upon since their stroke onset. Themes of loss of self, living with an older person's illness, frustration, isolation, persistent cognitive impairments and loss of valued roles in the home and community commonly appeared in the studies. Additionally, some of the studies highlighted the positive implications associated with stroke including reappraising life priorities.

However, although these studies are useful in capturing this rich information, these studies are almost exclusively focused on participants who have experienced an ischaemic stroke or are focused on participants without reference to their stroke type. Little research focuses specifically on the experiences and needs of young adults who have experienced a HS.

Given that risk factors differ between ischaemic stroke and HS (O'Donnell et al., 2010; 2016) and given that clinical recovery differs between ischaemic stroke and HS (Saulle & Schambra, 2016; Schepers et al., 2008), this current study set out to explore the experiences of young adults following HS. The focus on this specific cohort reflects the paucity of current research with this population (young adults HS survivors) – and it reflects the fact that HS represents a disproportion number of strokes in younger adults (relative to older samples).

The Stone (2005) study provided a platform for which this current study emerged. In that study, Stone investigated young women who survived a HS and she focused on describing their experiences. She did not, however, attempt to formulate a theory of recovery based on these experiences. Thus, this study sets out to gain a theoretical understanding of young adults living with HS.

As is apparent from the literature reviewed above, there is a limited understanding of how young adults stroke survivors are impacted by stroke and, particularly, a limited understanding of how they move on from the stroke. The studies reviewed above adopted primarily a phenomenological approach to capture the lived experiences of young stroke survivors. While this research is fundamental in helping researchers and practitioners gain an in-depth understanding of stroke survivors' needs and serve to inform this current study, the study reported here set out to move on from the lived experience literature to gain a theoretical understanding of the experiences of young adult HS survivors. To achieve this objective, a classic grounded theory (CGT)methodology was adopted.

For the purpose of this study, community-dwelling young adults' (aged between 18 and 55 years) living with HS were interviewed.

The objectives of the study were: -

1) To enhance understanding of how HS impacts young adults living in the community.
2) To identify how these young adults manage the impacts of their stroke.
3) To elucidate the young adults' perceived psychotherapeutic and other needs post-HS.

Together, the goals were to designed to inform professionals working with this population. Chapter 3 will provide a detailed account of the methodology and methods adopted in this study.

Chapter 3: Methodology and Methods - Conducting Classic Grounded Theory

Introduction

This chapter examines the research methodology, Classic Grounded Theory (CGT) and the procedures used in this study. The rationale for adopting this approach and how the key tenets of CGT guided the specific methods used in this study for sampling and data gathering and analysis is provided, alongside the procedures that were used for participant recruitment. The ethical considerations pertinent to this study are addressed, and the chapter concludes with the criteria used to evaluate the rigour of the study.

Qualitative Approaches

Qualitative approaches have become increasingly common in health research in order to understand complex health problems (Peter, 2015) and the use of qualitative approaches *"is consistent with developments in the social and policy sciences at large, reflecting the need for a more in-depth understanding of naturalistic settings, the importance of understanding context, and the complexity of implementing social change"* (Shortell, 1999, p. 1083). Healthcare is delivered in naturalistic settings by professionals working in private, organisational and community contexts and is continuously evolving and benefitting from qualitative research (Sofaer, 2002). Qualitative methods are used across a number of health and other disciplines including nursing (Sharif & Masoumi, 2005), education (Montrieux, Vanderlindea, Courtoisb, Schellensa & De Marezb, 2013), mental health (Yoshida, 1993) and health promotion (Perry, Thurston, Alford, Cushing & Panter, 2016). Qualitative approaches focus on the richness and depth of human experience to gain an understanding of the complexities, the meanings and the belief systems underpinning these experiences (Ritchie, 2003). One to one interviews are the most widely used method of data collection in qualitative research (Creswell, 2013). These interviews are considered purposeful conversations that can afford participants the opportunity to speak liberally and openly about their experiences (McCann & Clarke, 2003c). Ethnography, phenomenology, grounded theory, case studies and narrative approaches are the most popular qualitative methodologies used (Creswell, 2013) and each methodology can produce different outcomes relative to the study area (Fossey, Harvey, McDermott & Davidson, 2002).

Of direct relevance to this study, qualitative methods, particularly phenomenological approaches, are regularly used in stroke research and, as discussed in Chapter 2, have been successful in capturing the human experience from young adult stroke survivors' perspectives.

Of the qualitative research conducted to date, only one study investigated the experiences of female HS survivors and adopted the grounded theory constant comparison method of analysis (Stone, 2005). Thus, to add to the literature and provide a theoretical understanding of young adults' experiences of living with HS, a grounded theory approach and, specifically, a CGT approach was adopted using semi-structured, individual, face-to-face interviews.

Grounded Theory - Overview and Key Tenets

Grounded theory primarily aims to identify patterns of actions or behaviours, in under-researched areas, which enhances a greater understanding of the phenomenon (Glaser & Strauss, 1967). Grounded theory is considered the most influential qualitative approach in health and social science research (Byrant & Charmaz, 2007) and is "*the systematic generation of a theory from data acquired by a rigorous research method"* (Glaser, 1998, p. 2). There are three main versions of the grounded theory methodology: 1) Classic grounded theory (CGT) (Glaser & Strauss, 1967); Straussian grounded theory (Strauss & Corbin, 1990) and Constructivist grounded theory (Charmaz, 2000).

Published by Glaser and Strauss in 1967, 'The Discovery of Grounded Theory' was based on a study of the dying process in a hospital setting. They outlined a general research methodology that supported practitioners to develop a theory that was grounded in the reality of the social world. At that time, Glaser and Strauss (1967) viewed social research as attempting to verify theories of 'great men' through rigorous testing rather than generating new theories that would be understood and used by those who were included in the research. Although Glaser and Strauss (1967) acknowledged the benefits of verification studies, they believed theories should be generated in conjunction with these verification studies. However, until this point, verification studies were considered elite research methods, adding to the growing literature of quantitative research. Furthermore, the data obtained from the verification studies was used to fit into pre-existing theories that were not aligned with the social world, ultimately failing to advance the field under study. Therefore, grounded theory, later referred to as CGT, was developed to bridge the gap between theory and research as an alternative approach to the dominant theory-driven quantitative methods then employed in sociological research. Significantly, this grounded theory approach was regarded as a pioneering breakthrough in qualitative methodologies and sociology and is now considered a systematic research approach that generates theories that apply to the real world (Glaser, 2010).

Glaser and Strauss came from different theoretical perspectives and it was a combination of these perspectives that led to the development of CGT. Despite the growing popularity of CGT, it was these contrasting perspectives that ultimately led Glaser and Strauss to part ways, resulting in the controversial modification of grounded theory by Strauss and Corbin (1990). Strauss and Corbin's (1990) methodology is grounded in social constructionism, indicating that realities cannot be comprehensively known, but can be interpreted. Strauss and Corbin (1990) suggested the original iteration of CGT was incomplete and they presented a modified, linear account of the analysis procedures, otherwise known as Straussian grounded theory. Glaser (1992) later suggested that the modified analysis, which included pre-determined analytic categories, could be considered a means of forcing the data to fit existing theoretical ideas.

Constructivist grounded theory, by Charmaz (2000), is considered a contemporary advancement of the CGT approach and is also underpinned by social constructionism, and epistemologically rooted in a subjectivist paradigm. Constructivist grounded theory aims to represent what is happening in the here and now, free from general laws or theories. However, researchers' realities do influence the research outcomes (Creswell, 2013). All data that is collected is co-constructed between the researcher and participants - the analysed data includes the context and the historical and social interactions that take place during the research process (Charmaz, 2000).

There is an ongoing debate regarding the paradigmatic position of CGT (Ponterotto, 2005). Various critics have speculated grounded theory is rooted in positivism, constructivism, symbolic interactionism, pragmatism and social process paradigms (Charmaz, 2006; Holton, 2007; Simmons, 2011). CGT is a unique, adaptive, flexible methodology and is considered to be *"…a paradigmatic bridge between post-positivist, interpretive/constructivist and post-structural or critical approaches to qualitative research"* (Fassinger, 2005, pg. 157). Leaning towards the philosophical perspective of symbolic interactionism, CGT was developed on the assumption that reality is constructed through interactions (Charmaz; 2006). According to Glaser and Strauss (1967) however, and in contrast to Straussian grounded theory and constructivist grounded theory, CGT does not align itself to any epistemological or ontological paradigm. CGT lends itself to an open approach and toward the development and refinement of a theory that resolves a concern that arises for individuals in their social world. To facilitate this, CGT can lend itself to various ontological and epistemological perspectives and is dependent on the manner in which the grounded theory is conceptualised and used (Glaser & Strauss, 1967; Glaser, 1998; Glaser, 2005).

The analysis procedures, the philosophical perspectives and the use of literature differ between CGT, Straussian grounded theory and constructivist grounded theory (Kenny, & Fourie, (2015) but Glaser (2014) suggests no one method is superior. The CGT data gathering, handling and analysis procedures, discussed in the latter part of this chapter, are less structured and more flexible in comparison with Straussian and constructivist grounded theory, in order to generate a substantive theory that naturally emerges from the data. Ultimately, CGT is open and flexible and generates a theory that emerges from the data and fits with the real-world phenomena, for example, it is important that the participants understand the theory generated and that they can identify with it (Glaser & Strauss, 1967; Glaser, 1998; Glaser, 2005).

The key tenets of CGT, detailed below, are: 1) all is data, 2) theoretical sensitivity, 3) theoretical sampling and theoretical saturation and 4) the constant comparison analytic method. The tenets of CGT offer a systematic, yet open approach to a study, thus providing a method for generating a theory that is grounded in the experiences of those being studied and was thus deemed suited to the current study.

1. All is Data

“All is data” is a statement synonymous with all grounded theory methodologies, meaning that all sources and types of data can be incorporated into a study. It originated in the Classic approach and is:

> “…a true research perspective on all incidents that come the researcher’s way. It expands constant comparison and theoretical sampling. The briefest comments to the lengthiest interview, written words in magazines, books and newspapers, documents, observations, biases of the self and others, spurious variables, or whatever else may come the researcher’s way in his substantive area of research is data for grounded theory.” (Glaser, 1998, p. 8).

Semi-structured interviews were adopted as the primary source of data gathering and analysis for this study. As Glaser indicates, anything from a short comment to written words and videos can be used as data. In an effort to increase the sample size of this current study, the researcher identified some autobiographical accounts and Vlogs (a form of blog in which the content is videoed) of living with haemorrhagic stroke from the perspective of the young adult stroke survivor. However, the accounts identified were of haemorrhagic stroke survivors living in the United Kingdom and the United States. Given that this was an Irish study, these accounts were not included in the study as their experiences of stroke, healthcare and rehabilitation may differ in their country from the participants of this study.

Additionally, Irish documentaries were identified but discounted as one documentary included an older adult who survived an ischaemic stroke and another documentary did not specify the stroke subtype.

However, other forms of data were subjected to the data analysis process. Field notes and theoretical memos were maintained throughout the study process and later formed part of the data analysis. Collectively, the semi-structured interviews, field notes and theoretical memos were subjected to the data analysis process and contributed to the development of the theory.

2. Theoretical Sensitivity

Theoretical sensitivity refers to the researcher’s relationship with the area under study and their capacity to think theoretically about the data collected. It requires the researcher to frequently interact with the data gathering and analysis and suspend judgment on possible outcomes in order to “discover” the relationships between categories, which leads to the development of a theory that fits with the world and is relevant to the field under study (Glaser, 1978).

Glaser (1978, 1998) advocates that the appropriate use of the literature in grounded theory studies will increase researcher’s theoretical sensitivity. Starting with an openness to discovery in this study, a preliminary view of the relevant literature pertinent to haemorrhagic stroke in young adults was undertaken in advance of this study to contextualise the study, provide a rationale and obtain ethical approval. This review also sensitised the researcher to influences and cues that could potentially contaminate or hinder the theory generation process in this study (Glaser, 1978). Additionally, it encouraged the researcher to look at her relationship with the field of inquiry, which was a motivating factor for adopting CGT for this study because the researcher accepted that she had preconceived ideas about the stroke sequalae and the current stroke service provision from working professionally in this area.

A considerable review of theoretical literature not directly relating to the substantive area of inquiry is recommended to increase researchers' theoretical knowledge of general theoretical codes, the relationships between categories and their integration to the theory (Glaser, 1978, 1998). This theoretical knowledge will then enable researchers to identify and theorise patterns of behaviours / actions that emerge in their area under study. The researcher visited general literature in multiple domains such as health, nursing, mental health to increase her theoretical knowledge and thus increase her theoretical sensitivity. Manuals and literature related to the application of grounded theory were also studied throughout the research process and revisited multiple times to aid the researcher in how to do and write a grounded theory.

Once data collection and analysis has commenced and a core category begins to emerge, the researcher is advised to identify relevant theoretical literature and weave this literature into the analysis (Glaser, 1978, 1998). This theoretical literature can refine the analysis and guide additional data collection and be incorporated in to the write-up of the theory. In essence, Glaser is not advising that the relevant theoretical literature be ignored, which can sometimes be a misconception amongst grounded theorists, but rather this literature is parked until needed.

As data gathering and analysis progressed, the literature identified in the preliminary review was revisited in more depth and formed part of the analysis. As the core category emerged, the researcher reviewed relevant literature in the substantive area and other domains. This literature was incorporated into the analysis which sensitised the researcher further to the issues arising in the data and also helped her refine her conceptualisations of the data. The substantive theory was situated in this relevant literature (Glaser, 1978, 1992).

3. Theoretical Sampling and Theoretical Saturation

Theoretical sampling is an essential procedure in grounded theory methodology and refers to seeking additional data to add depth to emerging categories and ultimately, refine these emerging categories (Woods, Gapp & King, 2016). Research begins with sourcing data related to a particular topic, coding incidents within the data into as many categories as possible, and making comparisons between incidents within the same categories so as to start developing the theoretical properties of each category. Additional data collection is subsequently driven by the need to refine these categories and their properties and thus involves 'theoretical sampling'. Data is to be collected in relation to each emergent category until such time as ‘theoretical saturation’ is reached, i.e. when no new additional data contributes to the development of properties of a category (Glaser and Strauss 1967, Glaser 1978, 1998).

At the beginning of this study, there were no restrictions placed on the number of participants who might take part in the study. Selective sampling, involving individual face-to-face interviews, was adopted with young adults, who had experienced a HS and who were subsequently invited to participate in the study. This sample was considered most knowledgeable in this research topic based on the aims and objectives of this study. The participants were invited to share their experiences of life post-HS. During the initial analysis stage, the key question that was asked of the data to establish the main concern was “*What is going on in the substantive area*?”. The main concern and emerging categories that captured key processes these young adults engaged in to resolve their main concern were identified after initial analysis of the first four interviews. Further analysis of these four interviews further refined the categories; some categories collapsed and other categories developed into higher-level categories and relationships between these categories began to emerge.

The young adults in this study resolved their main concern by adapting to their new lives and moving forward. Theoretical sampling, which samples ideas based on the analysis rather than sampling specific populations, was then conducted. In this study, theoretical sampling involved sampling these ideas with more young adults in this substantive group to refine the emerging categories, seek variations and establish the relationships between the categories, leading to the emergence of the core category. Theoretical sampling of the additional two interviews focused on the processes these young adults engaged in to move forward since their stroke and how this was facilitated. The researcher also returned to the initial four interviews and reanalysed the data with the same focus on these key processes. This led to development of the core category which described how the young adults proceeded to situate themselves in the world with a post-stroke self that is meaningful and purposeful.

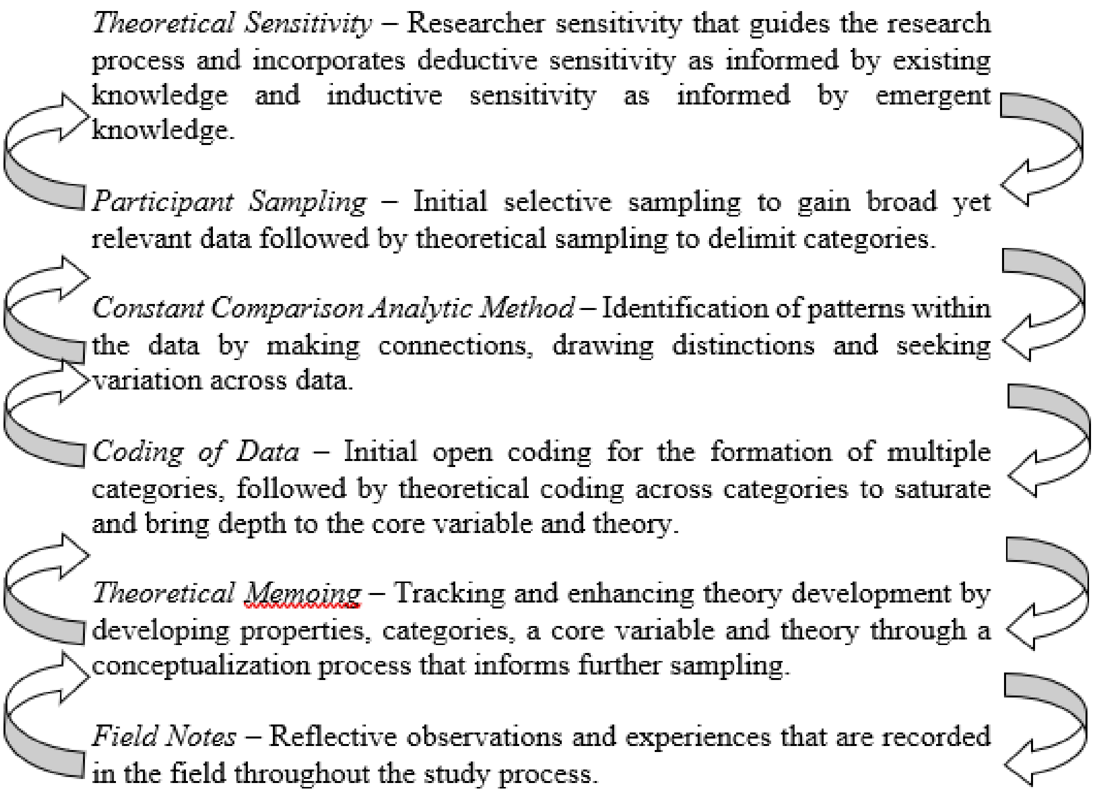
Taken together, the selective and theoretical sampling procedures adopted in this study enabled the researcher to source both open and specific data related to the experiences of these young adults and continue with the analysis process until theoretical saturation was achieved and a substantive theory developed.

Theoretical saturation refers to the point in data analysis whereby no new categories or variations within categories are discovered. The theory, therefore is based on well-developed categories. Glaser and Strauss (1967, p. 225) note that emerging perspectives can change and help delimit the theory at any given moment *"...but that it is now sufficiently formulated for his current work to be closed and published".* In the current studytheoretical saturation of the core category was achieved with six interviews. This includes the theoretical sampling and analysis of two face-to-face interviews and reanalysing the previous four interviews. There was no further evidence of new categories or variations in the core category and by following the systematic ordering of the concurrent analyses, the study was sufficiently formulated and met the guidelines for robustness (discussed in the subsequent sections of this chapter), therefore, the researcher was confident that the core category was saturated and the theory is developed as far as possible for the current study.

4. The Constant Comparison Analytic Method

A CGT theory is developed through a deductive-inductive research process (Glaser, 1978, 1992), moving freely between the data gathering and analysis procedures (Moore, 2010). Data collection and analysis occur simultaneously and repeatedly as each activity can inform the other until a comprehensive theory is generated. The constant comparison method provides an analytic framework to facilitate theory generation and is described by Glaser and Strauss (1967 p. 105) as comprising four stages: *"1) comparing incidents applicable to each category, 2) integrating categories and their properties, 3) delimiting the theory, and 4) writing the theory".*

This analysis method is described as an evolutionary process that allows for new concepts, categories, thoughts and ideas to emerge as the study progresses. Figure 1 demonstrates the processes, methods and tools associated with CGT analysis, as presented by Gordon (2010). The application of these analytic procedures is discussed in a subsequent section of this chapter.



Theoretical Sensitivity – Researcher sensitivity that guides the research process and incorporates deductive sensitivity as informed by existing knowledge and inductive sensitivity as informed by emergent knowledge.

Participant Sampling – Initial selective sampling to gain broad yet relevant data followed by theoretical sampling to delimit categories.

Constant Comparison Analytic Method – Identification of patterns within the data by making connections, drawing distinctions and seeking variation across data.

Coding of Data – Initial open coding for the formation of multiple categories, followed by theoretical coding across categories to saturate and bring depth to the core variable and theory.

Theoretical Memoing – Tracking and enhancing theory development by developing properties, categories, a core variable and theory through a conceptualization process that informs further sampling.

Field Notes – Reflective observations and experiences that are recorded in the field throughout the study process.

Figure 1: *Classic Grounded Theory Processes, Methods & Tools (Gordon, 2010, p. 92)*

Study Design and Procedures

This CGT study adopted one-to-one, face-to-face, semi-structured interviews with six participants. The data was analysed as per CGT's systematic and rigorous procedures as described below.

Recruitment Strategy

Ethical approval for this study was obtained from Dublin City University Research Ethics Committee (DCU REC) and Acquired Brain Injury Ireland (see Appendix A and B).

Recruitment for the study spanned a seventeen-month period. As this study was intended to explore the experiences of young adults across the Republic of Ireland, several brain injury and stroke organisations were approached by the researcher to seek help in bringing the 'Call for Volunteers' (see Appendix C) to the attention of potential participants (e.g. via online platforms and / or via distribution to relevant persons within the organisation who have direct access to this cohort). Some additional platforms were utilised to raise awareness of the study including attending conferences, workshops and seminars, sharing the study information with colleagues and presenting preliminary findings to allied health professionals working in stroke rehabilitation.

Sample

A sample of six adults was recruited to the study. The inclusion and exclusion criteria were:

Inclusion criteria.

1) Men and women with a diagnosed HS sustained as an adult that occurred at least six months before participating in the study.

   A survey of acute stroke admissions in Ireland suggested that the average length of stay in acute stroke care and subsequent rehabilitation was three months (Hartigan et al., 2010). Therefore, based on this finding, an interval of six months between the stroke and research participation was considered appropriate to allow participants time for the immediate effects of their stroke to settle, return home from an acute setting and be in a position to reflect upon the event and the impact of the stroke on their lives. There was no upper limit regarding the length of time post-stroke because the purpose of this study was to investigate the experiences of stroke in young adults over time thus, allowing for changing adjustment patterns at varying intervals to be captured.

2) Participants were aged between 18-55 years.

   This age group was chosen as it corresponded to the definition of young adults in the qualitative stroke literature summarised in Chapter 2. Additionally, this age group can serve to achieve a relatively homogeneous group regarding personal and work roles.

3) Participants were living in a community setting.

   For example, participants were discharged from an acute hospital setting to the community and were residing independently or with family. Community-dwelling adults were chosen to help elicit the motivators, barriers and challenges they encountered as young adult HS survivors following discharge from the hospital.

4) Participants were able to provide informed consent.

As a vulnerable group, informed consent was particularly pertinent to this study. How informed consent was obtained is described in the ethical considerations section of this chapter.

Exclusion criteria.

1) Those who experienced an ischaemic stroke.
2) Those with a diagnosis of a degenerative neurological condition, for example, Multiple Sclerosis or Parkinson's' Disease.

   Although symptoms between degenerative conditions and stroke may overlap, the risk factors, diagnoses and long-term treatment and implications differ (Levine, Jones & Bee, 1992; Porco, 2016).
3) Those under 18 years of age and over 55 years of age.
4) Those in an acute hospital setting.

   People in acute setting face issues that may not be considered applicable to those living with a HS in the community.

In response to the study 'Call for Volunteers', potential participants contacted the researcher directly, via telephone or email, to discuss their possible participation in the study and to ask questions regarding the study procedures and the implications of taking part. The researcher provided an overview of the study including the rationale for the study, the questions that would be asked at the interview and the approximate duration of the interview. Once eligibility was confirmed, each potential participant was sent the Study Information Sheet / PLS (see Appendix D) and a copy of the Consent Form (see Appendix E). They were advised to read the material and, if desired, to discuss the content with others. The researcher contacted each potential participant one week after initial contact to discuss any questions they had regarding the PLS and the Consent Form. If they were still interested in taking part in the study, interview arrangements were made.

Two people who contacted the researcher were not included in the study as they did not meet the inclusion criteria. They were thanked for their interest and because they had expressed an interest in research, they were directed to the website of a prominent organisation in the field where they could access information on other research projects.

Participant Profile

Participants were recruited, with support from stroke affiliated organisations, from a variety of locations across the Republic of Ireland. Although recruitment for the study was challenging as there are less young adult HS survivors when compared with ischaemic stroke survivors, six individuals (three men and three women) participated in the study. No participant chose to discontinue with the study. Table 4 describes the age profile and the time elapsed since the stroke.

Table 4: *Age Profile and Time Elapsed since Stroke*

	Current age (years)		**Age at stroke onset (years)**		**Time elapsed since stroke (years)**	
	30-44	**45-55**	**30-44**	**45-55**	**<10**	**10 - 19**
Number of Participants	3	3	3	3	5	1

The mean age of the participants at the time of interview was 46.1 years and the mean age at stroke onset was 40.6 years. The mean time elapsed between the stroke onset and the research interview was 5.3 years. Table 5 presents the sociodemographic characteristics and the stroke profile of the participants.

Table 5: *Sociodemographic characteristics and stroke profile of the participants*

Characteristics	
Current Mean Age (years)	
Male	43.3
Female	49
Mean Age at Stroke Onset (years)	
Male	37.6
Female	43.6
Type of Stroke (n)	
Subarachnoid Haemorrhage	2
Arteriovenous Malformation	3
Ruptured Aneurysm	1
Length of stay in Hospital (days)	
<21	4
≥21	2
Discharged to (n)	
Home	4
In-patient Rehabilitation	1
Community Services	1
Ethnicity (n)	
Irish	5
Eastern European	1
Education (n)	
Third Level Degree	4
Professional Training	2
Current Employment (n)	
Full Time	2
Part Time	2
Volunteering	1
Sick Leave	1
Current Marital Status (n)	
Married	4
Single	2
Current Living Arrangements (n)	
With family	4
Alone	2
Location (n)	
Urban	5
Rural	1

Participants were from a number of locations across the Republic of Ireland and came from a middle-class, socioeconomic background. As seen in Table 5, four participants completed third-level degrees and two participants completed post-primary education and professional training associated with their chosen careers. At the time of the stroke, all participants were working professionally. At the time of the interview, four participants were working full-time or part-time, one was volunteering in their community and beyond and one participant was in receipt of Illness Benefit.

Five participants were Irish nationals, and one participant was a foreign national, fluent in English and had been living in Ireland for a number of years. Three were married at the time of the stroke, two of whom had children. Since their stroke, one additional participant married and had children.

Participants were generally unaware of the precise location of their stroke, or the blood vessel involved. One participant had to confirm with family members what type of stroke they experienced. All participants were physically mobile at the time of the interview but were experiencing ongoing cognitive, psychosocial and / or emotional difficulties such as headaches, fatigue, speech difficulties, short-term memory difficulties, vocational difficulties, social isolation, anxiety and worry.

Data Gathering

An interview schedule (see Appendix F) was adopted as a prompt and provided the researcher with a guided structure to ensure the interviews were focused and pertinent to the study (Mruck & Mey, 2007). It also served as an additional measure to support the researcher with remaining objective to the participants' experiences (Fassinger, 2005). The schedule was modified, where necessary, to help participants answer questions. For example, the participants were asked to create a timeline of events from the stroke onset to their current ADL's. Additionally, questions were rephrased at the participants' request.

The procedure of theoretical sampling was adopted in the current study, which enabled the researcher to focus additional interviews on the processes these young adults engaged in to move forward following their stroke and to establish how this was facilitated. This focus was based on the concepts emerging from analysis of the first four interviews. Participants were invited to talk in detail about the key processes they engaged in their daily lives. For example, returning to work was an experience each of the first four participants raised during their interviews. Thus, the remaining two interviews asked about return to work experiences. Additionally, the relationships between the self and time and the self and others emerged during the initial analysis and these latter participants were invited to discuss whether and how these concepts related to their experiences. The researcher also returned to the previous four interviews to re-analyse the content related to these specific processes and concepts. All interviews were audio recorded for later verbatim transcription and that assisted with the data analysis phase. The duration of the interviews ranged between 54 and 90 minutes. The average interview lasted 79 minutes. Repetition, paraphrasing and rest breaks were afforded to all participants.

The researcher conducted a debrief after each interview, ensuring participants were not unduly distressed from sharing their experiences. No participant reported feeling distressed following the interview. The participants were asked if they could be contacted again for clarification of their data if required or if additional questions arose from the analysis. All participants agreed to be contacted again if necessary. The participant's contact details were clarified, and they confirmed if they wanted a copy of the findings report and how they would like to receive this, e.g. post /email. Details of support service helplines were offered to the participants at the end of the research interview, if they decided that they required further support, for example, the need for emotional support, peer support, further information on stroke (see Appendix G for support service helplines). Four participants requested this information. The participants were thanked for their time, and the interviews were concluded.

Glaser (1998) advises that researchers maintain field notes to later unlock the creative, analytic process of theory generation and also to develop a methodological skill. Field notes were prepared after the research interviews and later during the transcription phase whereby the researcher documented initial thoughts and reflections about the participants, the interview process and preliminary thoughts about the analysis of the interview (Glaser, 1998). These were later used during the analysis phase. Figure 2, adapted from Gray (2009), describes the content included in the field notes, which influenced the study as it progressed (see Appendix H for sample field note).

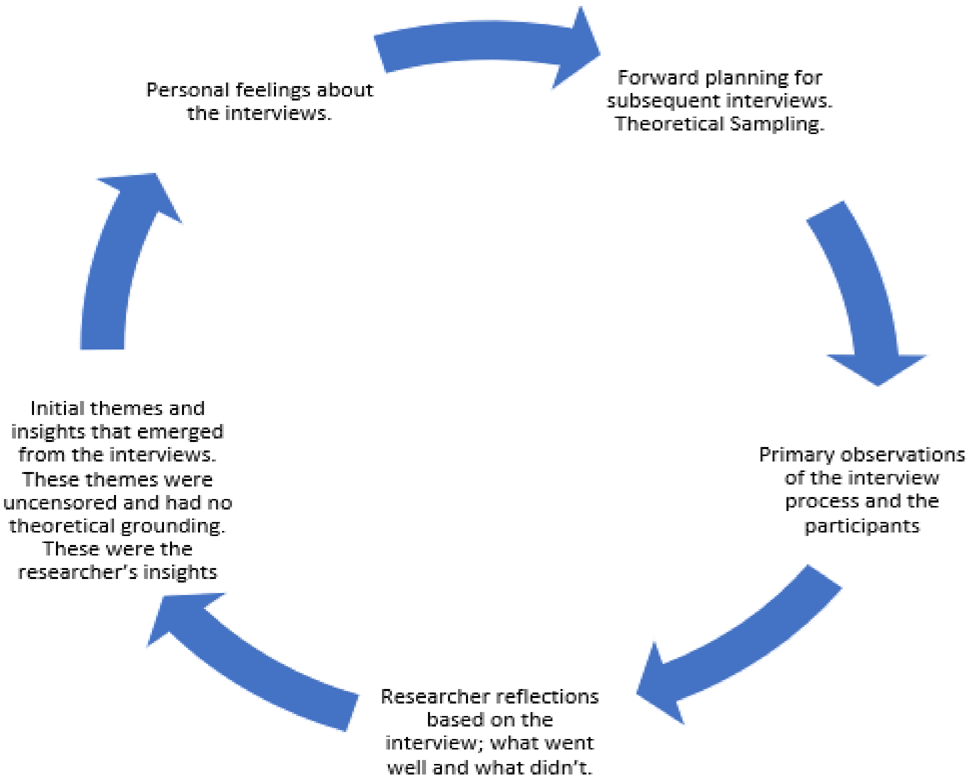


Figure 2: *Content included in field notes*

Data Analysis

Coding the data refers to the process of identifying and elevating categories from descriptive labels to theoretical concepts and is the initial phase of theory generation (Glaser & Strauss, 1967, Glaser, 1978). Glaser (1998) advises against recording and transcribing interviews as it can hinder conceptual thinking, can be time-consuming and is expensive. Instead, he advises that researchers jot down notes during the interview. Nevertheless, to assist with this study's analysis process, the researcher recorded the interviews and transcribed these audio recordings verbatim to ensure in-depth engagement with the data and the analytic process.

During the initial analysis stage, the key question that was asked of the data to establish the main concern was "What is going on in the substantive area". The main concern was identified after analysis of the first four interviews. Once the main concern was identified, the attention focused to categories that were emerging from the data and the subsequent identification of a core category that captured the key processes these young adults engaged in to resolve their main concern.

The stages of coding include:

Open Coding

Open coding (substantive coding) consisted of a line-by-line examination of the raw data to identify what the participants were describing. This coding procedure consisted of noting descriptive codes and thoughts in the margins of the transcripts together with the researcher's conceptualisations (see Appendix I for an example of initial coding). In total, 114 descriptive codes were identified in the raw data across all six transcripts. These codes were documented in a word document, colour-coded and had a number of participant quotes in each code. These were printed out and formed the initial building blocks of the theory.

Taking these descriptive codes and returning to the data, the researcher asked the following questions of the data 1) what is the main concern of the participants? 2) what category does this incident indicate? and 3) what property of a category does this incident indicate? (Glaser, 1998). Adopting these questions and using the constant comparison method, some 38 categories and their properties emerged. The researcher moved from comparing incident with the incident for similarities and differences to comparing incidents with the properties of the category to ensure variations within each category. Some categories collapsed (inviting helplessness) and other categories were elevated (merging fearing and living with uncertainty categories and reconceptualising this to holding fear / doubts which was later reconceptualised to grappling with life). These categories depicted the challenges, issues, actions and processes that were important to the participants. These categories were written on colour-coded cards so they could be easily modified and sorted during the concurrent analysis / data collection phase.

Theoretical Memos

Theoretical *memos "are the theorizing write-up of ideas about codes and their relationships as they strike the analysis while coding"* (Glaser, 1978, p. 83). Theoretical memos were maintained during the analysis phase. Memoing was a free writing exercise that happened at any time and documented any and all ideas about the analysis including ideas sparked from literature relating to the emerging core category, the constant comparison of incidents within a category, incidents with the properties of the categories and the relationships between these categories (see Appendix J for an example of a theoretical memo). These memos interacted with the coding procedures and assisted with elevating descriptive labels to abstract concepts (Glaser, 1978). For example, memos were written simultaneously while coding the data and assisted with the elevation and refinement of categories and their relationships. When a new concept was identified, it could be related to a new category, the re-conceptualisation of a category, the collapsing / building of a category, the properties of a category and / or the relationships between categories or properties, leading to writing amemo. After writing a memo, the researcher returned to the data and reconceptualised where applicable and developed greater understanding of the emerging patterns that captured the participants' key processes. This action encouraged further memoing and this process continued until the final write-up of the theory. Analysing the field notes also elicited new ideas and further memos were prepared based on the initial thoughts post interviews.

All the memos were typed (though hand written if away from the study office and later typed) in word documents. These memos were printed to aid the sorting process; moving memos around a large floor to identify the core category and stimulate ideas about categories and the relationships between categories. These memos were used in the write-up of the substantive theory and are incorporated into Chapter 4.

Selective Coding

Selective coding refers to the development of a core category that integrates the theory and accounts for relationships between the categories. The core category is the central phenomenon and it needs to recur frequently in the data, it must relate to other categories easily and with meaning, it must include variations and finally, it must have 'grab' (Glaser, 1978) and showcase how the participants resolve their main concern (Glaser, 1998).

Theoretical sampling involved sampling the categories and emerging core category with more young adults in this substantive group to refine the emerging core category and other categories, seek variations and establish the relationships between the categories until the core category and other categories were saturated.

Physically sorting and shuffling the colour-coded cards and memos on a large table, floor and wall enabled the researcher to establish theoretical links between the categories and compare categories on a conceptual level (Charmaz 2006) and aided in the discovery of the core category.

In the case of this current study, the theory write-up served as a long memo-writing process as categories were renamed and selective coding continued until the final draft of this thesis. A number of core categories were conceptualised but were re-conceptualised as they did not integrate with the categories. For example, the core category was initially conceptualised as ‘persevering through adversity’ which later evolved into ‘blending selves’. Continuous sorting, memo-writing and concurrent analysis further delimited the categories, which identified the core category and three interlinked phases of recovery within. The core category ‘Re-purposing My Self’ was central to the other categories, accounted for variations between the categories and in the categories and encapsulated the process the participants engaged in to resolve their main concern.

Theoretical Coding

Theoretical coding theoretically explains the empirical relationships and patterns between the substantive categories (Glaser, 1978). Grounded theorists should be aware of a number of theoretical codes in an effort to adopt the code that best fits with the substantive categories (Glaser 1978, 1998, 2005). In the current study, the concept of purpose is (McKnight & Kashdan, 2009, p. 242) *“... a central, self-organizing life aim that organises and stimulates goals, manages behaviours, and provides a sense of meaning. Purpose directs life goals and daily decisions by guiding the use of finite personal resources”*. Purpose is considered a fundamental core of our identity and it provides direction to life and earned its way into the emergent theory. The conceptualisation of the core category ‘Re-purposing My Self’ captures the dynamic and fluid process whereby the young adults, in looking for purpose, integrated their pre and post-stroke selves to function and live with a sense of meaning in the world.

Study Quality and Rigour

This study aimed to gain a theoretical understanding of young adults’ experiences of living with HS. A good grounded theory study is robust, has ‘grab’ and is grounded in the data of the participants’ experiences of the real world (Glaser & Strauss, 1967). The rigour of a study describes the quality of the research process and rigorous qualitative studies can be considered useful and credible when following a set of criteria (Saumure & Given, 2012). Therefore, it is useful to explain the rigorous process used to develop the substantive theory in this study. Glaser (1978) identifies four criteria to evaluate a CGT study and these criteria were adopted in this study: -

1) Fit – The categories must fit the data and should not be forced to fit pre-existing categories or discarded in order to keep a substantive theory intact. First, the categories that were developed and conceptualised in this study emerged from the raw data during the analysis phase and therefore, automatically fit with the data. Once

theoretical saturation of the core category was achieved, attention shifted to the emergent fit of theoretical codes that could work in the study. Theoretical codes account for the relationships identified between the concepts and explained the patterns of behaviour that formed the basis of the emergent theory (Glaser, 2005). The theoretical code, identified as a basic social process, earned its way into the theory and explained the latent pattern of social behaviour that formed the basis of the theory.

2) Work - The theory needs to clearly explain what happened, interpret what is happening in the substantive area and predict what will happen. The substantive theory developed in this study clearly interprets what is going on in the substantive area of living with HS and demonstrates what happened the participants and the course of action they undertook to resolve this. The emergent theory generated in this study can predict what may happen for other young adult HS survivors.
3) Relevance - The theory is relevant to the real world as the main concern and core category emerged from the data collected and not from pre-existing ideas or theories.
4) Modifiability - The emerging theory is naturally modifiable as the real-world changes. The substantive theory generated can be modified as new data becomes available. The categories and theoretical codes were readily modified as new data emerged during the data gathering and analysis phases, while still maintaining its relevance to young adult HS survivors. Additionally, the substantive theory can guide future research in this area as the real-world changes. Thus, this study is *"theoretically tractible"* (Glaser,1978, p. 3).

The criteria as set out by Glaser (1978) evaluated the quality and rigour of this CGT study. Not unsurprisingly, different qualitative research methodologies have different criteria and methods when appraising the quality of the study undertaken (Yardley, 2000). Yardley (2000) developed a framework so that any qualitative study could be evaluated using this framework. For a qualitative study to be considered as that of high quality, the study needs to be legitimised by criteria which are meaningful to those who will benefit from the study.

Yardley based this quality framework on four principles 1) sensitivity to context, 2) commitment and rigour, 3) transparency and coherence and 4) impact and importance. An overview of these principles is provided here. The application of these four principles is discussed in detail in Chapter 6.

Each of these four principles can take on many different forms which can accommodate differing qualitative approaches. Regardless of the methodology adopted, sensitivity to context involves considering in detail the prior relevant literature, empirical data, in so far as it exists, sociocultural settings within which studies took place, participant's perspectives and ethical issues. Commitment refers to the in-depth engagement with the topic and demonstrating dedication to develop research skills. Rigour relates to the rigorous approach of the study process. Transparency refers to the transparent methods of data analysis and data presentation. Coherency accounts for the clarity and power of participants' accounts and that the research method and the aim of the study fit together. The impact and importance of the study refers to the benefit of the findings.

This current study which aimed to gain a theoretical understanding of young adults living with HS, can be considered a rigorous study based on the application of Glaser's (1978) criteria for quality and rigour. In addition to Glaser's (1978) criteria, Yardley's (2000) quality framework was considered useful to evaluate the quality of this study further.

Ethical Considerations

The main ethical considerations pertinent to this study were as follows:

1) Researching a vulnerable population;
2) Informed consent;
3) Discussing a sensitive topic;
4) Participant and researcher's safety;
5) Being an insider researcher;
6) Data management.

There are some well recognised cognitive and emotional vulnerabilities associated with this sample. For example, cognitive dysfunction, fatigue, depression and anxiety (Powell et al., 2002; Koivunen et al., 2015; Vetkas et al., 2013; Persson, Törnbom, Sunnerhagen & Törnbom, 2017). Other specific factors that are identified in the ABI population and that are relative to this sample include inconsistency with recounting narratives, confabulation and emotional lability (Klonoff, 2010; Lewington, 1993). Thus, the participants in this study were considered a vulnerable sample. Strategies such as repetition, paraphrasing, visual imagery, rest breaks and reducing stimuli were introduced, where needed, during the interview process to assist participants to manage these difficulties (Carlsson, Paterson, Scott-Findlay, Ehnfors & Ehrenberg, 2007).

Stroke-related impairments can affect stroke survivors' ability to provide informed consent (Rose & Kasner, 2011). The participants contacted the researcher voluntarily to express their interest in participating in the study. The participants were fully informed of the research study and the implications of their participation during the initial telephone call. The PLS and consent form were forwarded to the participants to review, and they confirmed that they understood the information and wished to continue with participating in the study. The purpose of the study, the interview process, confidentiality and the potential benefits and risks of participating in the study, as outlined in the PLS, were discussed again between the researcher and each participant at the beginning of the research interview. To verify the participants did not have any difficulty in understanding the interview process, the researcher asked the participants questions regarding the study process, for example, "Can you withdraw from this study?" and "Are there potential risks to you participating in this study?" All participants were invited to ask further questions should they so wish. The consent form was discussed, and both the participant and the researcher signed this before the interview commenced.

It was reasonable to expect that the participants could become distressed during the research interview, evoked by discussing sensitive issues such as difficult life experiences and the impacts associated with their stroke (Richards & Schwartz, 2002). Care was, therefore, taken to minimise this. Draucker, Martsolf and Poole's, (2009) two-stage management protocol was adapted to this interview context, and this guided the researcher in observing any signs of emotional distress in the participants. Strategies were devised on how to support participants who may become distressed during the interview. For example, suspending the interview and /or encouraging the participant to contact their GP if appropriate (see Appendix K for the two-stage management protocol adapted for this study).

Data were gathered in a number of locations across the Republic of Ireland, and the research interviews were conducted in a private conference room, in a hotel, in the locality of the participant, to ensure the safety of both parties. The researcher's supervisors were notified of the date, time and location of all interviews and were notified once each interview concluded. The researcher secured a separate phone number, specifically for this study, to ensure that any personal information was not shared with the participants.

As an insider researcher, the researcher was aware that the participants' stories might elicit emotional or problem-solving responses from the researcher and good psychological care was important. For example, the researcher ensured she had sufficient time to travel and prepare for the interview and enough time after each interview to reflect upon the interview content and the impact it had on her. Field notes regarding the interview process were prepared after each interview, and the research interviews were discussed with the researcher's supervisors. The interview schedule guided the structure of the interviews. The transcripts and analysis were reviewed by the research supervisors to ensure the analysis procedures were conducted systematically and were free from the researcher's biases.

A number of measures were taken to ensure that the confidentiality and the anonymity of the participants were held in the highest regard. For the duration of the study, only research personnel, namely the researcher and her supervisors, had access to the data. All hard copy information including the consent forms, transcripts, field notes, and details of interview appointments were stored separately and securely in a locked filing cabinet in the researcher's home. All electronic information including transcripts and the audio files were password-protected and stored on the researcher's password-protected home computer. These audio files and electronic transcripts were backed-up on password-protected computers in the offices of the researcher's supervisors. The hard copies of the transcripts were numbered (to ensure anonymity) and stored in a locked filing cabinet in the researcher's home for the duration of the study. With the participants' consent, hard copies of the transcripts will be stored until October 2023 to facilitate publications and future research. The research team will ensure best practice regarding data storage and destruction for five years after study completion (October 2023), in line with Dublin City University Information Systems Services, Dublin City University 'Data Handling Guidelines' and the Data Protection Act, 1998 & 2003.

Summary

A CGT methodology was adopted to gain a theoretical understanding of young adults' experiences living with HS. Six one-to-one, face-to-face, semi-structured interviews were conducted and analysed.

Ethical considerations, pertinent to this study, centred on the sample which could be considered vulnerable, the topic, which could be considered sensitive and the safety of all concerned in the study process. The procedures that were devised ensured that the participants were not exploited in any way and a safe research context was created.

The quality and rigour of the study were evaluated, ensuring that the theory generated from the data is robust, has ‘grab’ and is relevant to the real-world of HS survivors and those working with them. The substantive theory was identified following a systematic and rigorous set of data analysis procedures and are presented in Chapter 4. This theory describes a non-linear, phased recovery process over time and is grounded in the real world of experiences of young adults living with HS.

Chapter 4 - Findings: Re-Purposing My Self

Introduction

This chapter describes the key findings from this study that investigated the experiences of young adults living with HS. The concurrent data gathering and analysis procedures were consistent with a CGT methodology, as outlined in Chapter 3. This chapter outlines the main concern, the core category and the three major categories that describe the recovery process post-HS. Participant quotes are included to illustrate patterns identified in the data and bring richness to the findings.

The main concern '**Losing My Self'** describes the sudden and profound impact the stroke had on the participants' sense of self. Their beliefs and assumptions about themselves and the world were stripped from them and what remained was a fragile, under-developed sense of who they were in the world.

The core category conceptualised as **'Re-Purposing My Self'**, captures the non-linear process the young adults engaged in over time to process and resolve their main concern. As conceptualised here, 'Re-purposing My Self' means finding a self that is meaningful and purposeful, which can take months or years post-stroke.

The major categories within the core category capture three interlinked phases in the re-purposing process, ***'Reeling from the Shock', 'Living Cautiously'*** and ***'Reshaping Life'.*** Participants engaged in this process to develop a meaningful sense of self that enabled them to fit in the world as people who have survived a HS. This involved them coming to realise what had happened to them and prioritising their recovery, mourning their pre-HS lives, finding ways to manage and live with the impacts of their stroke and making changes that helped them to develop an acceptable sense of self and life as a HS survivor.

Figure 3 outlines the core category, the three major categories and their sub-categories that constitute the interlinked phases of resolving the main concern of '**Losing My Self'**.

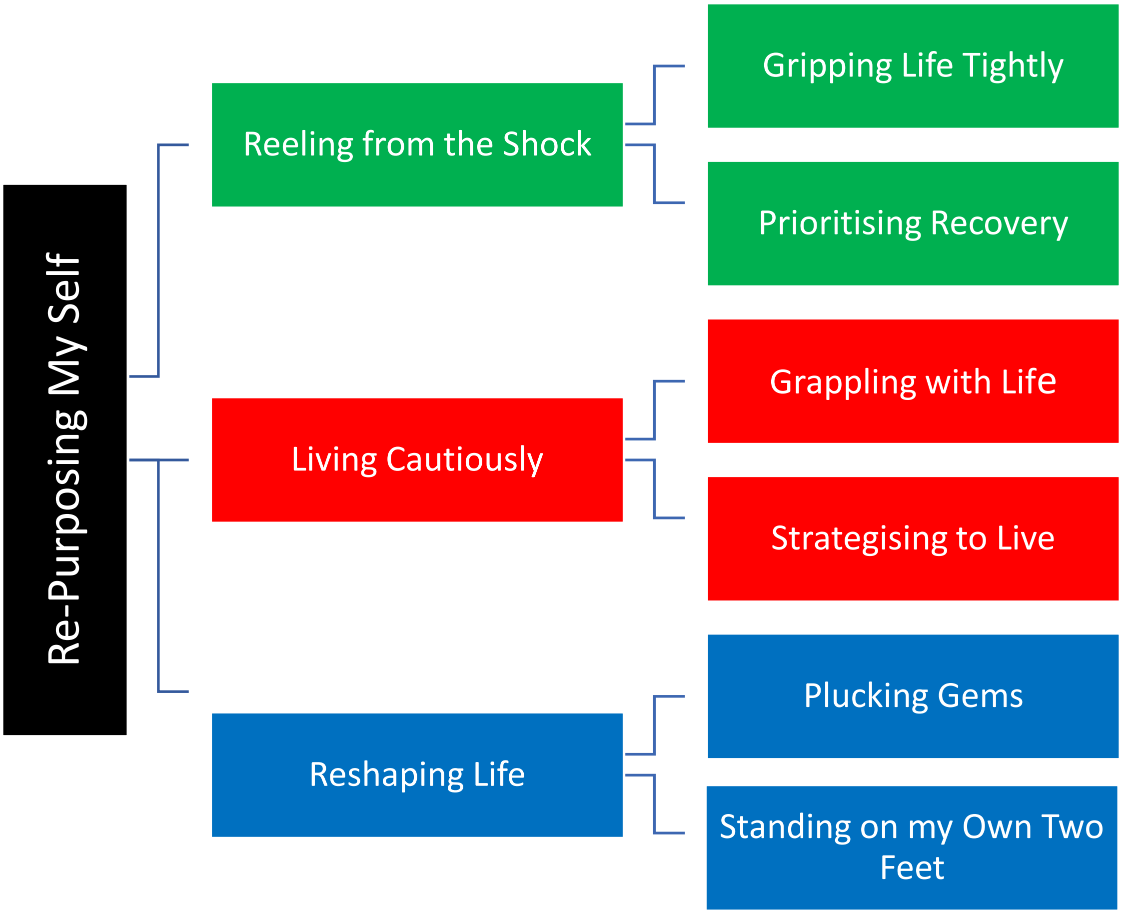


Figure 3: *Resolving the Main Concern: The Core Category, Major Categories and Sub-Categories*

The concept of 'the self' has been defined and subsequently theorised in many different ways, spanning across philosophy, psychology and education literature (Chen, Boucher & Tapias, 2006; Robbins & Hong, 2013; Zander & Hannover, 2014) and beyond. For the purpose of this study, the self, from the young adults' perspectives, describes the unique implicit and explicit totality of a person. The self is the individual's perception of themselves and the feelings one has about themselves, which are influenced by their personality traits, strengths, weaknesses and relationships with others. The self is an evolving phenomenon that is shaped by positive and negative life experiences. Life experiences influence the meaning attributed to those experiences, our relationships with our selves and others and our worldview. Thus, the self is a by-product of life experiences and is, shaped by significant life events, such as experiencing a stroke.

Main Concern: Losing My Self

The main concern that emerged from the data was conceptualised as **'Losing My Self'** which captures the central issue for these young adults - a loss of self, caused by the stroke. After experiencing a HS, the participants' sense of self changed significantly.

> Do you ever get stuck in the world, like a cyclone? Everything was spinning. My life was out of control. The loss of function, the loss of life, what am I doing? What am I meant to do with my life here?…I'm [age] …living in a trance…I just wasn't in a good place. (P5)

> Initially…I just thought that there was no chance of recovery…this is the way I was… (P3)

As revealed in the data, participants fell victim to the stroke and no longer fitted in their world as they knew it pre-stroke. How they perceived themselves and the world around them and how others perceived them suddenly changed. Who they were and what they aspired to be was taken from them. The stroke caused immediate disruption to their lives and influenced their future life-orientation. Their daily routines and relationships with family, friends and colleagues changed, and their lives were dominated by their stroke. Their beliefs and assumptions about themselves and the world were stripped from them. They began questioning who they would become and what their future would hold.

> ...all the time...I'm still sort of looping around that concept [of having a stroke]... (P1)

> I didn't know up from down...everything was wrong...I was just...out of sorts …I was stressed and tired and...distressed as well with...that blow...that life had dealt me... (P2)

Faced with many new challenges, for example, learning to walk and talk, remembering names and conversations, managing fatigue and trying to resume pre-HS roles was distressing. All aspects of the participants' lives were impacted, and they experienced reduced control over life. Their purpose in the world no longer made sense and their future orientation was uncertain. Their sense of self was, therefore, compromised.

Having identified the main concern, the second stage of the analysis involved identifying the key processes the young adults engaged in, over time, to resolve this concern**.** This lead to the identification of the core category ‘Re-Purposing My Self’ and its constituent major categories and sub-categories, which together reveal the non-linear, yet interconnected, phased recovery process to resolve the main concern.

Core Category: Re-Purposing My Self

As noted above, the stroke caused participants’ lives to stop abruptly. This was followed by significant impacts, and that led to a need to re-purpose the self. The core category conceptualised as ‘Re-Purposing My Self’, and the three major categories outlining the distinct, yet interlinked, phases in the re-purposing process are described in detail.

Participants, in the immediate aftermath of the stroke, were in anguish and at a standstill in time, wondering how the stroke happened and, specifically, how and why it happened to them. They wondered how and when they could resume their lives, only to be faced with the realisation that their life, as they knew it, was on hold and that life post-stroke was different.

> After the stroke, everything is paused… (P1)

The post-HS recovery involved a complex process of re-affirming the skills and attributes they possessed pre-HS. They realised they were living a life with an unexpected disability and that changed who they were in the world.

> …People have this perception that if you have a stroke that you're disabled and that you're not a whole person anymore and that's how that's how I felt… (P6)

The participants initially began living a life that required support from others, particularly from family members. Some participants had to re-learn basic skills such as walking and talking, and all had to develop strategies that enabled them to adapt and function in the world. Making these changes empowered the participants to regain and /or develop their sense of self so they could comfortably fit in the world post-HS.

> Day to day…it’s…consolidating what you've eh had to learn or relearn…just simple, simple stuff like…how to move your hand a certain way or how to make your leg…sit down and then rise up again…simple stuff and then do gradually more complex stuff. (P2)

Various mitigating and motivating factors influenced the re-purposing process as the participants began the difficult journey of making life meaningful and repairing their fragmented selves. Although challenging, the re-purposing process was considered positive as they learned to integrate their pre and post-stroke selves. They developed new skills, made necessary lifestyle changes and established renewed relationships with others. They were regaining a totality that enabled them to modify their worldview and create meaning and a sense of belonging in the world.

> Life will never be the same again but…it's taken in a negative context...but I mean it in a positive context...you know, it's just… different. (P2)

Re-Purposing My Self - Phase 1 - Reeling from the Shock

In this first phase of re-purposing, the young adults struggled with the suddenness of their stroke onset which caused an immediate disruption to their life and a devastating impact on them. They were reeling from the shock and were left with unanswered questions as to why this had happened and what the future would hold.

They vividly remembered the initial shock and what they were doing at the time of the stroke and the warning signs they experienced, such as a severe headache, nausea, visual impairment, face drooping and swelling.

> When I got the stroke that evening, oh my God, and the headache…if I sat here forever telling you the pain [of] that headache…I couldn't tell you how painful it [was]. It [was] excruciating and the vomiting and the bright light, oh my God, [the] light from the ceiling I thought was boring through my head. (P4)

> I got the thunder clap…it went dark, and my hearing went. [There was a] tightness in my throat…[my] sight went and [I] didn't fall down but the symptom came back up again. But it was like you know sometimes you see movies like…somebody going underwater, and it's like a dark veil coming up… and I knew I was making no sense… (P5).

Three of the participants were with others when the stroke occurred, so an ambulance was called immediately. One participant was in a hospital for unrelated treatment when their stroke occurred. Another presented themselves to their local Accident and Emergency Department because they did not feel well whilst the sixth participant was at home alone, physically sick for two days before driving themselves to hospital. This individual still wonders how they arrived there safely. All were reeling from the shock that they had suffered a stroke.

> ...I obviously wasn’t expecting it. I didn’t sign up for it. Life changed dramatically in the space of a few seconds. (P5)

> They [medical professionals] just couldn't believe it. They were saying we can't believe [it]...nobody could believe it... it was such a shock to everybody. (P6)

In the immediate aftermath, they were **gripping on to life tightly**, hoping that they would survive the stroke and be fine and they felt the need to **prioritise their recovery** so they could resume their pre-stroke lives.

Gripping Life Tightly.

This sub-category describes how the participants tried to restart the clock after the stroke caused their lives to stop. Two of the participants required longer stays in hospital than did the four who were discharged relatively quickly. This longer hospital stay prolonged their state of shock and confusion. These two individuals were gripping life tightly in the hope of surviving the stroke in the first instance and then regaining some physical functioning.

> …It’s only maybe the third day of having a stroke so I wouldn't have been even on my left side. I would…try and pull [myself] up in the bed. I was totally in incapacitated we'll say and my speech…it slowly came back in dribs and drabs…(P3)

Of note, some participants did not realise that they had survived a near-death experience, nor did they appreciate fully the seriousness of the situation.

> I was convinced people were making way too much fuss about it, I mean…I did not see. It was weird because at first, I was so convinced I was going to be let go straight away, I did not even want to change into a hospital gown. I’m just going home tomorrow…why change… (P1)

> Do people die of this stuff? (P5)

The four participants, who left the hospital in a matter of days, one of whom discharged themselves against medical advice and returned to work, were clinging to the hope that all was now well and that they could move on with their normal (pre-stroke) life.

> ...you have no rational thought [immediately after the stroke]...I discharged myself and went back to work against the wishes of my neurosurgeon… (P4)

Two of the four participants began testing reality, trying to resume daily activities as quickly as possible.

> I talked to the doctor, and I asked him “Do you think I can go back to work next week?” He started laughing so badly and goes “No” and I go “Week after next?” and he goes “No, maybe three months”… (P1)
>
> Even in the hospital bed, I said bring in the laptop, to pay the bills from the hospital bed. I couldn't remember the password. (P5)

For all, the experience of stroke evoked curiosity, and they were looking for answers regarding what factors might have contributed to the stroke.

> I was a healthy young, well youngish, woman, you know, I’d moderately drink, don’t drink during the week, I don’t smoke...I’m relatively fit, and I had this [stroke]…(P4)

Without exception, the participants began to realise how vulnerable they were and felt their bodies had let them down in ways that they had no control over. Their lives were changed, without their consent, and they wanted explanations as to how and why this happened. Ultimately, they sought answers so that they could avoid a recurrence and, where possible, influence their recovery.

Prioritising Recovery.

In this sub-category, though living with the unanswered question of why the stroke happened, the participants shifted their attention to what they could do to help their recovery. They were at various life stages; therefore, their unique recovery patterns reflected this variability.

One female was married and had just had a baby. Although very difficult for her, she chose not to see her baby while she remained in hospital and she focused entirely on her recovery so that she could return home to her newborn as quickly as possible. Two female participants, both of whom were single, isolated themselves from their family for a period of time so that they could focus on getting well. Initially, for fear of worrying their family members, they did not disclose that they were in the hospital following a stroke. Both thought this would be easier for themselves and their family and would, indirectly, allow them more time to come to terms with what happened.

> I did not want to worry my family, so I did not tell them what had happened… (P1)
>
> I didn't tell my family because my mother lives on her own. She's 87. She lives at home in [location]… My father's dead and…there was no one to tell other than my friends, and I would be very independent, and I was thinking oh sure why would I worry them, I'll be out of there soon… (P4)

In contrast to the women who sought to protect others (and possibly themselves) by not disclosing their stroke, or not leaning on family for support, the male participants utilised all necessary familial support to prioritise and to maximise their recovery for as long as needed.

> I was very self-centred, and I was very focused on getting me right and getting back to the place where I thought I should be and wanted to be. (P3)
>
> ...stay strong in yourself...and...that includes...rallying the troops of the family and the friends and whatever resources you have. Make the most of them...this is...potentially the worst moment in your life...and...all else pales into insignificance compared to this... (P2)

Both ways of dealing with the stroke and prioritising recovery were considered useful for the participants at that time. They survived the stroke, and now they were looking to survive life. During this part of the 'reeling from the shock' phase, participants did what they felt was best for themselves and their recovery, so that they and their family could return to their normal status quo.

> I wasn't worrying about work and I wasn't worrying about the bills or anything like that...I was thinking this is great, I can concentrate on getting back on the bike...my focus was getting back on that bike. (P3)
>
> …I took the month off in October after I'd had [the stroke]…my body was begging me to stop… (P4)

Although deemed essential, prioritising their recovery was an overwhelming time for the participants, and this had consequences in terms of fitting back into their lives. For example, the mother who chooses to take time away from her baby struggled with attachment issues later.

> ...when I obviously got out to [baby]...I probably had attachment issues with [baby] because...I wouldn't allow anybody to touch her...and she actually stayed in the room with me for about twelve months. I wouldn't allow anybody to go near her. She was stuck to me... (P6)

Participants described the stroke as a dramatic life-changing event for themselves and their entire family. One participant moved home to recuperate while two had family members move in with them following discharge from the hospital. Two participants did not have an immediate family support network and thus managed this traumatic, draining and emotionally charged experience alone.

> I would have loved somebody to come along and say, do you know what, I'll mind you, it's alright…I'll mind you, it's fine. Come on away with me now, and I'll look after you. But there wasn't anybody. (P4)

In essence, the stroke onset and subsequent immediate recovery were very overwhelming for the participants. Without understanding the implications of their stroke, they were gripping life tightly either trying to return to their pre-stroke lives or regain physical functioning. How they managed this was individual and prioritising their recovery became the focal point for all of the participants.

Re-Purposing My Self - Phase 2 - Living Cautiously

The participants realised how unpredictable life was and they feared their actions might cause a second stroke. They felt misunderstood and subsequently isolated during this phase in their recovery. They were living in a vacuum, moving cautiously between their pre and post-stroke lives. As the catastrophic impacts became clear, the participants, thus, began the arduous, lonely process of adapting to their limitations, which was challenging and required patience and adjustment.

> …I had to basically adjust my life…(P6)

At the same time, it allowed them to regain a sense of purpose in life. They began repairing and subsequently re-purposing their sense of self through the dynamic process of **grappling with life** and **strategising to live**.

Grappling with Life.

As the data reveal, clinging to an old life while contemplating a new life was daunting and challenging. Participants were treading in unknown territory, which was, for them, frightening. Living with this level of uncertainty was challenging as many questions remained unanswered, even by the professionals who were the experts in stroke and healthcare. Participants were living in a timeless vacuum, filled with fear and trepidation about the future.

> Oh my God! What am I going to do now?...Everything is a question mark. My body is a question mark. Is another stroke going to happen is a question mark? That freaks me out. (P1)

During this phase, as they became aware of their stroke impacts, there was a heightened sense of grief. The participants felt lost in themselves and for the person they once were while at the same time recognising their lives would be different. They were craving a sense of normality and wanted their pre-stroke lives back. They were stuck at a crossroads, not knowing what direction to take.

> I want my life back and I know I cannot go back to that life and I don't know which life I will have. (P1)

They felt their future was bleak and that the stroke had changed their sense of who they were and they felt incomplete.

> The person that went out the door that day is not the person that went back in again. It’s getting to know you all over again. (P5)
>
> I felt I wasn’t whole anymore, I was broken. (P6)

Three participants were fearful of a recurring stroke, and one suffered a second stroke while in the hospital for medical treatment for the first. For all participants, the stroke and its consequences propelled them into insecure territory. They were on tenterhooks, existing under the influence of the stroke. Despite not understanding the seriousness of the stroke initially, they were now fearful of facing their mortality. They were living in a dichotomy of trying to progress their recovery while fearing that this might actually cause another stroke. Their lives were paused, and they were frustrated with this.

> The accident happened less than halfway in-between the two points pretty close to my house…I cannot go back there. I stupidly…tried…I thought ok, it’s a new year, new beginning, let’s go for a walk…the normal way…I hit the point, and I got paralysed yes, and I could not walk, and it was the closest thing to a panic attack. Consciously it was a panic attack, and I was straight back… (P1)

> I would wake up during the night drenched in sweat, and I remember just always constantly feeling my face thinking “I'm having another one, I'm having another stroke”… (P6)

The participants experienced a sense of loss about the things they could no longer do and missed the essence of having a purposeful existence. They had lost important identity markers, such as their job.

> I was hoping to start my own [type] practice, that all disbanded…(P2)

Their sense of self was entrenched, at least to some extent, in their work as it gave them financial security as well as a purpose. Not working and experiencing financial loss was difficult and contributed to participants living in a constant state of flux, uncertain about their future. This was a source of added stress for some of the participants.

> I have to explore from welfare if they will continue paying me or help me…with rent supplement if I go back to work part-time, as part of rehabilitation. Because if I only have money from work I will not be able to live and that will create stress that I don't need right now. (P1)

Of this who did return to work, their experiences were varied when attempts were made to return to work. In some instances, employers were accommodating and were prepared to be flexible and modify work activities, while in other cases, they were not.

> They were very fair to me. They used to bring me in for only a couple of hours or an hour at a time, but they brought me in nearly every day or at least every second day… (P3)

> I actually don't think my boss really believed that I had had a stroke. (P4).

Others sought alternative careers or made their own modifications to the way they worked.

> …if I'm doing a task at work, I know that I have to … step it out, step one, step two. I have to step it out. If I don't step it out, I actually start inside panicking… (P6)

Therefore, finding a place between their old and new selves and lives meant letting go of some past identity markings and finding new ones that were more in keeping with their emerging new roles.

Strategising to Live.

Over time, the participants' physical symptoms resolved. For example, pains eased, the frequency of the headaches reduced, and mobility and speech improved. Although improving physically, participants realised that they were experiencing ongoing issues such as fatigue and cognitive deficits including difficulties with initiating and completing tasks, memory, attention and concertation difficulties.

> I had tasked myself to change the bed and…I went to make the bed, and…it took me three hours. I couldn't get the coordination, which was dirty, which was clean, putting the sheets on, putting the duvet on…when I was done, I wanted to get into the bed…I was clueless. (P5)

The realisation that they were experiencing new difficulties at home made them aware that life would be different.

> …I have such sensitivity to light…I still have headaches…I cannot…venture out without getting dizzy or I get tired…now I'm becoming aware of how much it has impacted on my life. (P1).

> I suppose the aftermath of [the stroke] is a huge, huge…issue for me… (P2).

This was difficult to cope with and was influenced by the need to adapt to their current situation so they could function in the world.

> It' a life altering event. I could see how it could bury a lot of people. (P4).

> Prior to the stroke, I would have been like a little battery…I would have survived on little sleep…I would have been running around, doing everything…and then after the stroke, I just had basically no energy to do any of that. That was frustrating because I felt I could still live that life…and … it took me a while to adapt to that. (P6)

They felt ill-equipped returning to normal life. Four participants were discharged from hospital to their home and were not involved in any rehabilitative services nor were they ever. They received little support and education about stroke or community stroke services that would help them regain their autonomy. Therefore, the participants called and drew upon internal resources such as determination, perseverance and self-direction to learn more about their difficulties and how to overcome them.

> I was off out into the world googling after effects of haemorrhagic stroke- is tiredness an after effect of haemorrhagic stroke? (P4).

As they adjusted to their current situation, they developed strategies to manage their difficulties and their daily lives. These included strategies such as writing things down, setting alarms to remind themselves of tasks to be completed and taking regular rest breaks to avoid fatigue. Two people who availed of inpatient rehabilitation learned to strategise with the help of professionals. The remaining four individuals did not receive formal rehabilitative support and learned to manage their challenges and develop strategies on their own.

> I write down, or I put [it] on the phone. Pretty much everything that I need to do and actually, I underscore it by putting it…on a…physical calendar as well. (P2)

Strategising to live was often a process of adaptation and adjustment, and the participants needed to find strategies that suited their individual needs.

> I was taking two part-time courses; I'm only taking one as a way of having social contact as it's the least demanding of the two. (P1)

Strategising was considered a useful technique to help re-purpose the self. Strategising enabled participants to take control of some aspects of their life and situate themselves in the world, albeit now different from their pre-stroke self.

> I have structures in place... I am lucky enough that I was still young enough to use the technology but still have the calendar at the back door. I have...a tablet...with all the different emails accounts going with it and the calendar so if...we have to order oil in to the house...[I'll] go in to the back hall and click on the wall and [I] can see… (P5)

The participants' relationships with others had often changed as a result of the stroke, and the realisation of their post-stroke limitations gave rise to strains in these altered relationships. Typically, roles within the family had changed because of the need to support the participant. These altered relationships caused participants to feel frustrated with their current situation, and the emotional impact of stroke was beginning to emerge.

> Ours was a pressure cooker and was seriously not a good spot… (P5)

Being dependant on others was challenging, which significantly impacted the participants' feelings about themselves.

> I did not like him telling me "you shouldn't be going out now Saturday night because you're going out Friday night and you know you can't do two nights now"… Don't have anything planned in the afternoon 'cause you got to sit down, and you got to rest". That drove me mad…"you're not my carer you know." (P6)

Four participants identified changes in their relationships with their friends and this significantly impacted their sense of self.

> My friends were all fed up with me saying that I was too tired…so I did feel very isolated. (P4)

Participants began strategically choosing and limiting their social experiences to avoid discussing or disclosing their stroke. They were also discreetly strategising, hoping no one would notice they were living with a disability.

> I find it easier to make new friends after the stroke…because I felt [old] friends were judging me. (P5)

Interestingly, the female participants were limiting their social experiences and /or masking their stroke more than their male counterparts. Choosing to limit their social experiences or masking the stroke difficulties, served as a self-protective measure to enable participants to continue engaging in positive life experiences that would then positively influence their sense of self.

> I told my close friends…but I played it all down…I masked, and I hid the tiredness from everybody. My mother would only see me at the weekends, but then she didn't know what was wrong with me…I didn't want anyone to know. (P4)

> Nobody at work knows I've had a stroke…I've never spoken about it to anybody. I don't tell anybody. Anybody who personally knows me knows I've had a stroke…I don't look as if I've had a stroke… (P6)

Thus, while trying to navigate the difficult grappling process of mourning (and yearning) for their pre-stroke lives, participants used a range of strategies to manage their limitations following the stroke so they could live an adapted life that took these limitations into account. Sometimes this meant concealing their stroke while at other times, it meant finding ways to overcome limits.

Re-Purposing My Self - Phase 3 - Reshaping Life

This major category refers to how participants integrated their pre and post-stroke life through the combined processes of selecting or **plucking gems** from current experiences so that they could appreciate life again and learning how to be independent by **standing on their own two feet.** They reappraised their life priorities, made positive lifestyle changes and established renewed relationships with others. The participants could reflect on their needs and advise on appropriate care pathways for other young adult HS survivors. The stroke was no longer in the foreground of their lives but had positively influenced their thoughts about life. They were determined to live life to its potential.

> When I hit the bottom, I will come back up…(P5).

Their worldview had changed and, as such, their sense of self was now being re-purposed. The adage 'time heals all' seems significantly poignant during this phase, as the participants made peace with previously being victim to a stroke.

> I’ve definitely seen life with a bit of a different perspective. (P5)

Plucking Gems.

Although the participants no longer felt shackled by the stroke, they did not lose sight of the traumatic experience they had been through and the arduous recovery journey that they were still on. Facing a devastating and incapacitating event like a stroke is never truly forgotten, but the stroke no longer consumed them and they viewed the stroke as a warning sign and were plucking gems of life lessons they had learned. The stroke was no longer in the foreground of their lives but had positively influenced how they lived their lives. The participants were able to reflect positively on their stroke experience and acknowledge the progress they had achieved from the stroke onset.

> I have lived all my life in overdrive…either I change things, or I will kill myself [with a second stroke]... (P1)

> …It’s been…relatively easier to get…not mended, but just as, as good as I can be…(P2)

Furthermore, they recognised the importance of improved self-care and prioritising their needs, which included looking after their physical and emotional health. They developed new skills, developed and maintained meaningful relationships and found a new appreciation for life. The participants continued to live with residual difficulties including fatigue, memory loss and mobility issues and they confirmed that they remained reliant on the strategies they had developed during the living cautiously phase.

> I would say I enjoy people and surroundings and [I’m] much more appreciative of the kids and…and (name)…than I was before (P3)

> I would go grocery shopping and I would get all the groceries…four bags…and now [I’m] maybe going to [the] supermarket every other day and getting small loads of stuff…because I'm understanding some limits. (P1)

They realised they had risen to the challenge of the stroke and their sense of self was no longer dominated by the stroke experience. Regardless of where they were on their stroke recovery journey, they acknowledged their progress, which included returning to work, successfully managing their post HS symptoms and /or fulfilling short-term goals.

> I'm speaking now which I couldn't do…I have full movement which I couldn't do…when I had the stroke… (P2)

> I kind of just slotted back into where I left off and just got on with things… (P3)

Standing on my own Two Feet.

During this latter part of the reshaping life process, the participants were in a stronger emotional position to reflect on their journey and had reached a point where they could acknowledge how lucky they were to survive the stroke. They readily identified what helped them during their journey. They were now standing on their own two feet, comfortable with who they had become, albeit different to who they were pre-HS.

> I'm still a whole person, I'm not broken. (P6)

> I am not the same girl I was not really…I might think I like to think I am and I'd certainly fool everybody else into it but am I really the same person? No. I have fundamentally changed and having a HS is a seismic explosion. It's…a life-changing event. (P4)

They developed new understandings of themselves and their perceptions of themselves and others changed. Their beliefs and assumptions about themselves and their perceptions of how others saw them had changed, therefore how they presented themselves to the world also changed. Though the stroke had shaken the core of their being, they now experienced a sense of personal growth that allowed them to come out the other side of a difficult journey.

> Before the stroke, if I were to have introduced myself, I would have said my name, and I would have said, said 'I'm a teacher, I'm also a writer'. Now… and I don't know how this came about… I will say my name and 'I'm a writer'… (P1)

The participants were hopeful in terms of their future and were mindful that all stroke journeys are individual. They reflected on the importance of needing time during the recovery process to come to terms with their stroke and of the necessity of being afforded enough time to recover. They were also able to reflect on what supports helped them and what supports they needed. Despite some of the participants' relationships becoming strained and others concealing their stroke from friends, all of the participants, upon reflection, acknowledged their friends and /or family were a great support when needed. The participants who were living alone acknowledged that their friends, who later knew about the stroke, were supportive, at least to a degree. Four of the participants who were living with family acknowledged the positive influence their support was in their recovery and in allowing them to reach a point where they could stand on their own two feet.

> I was just lucky I had a good network of people you know between work, friends, medically you know physically with (name) and eh, so I was just lucky that's, that's my, my opinion anyway…people enabled me you know, for me to recover whereas if I didn't get all that support back along the way you know, I don't know what the outcome would be. (P3)

The two participants who received inpatient rehabilitation reported that they found it beneficial in terms of their understanding of stroke and their recovery. The remaining four participants did not receive inpatient rehabilitation and were not educated specifically about the consequences and impact of stroke. Notably, they indicated that a service that they could have linked in with upon discharge from the hospital would have been helpful.

> I would have benefited greatly from…a liaison or community Doctor and they would sit you down and say "you're going to experience tiredness like you never experienced it" (P4)

To aid the recovery process, one participant was offered psychotherapy during inpatient rehabilitation, but they declined the service as they felt they did not need it. Their child did, however, avail of the service to talk about the changes in the home environment after the stroke, which the participant reported was very beneficial to their post-stroke relationship. Another participant requested psychotherapy early on after the stroke as they were struggling with their sense of self during their recovery. They were advised that there was a twelve-month wait list to access the services of a specialist brain injury organisation, which they felt was too long to wait. As a result, this participant availed of a pilot couples-counselling service offered by another brain injury organisation that they managed to access within one week of hearing about the service. They reported finding this service beneficial for renewing their relationship and enhancing their sense of self. Another participant was referred to a counsellor by their GP within the first six months of their stroke which they found useful to process the impact the stroke had on their life.

> …[The] service was very good. (P5).

Of relevance, the participants viewed post-stroke services as fragmented and often inadequate, thereby acting as a barrier to their recovery and to their ability to stand on their own two feet.

> …one glove kind of fits all. (P3)

They also suggested the need for age-specific services for young adults that proactively address their individual needs including information about returning to work, exercise and nutrition. One participant recommended single-site community services that address both the physical and emotional needs of stroke survivors. Two people recommended education in the hospitals to prepare other young adults for the possible challenges they may face upon discharge, such as fatigue and emotional adjustment. Information regarding community services to aid recovery and reduce feelings of isolation was also recommended. There was a consensus among the participants that resources for stroke were vastly limited in comparison to cardiology and oncology services. They were unsure of the reasons for this, particularly given the increased advertising campaigns for a healthy heart and F.A.S.T. (Ireland's current stroke awareness campaign), but they indicated there was an ongoing need for increased services to support young adult stroke survivors.

> Stroke is definitely the poor cousin to all of these things … (P3)

> …Don't forget the strokeys, it's all about the hearties, and that is not fair. We're here too. (P4)

Thus, in gaining independence and adjusting to their new selves and lives the participants were able to reflect upon and advise regarding the needs of other HS survivors in addition to learning about how to adjust to and plan their own lives and futures.

Summary

The findings highlight the centrality of the self in the recovery process for participants and how this becomes impacted as they experience a significant loss of self post-stroke. Through a dynamic process, they create a re-purposed self that is meaningful. The sudden loss of self becomes, in time, the impetus for change, encouraging the young adults to adapt and re-purpose their self.

The recovery process is dynamic and fluid, with the participants moving between the three phases. These three distinct, yet interlinked, non-linear phases are presented as a model and account for the fluctuating and evolving sense of self over time. Participants re-purposed their self and integrated their pre and post-stroke selves to function and live with meaning. Hence, the re-purposing process reflects how the participants were able to overcome their post-stroke challenges and adapt to discover a self that was meaningful and purposeful as a HS survivor. Chapter 5 will situate the theory of ‘Re-Purposing My Self’ in the extant literature.

Chapter 5: Discussion - The Substantive Theory of Re-Purposing My Self

Introduction

This chapter seeks to use relevant literature from the field under study to situate the substantive theory generated in this study. This theory of *"Re-Purposing My Self"* following HS stroke is grounded in the experiences of community-dwelling young adults living with HS and is a dynamic, interrelated self-discovery process. The chapter will discuss how it resonates with and adds new dimensions to the existing literature, pertinent to the areas of stroke recovery and psychotherapeutic intervention with this population, specifically focusing on the concepts of loss of self, existentialism and creating meaning in life.

The Self

A central theme identified in this study, as with other stroke literature, is the fact that the onset of stroke is typically associated with overwhelming feelings of shock and disbelief that uproots their sense of self. Initially, the participants struggled to comprehend how they came to suffer a stroke. This struggle to understand what had happened was also identified in previous young adult stroke studies (Leahy, 2010; Stone, 2005). While the onset of stroke, not unexpectedly, causes all stroke survivors to experience shock and disbelief, some research with older adults suggests that they can view their stroke onset as part of the normal ageing process (Faircloth, Boylstein, Rittman, Young & Gubrium, 2004; Nasr et al., 2016).

As is evident from the accounts provided at the interview, the participants' daily lives were interrupted, relationships with friends and families changed, and they experienced social isolation, which caused feelings of uncertainty about the future. These findings are also evident in other qualitative stroke studies pertinent to young adults (Hanney, 2012; Hutton & Ownsworth, 2017; Immenschuh, 2003; Kuluski et al., 2014; Leahy, 2010; Roding et al., 2003; Stone, 2005).

Some of the participants in this study could not understand how they suffered an illness that they typically associated with the elderly. Bury's (1982) study on young adults with rheumatoid arthritis concluded that young adults became distressed when diagnosed with a chronic illness that was typically associated with the elderly. Bury (1982) conceptualises chronic illness as a biographical disruption that disrupts knowledge, experiences and everyday routines which ultimately disrupts the self. A critical event (the onset of chronic illness) is associated with pain, suffering and death, concepts not usually in one's life. Like Bury, Charmaz's (1991) grounded theory study on chronic illness suggests that individuals living with a chronic illness become aware of death. This awareness, however, disrupts one's identity, particularly if one is too young to typically experience such an illness.

Stroke is considered a chronic illness (Becker, 1993; Becker & Kaufman, 1995; Kaufman, 1988) so Bury's and Charmaz's thoughts on the impact of biographical disruption, interruption and chronic illness on one's identity resonate with the main concern of the participants of this study - *Losing My Self*. The participants experienced a traumatic crisis-like event that disrupted their meaning of being in the world. Similar studies have identified biographical disruption post-stroke. Pound et al. (1998) outlined that community-dwelling adults experienced difficulties with personal ADL's and communication and memory impairments. Living with these impacts caused an unexpected disruption and attributed to feelings of living in an altered body which ultimately impacted the survivors' sense of self. Kuluski et al., (2014) concluded that disruptions to personal, vocational and social activities, caused by stroke impairments, attributed to feelings of loss of self. The stroke not only disrupted the participants' body and mind but also disrupted their sense of a coherent self and their future life plan according to Hutton & Ownsworth's (2017) study of young adult stroke survivors. Studies in traumatic spinal cord injury (Yoshida, 1993) and young-onset Parkinson disease (Ravenek, Rudman, Jenkins & Spaulding, 2017) identified similar issues. Thus, stroke and other chronic illnesses trigger biographical disruption which indicates how unpredictable life is and can lead to an emerging vulnerable self (Faircloth, Boylstein, Rittman & Young, 2004b).

The current study, however, looked beyond the immediate disruption that is associated with HS, as conceptualised by Bury (1982) and others. Kirkevold (2002)'s study of the illness trajectory one-year after stroke, discussed in Chapter 2, adds a different dimension to Bury's biographical disruption concept. She stresses that stroke does not always result in an instant biographical disruption because the stroke is not always considered an immediate crisis. Interestingly, she suggests stroke survivors experience a crisis only when they are living with the long-term consequences of stroke that affect the self. Thus, awareness of change causes the biographical disruption. This sample comprised of stroke survivors who were one year post-stroke and who attended rehabilitation and as such, their awareness of the stroke impacts and the impacts on their identity would be expected given the relatively short time since the stroke onset. Hawkins et al., (2017) grounded theory study exploring the long-term trajectory of stroke aligns with Kirkevold's findings. Hawkins and co. suggested stroke survivors experienced an ongoing disruption as the stroke recovery process was a continuous process that was shaped by the participants' evolving sense of self over time. This is congruent with Charmaz's (1991) thoughts on time and chronic illness. Charmaz theorises that living with chronic illness forces individuals to restructure time. Dealing with a chronic illness means living one day at a time which automatically, creates a sense of uncertainty and evoked feelings of vulnerability. This was evident in the current findings whereby the participants were living cautiously, uncertain about their futures and afraid to function for fear of suffering a second stroke.

This study represents an extension of Bury (1992), Charmaz (1991) and Kirkevold (2002) studies and suggests that young adult HS survivors experience two biographical disruptions following their stroke, i.e. they experience two crisis like events. In this study, biographical disruption in this first phase of the re-purposing process *(reeling from the shock*) is considered the immediate interrupter in the participants' everyday lives. Because some participants associated stroke with an ageing population, which impacted, at least to some extent, their sense of self. When they were discharged from the hospital, they focused on prioritising their recovery. For some participants, they attempted to resume their pre-stroke lives immediately, and for others, they concentrated solely on their recovery and utilised all necessary supports to achieve this goal. The stroke impacted their physical and cognitive capacity, daily routines, roles, relationships and worldview, which also contributed to the feelings of loss of self. The stroke and its consequences caused the participants significant distress and interrupted how they fitted in the world.

This study also suggests that young adult HS survivors experience a second biographical disruption during the second phase of the re-purposing process (*living cautiously*). As the participants' physical functioning improved, they became increasingly aware of persistent cognitive deficits that impacted their day-to-day functioning and the manner in which they could fit in the world. They perceived their future as bleak. This second disruption had a significant psychosocial and emotional impact on the participants' sense of self as they mourned their pre-stroke lives while contemplating a new, post-stroke life. This significant second disruption might be associated with the realisation of the long-term implications of living with a HS. This contrasts with the initial disruption caused by the stroke onset from which the participants survived and were subsequently able to prioritise their recovery to repair their sense of self. However, these disruptions evoked feelings of loss for their pre-stroke lives while contemplating a new life while grappling with suffering an unpredictable life-changing event, of which the cause was unknown. This study proposes that there is a connection between the biographical disruptions experienced during the re-purposing process and existentialism as described in the next section.

Existentialism

The participants in this study questioned what they knew previously about themselves, their future and their world as they attempted to come to terms with experiencing this life-altering crisis event. They were fearful of a second stroke and of facing their mortality, and as such, the stroke caused the participants to lose control and essentially, their lives were paused. Yalom's (1980) existential theory recognises that all individuals are mortal, free and alone and are ultimately responsible for their existence, quality of life and creating their meaning in the world. However, the participants studied here did not feel they had autonomy over their lives and, thus, their meaning, purpose and sense of self were impacted. Furthermore, life and death exist simultaneously (Yalom, 1980) and death is inevitable (Bauman & Waldo, 1998). The participants in this study were living and dying at the same time. They survived the stroke, but their pre-stroke lives were dying as the impacts of stroke emerged. Additionally, issues of mortality arose for these young adults - albeit not necessarily at the time of the stroke. For example, one participant realised that one could die from HS and the fear, plainly expressed, from three other participants of a stroke reoccurring indicated how the young adults were forced to face their mortality and become aware of the fragility of life. The biographical disruptions experienced as a result of stroke almost certainly caused the participants to experience existential distress and confront existential issues, which raised profound questions about mortality, freedom, responsibility and the meaning and purpose of life. Such issues are evident in both the ABI and trauma literature (Klonoff, 2010; Patterson & Staton, 2009).

Experiencing existential distress and having existential concerns has been documented previously in terminally ill cancer patients. (Chockinov et al., 2006; Henoch & Danielson, 2009). The participants in these studies experienced an array of emotions, including feeling worthless, experiencing a loss of control, feeling like a burden, not being treated with respect, issues with self-identity and feeling like they had not made a meaningful or valuable contribution in their lives. No one definition of existential distress exists but, Appleabaum, Kulikowski and Breitbart (2015) describe existential distress, in the cancer literature, as *"...feelings of hopelessness, demoralization, loss of personal meaning and dignity, feelings of burden towards others, and the desire for death or the decreased will to continue living"* (p.

1632). Emotional distress in cancer patients has a significant impact on their well-being and not surprisingly, the same can be expected for stroke survivors, albeit different. For example, the studies involving terminally-ill cancer patients and stroke survivors, generally speaking, do not live with the same impacts. However, stroke survivors can also feel hopeless and demoralised at the stroke onset. Confronted with the uncertainty of life and facing their own mortality, the experiences conveyed by the participants of this current study indicated they experienced a loss of meaning in the world as they grappled with coming to terms with the sudden onset of an illness and living with, to some extent, their debilitating consequences.

As identified by Brown (2003) in his study of a mixed sample of young and old motor neuron disease patients, chronically ill individuals can experience “existential shock” when they become aware that their bodies are failing them due to illness. The participants in this study, likewise, became aware of their physical vulnerability and were fearing mortality. As evident from the data obtained in this study, surviving a near-death experience like that of HS had a profound effect on participants and caused them to propel into action as evidenced by gripping life tightly and prioritising their recovery. In this study, with self-reflection, the participants confronted their sense of mortality by proactively trying to understand what caused the stroke so they could take measures to avoid a reoccurrence and regain autonomy over their lives and repair their sense of self. They aimed to persevere with life and avoid the concept of death.

Creating Meaning in Life

As noted above, an event such as a stroke disrupts individuals’ health and well-being, and their sense of a coherent self becomes interrupted as they grapple between their pre and post-HS lives. As noted by Antonovsky (1987), individual coping capacities influence the meaningfulness, comprehensibility and manageability of such events. In this study, the participants’ coping capacities, although varied, influenced how their lives and how they placed meaning on their lives, the stroke event and their future. Strategising and shifting perspectives were the active behaviours the participants engaged in so they could make sense of their experience, adapt to their post-stroke changes and ultimately, regain control of their lives.

Becker and Kaufman’s (1995) study of uncertainty in a post-stroke ageing population concluded that recovery was possible when the implications of stroke were understood and managed. Charmaz (1995, p. 657) concludes that *‘adapting shades acceptance’*, implying that individuals adapt their lives based upon a growing awareness that their impairments require adjustments and sacrifices in order to live autonomously. In this study, realising the nature and extent of their limitations negatively impacted the participants' sense of self as they realised that their lives were now different. How they saw themselves and their engagement with the world changed, and they attributed the loss of their pre-stroke life (and their self) to a lack of understanding of how to self-manage their limitations. For the participants, this loss was the impetus for change as they realised they needed to adapt and find alternative ways to help and be themselves.

The findings of this study indicate that the participants relied heavily on their own ability to self-manage and in turn, strategise so they could regain their independence. The participants learned to adapt to their post-stroke limitations by adopting a self-directed process of identifying appropriate strategies, for example, setting reminders and writing things down. Participants used planning and regular rest break strategies to manage fatigue as successful adaptations. Boger, Demain and Latter (2015) suggest that self-management is a common, unavoidable consequence after a stroke, regardless of age.

As in other studies of stroke (Anderson & Whitfield, 2013; Kuluski et al., 2014; Persson et al., 2017), the emotional and practical support of family and friends aided the recovery process for the participants in this current study. Of relevance here is the fact that although the participants acknowledged the support from family and friends, the quality and nature of these relationships often changed post-stroke and had a negative impact on their sense of self. This was a common theme identified in the all the studies related to young adults, that are discussed in Chapter 2. The participants of the study felt misunderstood, and the meaning of their pre-stroke role was now lost post-stroke. The participants needed to adapt to these roles while they were developing strategies to become more autonomous, find meaning in their social worlds and in turn, strengthen their sense of self.

As noted by Charmaz (1991, 1995), individuals living with chronic illness can feel estranged from their lives - what was familiar now seems strange, and the strange becomes the familiar, as they learned to live with their illness, e.g. their pre-stroke relationships. Coping with chronic illness can, according to her, take on many forms including minimising and disassociating oneself from the illness to regain a pre-illness sense of self. Notably, four participants in this study, who wished to resume normal pre-stroke activities immediately upon discharge from the hospital, appeared to be attempting to disassociate from their stroke.

This interpretation is based on the fact that they appeared to be testing reality by trying to resume their pre-stroke lives too quickly. Although the participants did not initially seem to appreciate the full implications of their stroke, disassociating from the stroke potentially served as a coping mechanism to repair their loss of self. Obviously, returning to pre-stroke life quickly and without obvious disruption would give the participants in this study a sense of belonging and a sense of a coherent self.

A similar coping mechanism of minimising and disassociation was identified in other qualitative stroke studies, regardless of age and stroke sub-type (Nasr et al. 2016; Pound et al., 1998). The data revealed that the female participants in this study masked their stroke impacts from others. Although this study did not set out to explore gender differences, it is proposed that this masking action was a self-protective measure, possibly, to enable participants to continue engaging in positive life experiences that would then positively influence their sense of self. Of interest, this finding was also documented in Stone (2005) study of young adult female HS survivors. In her study, the participants were concerned about the reactions of others, particularly in misunderstanding the impact of stroke. The participants in Stone (2005) study either justified themselves to others or concealed their difficulties from others and limited their social experiences. Minimising and disassociation have been conceptualised as denial in TBI survivors (Deaton, 1986) and in individuals living with chronic illness (Livneh, 2009). Millen and Walker’s (2001) study of chronic illness conceptualised this as a normalisation process, whereby re-engaging in pre-illness life strengthened the sense of self.

In their study of gender differences in post-stroke rehabilitation, Perna, Perkey and Le (2014) identified that female stroke survivors found psychosocial adjustment more difficult when compared with their male counterparts. The literature suggests that masking cognitive impairments enables individuals to construct identities and disassociate from their difficulties, so they avoid stigmatisation by others (Lingsom, 2008). This may suggest that females are more concerned about stigmatisation than are males and require, therefore, to adopt different strategies in order to adjust to life after stroke.

An adverse life event, such as a stroke, can be considered salutary, as conceptualised by Antonovsky (1979). As documented across the stroke literature, stroke events can cause personal growth, regardless of age and stroke subtype. The biographical disruptions identified in phase one and two of the re-purposing process, which were invariably negative, resolved in phase three (*reshaping life*) and presented differently. Typically, in this phase, participants were, in line with previous research, more positive. The literature suggests stroke survivors adapt to their new situations by either resuming their pre-stroke life or creating a new life (Ahuja et al., 2013; Becker & Kaufman, 1995; Faircloth et al., 2004; Pound, Gompertz & Ebrahim, 1998). Kuluski et al., (2014) and Hutton and Ownsowrth (2017) study of young adults, discussed in Chapter 2, indicate that their data revealed that young adults display resilient traits when trying to recover from stroke such as positive attitudes, restoration of pre-stroke selves and regularly achieving goals.

Gubrium, Rittman, Williams, Young and Boylstein (2003) suggest that stroke survivors set individual benchmarks, or goals, post-stroke and due to the personalised nature of these benchmarks, stroke survivors are eager to achieve these. In the current study, returning to work was considered to be the single most successful benchmark of recovery for the participants. Our Identities are rooted in employment roles and, as Christiansen (1999) points out, the question "What do you do?" highlights the interconnection between work and identity. Kielhofner et al. (1999) suggest that work is essential to individuals who value work and see it as part of their identity. As might be expected, returning to work after a stroke can be difficult and may take a number of months or years, which, given the link between work and identity, negatively affects stroke survivors' identity and wellbeing. Most of the participants returned to work at varying times during their recovery process, though their return to work experiences was varied. This influenced how they felt about themselves and how they acted and behaved at work. One participant spoke positively about their experience of returning to work less than a year after their stroke while another, who returned to work three days after their stroke, felt they were unsupported, and their plight was ignored. One participant returned to work but subsequently had to leave the workforce as they were unable to fulfil their duties post-stroke.

It should be noted that return to work decisions was influenced not just by post-stroke recovery but was also influenced by the economic burden placed on the stroke survivors after the stroke. Economic necessity was a motivating factor in returning to work, at least for some. Notably, this was most evident in the stroke survivors who lived alone and is consistent with the finding of post-stroke studies conducted by Balasooriya-Smeekens, Bateman, Mant and De Simoni (2016) and Persson et al., (2017).

Super, Wagemakers, Picavet, Verkooijen and Koelen (2016) suggest empowerment and reflection can foster meanings from events and in turn, strengthen individuals' sense of coherence. Feeling empowered can support individuals living with chronic illness to develop positive life skills, as identified in Zoffman and Lauritzen's 2006 study of individuals living with diabetes. In the current study, the participants were empowered to persevere with life by coping with the shock of suffering a stroke and subsequently, strategising and shifting their perspectives of the world to create new meanings for themselves as HS survivors. In Immenschuh (2003) study, described in Chapter 2, she describes shifting perspectives as a turning point in the stroke survivors' lives. In this study, the participants experienced a positive shift in their lives as stroke survivors. The participants made positive lifestyle changes including slowing down, and some participants changed careers. They established renewed relationships with others, their thoughts about life had changed, and they lived life with hope for the future. The stroke was no longer in the foreground of their lives but positively influenced their selves moving forward. For the participants, their meaning of life had shifted as they moved on from the stroke. The stroke was not an ongoing disruptor but influenced the stroke survivors' life tapestries (Faircloth et al., 2004). This is evidenced in other young adult stroke studies that emphasise the traumatic experience, that is stroke, can create a positive, meaningful relationship with the self and others.

The findings from this study confirm that young adult HS survivors learned to integrate their pre-stroke selves with their post-stroke selves, achieving, in the process, a re-purposed self that was meaningful and purposeful.

Phased Models of Recovery – Re-Purposing My Self

In this study, a phased recovery model is proposed that has relevance specifically for young adult HS survivors. This phased recovery model provides a holistic view of young adults' experiences of living with a HS as it focuses on the individuals, not just the symptoms. This phased recovery model recognises that stroke recovery is a journey and not a destination.

Some proposed stroke recovery models (e.g. Eilertsen et al., 2010; Hawkins et al., 2017; Kirkevold, 2002) (discussed in Chapter 2) could be considered time limited, linear and rigid and are based on recovery phases identified within a 1-2-year period from the stroke onset. This limited timeframe seems quite short given the long-term challenges associated with stroke, also identified in Chapter 2.

In contrast to these linear short-term models, the phased model identified as a result of this study is dynamic, continuous and extended. Similar to Pallesen (2014) who, from their data, identified that stroke recovery was a dynamic process. Other studies also identified stroke survivors' recoveries as phased recoveries that evolve over an extended period of time (Ahuja et al., 2013; Arntzen et al., 2015).

In line with the extended nature of the recovery process identified here, Arntzen et al., (2015), discussed in Chapter 2, indicated that the stroke recovery process is a long-term process. Ahuja and colleagues (2013) also identified a stroke recovery model that they considered was a long and individual process. This study adds to the existing qualitative stroke literature as the proposed 'Re-Purposing My Self' model is grounded in young adult HS survivors' perspectives and experiences, a neglected area of study, as indicated by Stone (2005).

The findings of this current study and the phased recovery model proposed resonates with the models proposed by others in that the current study portrayed young adult stroke survivors' recovery is individual. The loss of self post-HS required the survivors to negotiate their lives at multiple levels and engage in a period of adjustment, adapatation and transformation as they faced new challenges, new circumstances and new considerations. These multiple negotiations were contexutally influenced by personal, environmental and cultural factors in this study. For example, returning to work and the reasons that necessitated this action, e.g. feeling productive, econmonic burden, occupation. For those that returned to work, this experience was both positive and negative and caused financial hardship and more often required significant adaptations, adjustment, self exploration and possible vocational changes.

The visible and invisible effects of the stroke impacted the survivors' relationships with the self and with others. Self management was required of the particpants in order to function and adopting strategies was both rewarding and difficult. At this juncture, it is important to note the manner in which gender roles were implicit in this study. It manifested mostly in relation to the female participants in this study not seeking support and masking their stroke impacts from others, potentially to avoid stigmatisation. This mirrors international research by Stone (2005), Lingsom (2008) and Perna, Perkey and Le (2014).

Immediate family members / partners provided practical, emotional and financial supports and as such, their lives changed to support and accommodate their loved one. Therien, their relationships often changed and family members often became carers for a time, as identified in this study. For many, the adjustment process was both a positive and negative experience but the crux of it is that relationships changed. The importance of and reliance on support from immediate family members is well documented in the available identified in Chapter 2.

The study findings and the emerging conceptualisation of the recovery process, therefore, aligns itself with the findings of Arntzen et al.'s, (2015) study, wherein they indicated that the implications of stroke are diverse and residual symptomology can extend over many years or perhaps even a lifetime.

This 'Re-Purposing My Self' model propsed here extends the current literature by proposing a recovery model that spans three interconnected, non-linear phases for young HS survivors specifically. These three phases highlight the key struggles identified by young adult HS survivors during the recovery process and focus on reeling from the shock, living cautiously and reshaping life. The re-purposing process is about the extent to which the participants can overcome their post-stroke challenges and adapt to discover a self that is meaningful and purposeful as a stroke survivor. Whether or not this recovery model can be extended to other age groups or other stroke types remains to be determined in future studies. However it has the potential to inform healthcare professionals who work with this young adult population in the aftermath of their HS.

HS Recovery – Rehabilitation and Psychotherapy

The concept of recovery is multifaceted and has been defined in many ways in the literature. Traditionally, the concept of recovery was conceptualized within the medical model and referred to recovering from physical illness. Recent decades have seen a paradigm shift in the treatment of health and illness and a move towards holistic models of recovery. For the purpose of this study, recovery post-HS is adopted from the Neuro-Rehabilitation Strategy, Ireland (2011-2015) definition of neuro-rehabilitation which is defined as *"a problem-solving process in which the person who experiences a neurological impairment or loss of function acquires the knowledge, skills and supports needed for their optimal physical, psychological, social and economic functioning"* (Department of Health, 2011, p. ix).

The recovery process in this study, could be described as a problem-solving process as the participants learned to manage the impacts of their stroke. Despite the advances in neuro-rehabilitation, nationally and internationally, community stroke care continues to be underdeveloped, and rehabilitation largely focuses on the physical recovery after an illness.

The National Audit of Stroke Care (2008) recommended that long-term follow-up with stroke survivors was needed, given the complexity of their needs. This could enhance long-term recovery and reduce the burden of stroke. Ten years on and the findings of this study show that stroke services, particularly in the community, continue to be fragmented. In this current study, the findings indicate that addressing the psychosocial and emotional needs of the participants in this study were not met, for the most part, as identified in the data. Healthcare delivery was marginalised and successful recovery, in this study, was largely dependant on survivors' intrapersonal and interpersonal resources without the corresponding community or psychological support.

This continues to be a recurring issue as other bottom-up Irish studies corroborate the findings of this study that the psychosocial needs of the stroke population are under-treated (Hanney, 2012; Leahy, 2010). Additionally, international research, as evidenced in Chapter 2, also identifies these needs as under-treated in the stroke population of all ages. It would appear that current service provision does not adequately address the range of needs that the stroke survivors described in this study.

This is contrary to the aspirations of the National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011-2015, which aims to improve and enhance rehabilitation services for those living with neurological illness, including stroke. Several published national studies in Ireland between 2008-2016 (Hickey et al., 2012; Horgan et al., 2014; Horgan, et al., 2008; National Stroke Audit, 2015; National Stroke Audit of Rehabilitation Units, 2016; Wren, Gillespie, Smith, Kearns & Wolfe, 2014) continued to identify recurring issues about lack of psychological and community-based services, lack of follow-ups and the absence of age-related services.

The main finding of this study indicates that the suddenness and unexpectendess of a HS is a dramatic, life changing event for both the survivor and their family. The impact of the stroke necessitated the repurposing of their lives. From the literature reviewed in Chapter 2 and the findings of this study, it is clear that stroke is very much a visible and invisible disability and significantly impacts survivors' lives and those of their network. Furthermore, this study proposes, on the basis of the data, that young adult HS survivors are a vulnerable population who experience these impacts over an extended period of time. More significantly, they experience a devasting loss to their sense of self. Their world as they know it is turned upside down and the wider familial, economic and societal impacts are significant.

Given that the incidences of young haemorrhagic strokes are on the rise, and that these individuals are likely to live with ongoing psychosocial and emotional impairments that impact their sense of self, the provision of extended and ongoing rehabilitation, community services and psychotherapeutic support simultaneously, or as required, should, it is contended, be prioritised. Based on these findings, it is proposed here that readily accessible psychotherapy available in the community as part of a psychosocial rehabilitation process, could be fundamental in supporting survivors to repurpose their lives and the lives of their family. Despite the paucity of literature pertinent to psychotherapy benefits, outlined in Chapter 2, (Hackett et al., 2008; Hadidi et al., 2017), this study mirrors a number of other studies that recommend psychotherapeutic supports to support young adult stroke survivors to cope with the psychosocial and emotional impacts of stroke (Hanney, 2012; Hutton & Ownsworth, 2017; Stone, 2005).

Psychotherapy, as part of a psychosocial rehabilitation intervention, may potentially support young adult HS survivors at various stages during the long-term re-purposing process. Additionally, psychotherapy for this cohort, over an extended period, could potentially contextualise the recovery process and validate their experiences. The positive impact of therapy interventions was identified by two participants in this current study who availed of therapy services.

Psychotherapy could support young adult HS survivors to mourn their losses and to normalise the biographical disruptions that affected their relationships with their self and with others. Psychotherapy could be of particular value to empower young adult HS survivors and support them to regain control over their lives and feel empowered to generate a new worldview that is meaningful and purposeful. Psychotherapy could possibly assist with addressing the loss of self, existential issues and the lack of meaning that is attributed to the stroke that the young adults of this study experience and grapple with.

Instrumental to the recovery post-HS was the support of immediate family and close friends, who formed the young adult survivors’ immediate natural support network and who assisted with the re-purposing process. This was also identified in other stroke research outlined in Chapter 2. The impact of HS on the family is significant and psychotherapy could potentially support family members / partners to adjust to changes in the family unit and adapt to new roles taken on, for example, caring roles. Additionally, couples therapy could support partners in dealing with potential relationship / role changes post-HS.

Summary

This chapter set out to situate the substantive theory generated in this study with the existing literature, identifying resonances and new knowledge gained. The substantive theory generated proposed a model of recovery, grounded in young adult HS survivors, that spans three interconnected non-linear phases. The model highlights the complexity, longevity and diverse difficulties young adult HS survivors face when trying to re-purpose their self. A distinct feature of this theory is the manifestation of two biographical disruptions in phase one (reeling from the shock) and phase two (living cautiously) of the 'Re-Purposing My Self' model and a resolving of these biographical disruptions in phase three (Reshaping Life). Additionally, the study highlighted the issues of loss, loss of self, existentialism and meaning-making, which can be specifically addressed in psychotherapy.

Given what we know are some of the benefits of psychotherapypsychotherapy may support young adult HS survivors and their families with the 'Re-Purposing My Self' process at varying intervals, but most importantly, over an extended period. Indeed, although not readily available to the sample studied here, the benefits of such intervention and support was confirmed by those in the sample who had an opportunity to avail of it.

Psychotherapy, as a discipline and as a profession, may support these young adult stroke survivors to embark on a journey of self-exploration. This approach can support these young adults deal with the recurring biographical disruptions that contribute to the extended psychosocial and emotional difficulties. The model proposed here could potentially inform psychotherapy practice and the wider support services for those who have survived stroke - facilitating more targeted services for young adult HS survivors and their families. Chapter 6 details the implications for psychotherapy practice and training, service provision and policy and future research.

Chapter 6: Conclusion - Moving Beyond the Study

Introduction

This chapter summarises the key contributions of the study. The chapter will discuss how psychotherapy can address the key struggles identified by the participants at different stages in the post-stroke recovery process. The implications of the study for psychotherapy practice and psychotherapy training, service planning and policy and future research are highlighted. The strengths and limitations of the study are addressed, and the quality of the study evaluated with Yardley's (2000) framework is provided. This chapter concludes with a personal reflection of engaging in this study and a closing summary.

Key Contributions of the Study

The current study is, the first CGT study investigating the views and experiences of men and women, between the ages of 18 and 55 years, who have experienced a HS living in Ireland.

In keeping with the aim and objectives of this study, the current findings provide a novel contribution to the qualitative stroke literature and, specifically, to the neglected area of the HS literature. This grounded theory study provides an understanding that is grounded in young adults' experiences of living post-HS, highlighting the psychosocial and emotional challenges and needs of community-dwelling young adult HS survivors. Hopefully, this pioneering study will serve as a catalyst for future research in this neglected area.

As an addition to the stroke literature on the psychosocial challenges facing young adults stroke survivors, this study has elaborated on current knowledge and proposes that the self is impacted by more than one biographical disruption. An immediate disruption during phase one, at the time of the stroke, and a more profound disruption during phase two as the long-term stroke implications became evident. Directly addressing the loss of the self after HS may support young adult stroke survivors to maintain realistic perceptions of the self, thus, optimising recovery outcomes.

This study is novel because it looks at the stroke recovery process over an extended period; between six months and twelve years post-stroke, thus, identifying the long-term needs of this population. Previous studies have typically focused only on short-term consequences and outcomes. The study contributes to the overall sparse literature on the impact of HS from the survivors' perspectives and to the field of rehabilitation and by extension, psychotherapy. This study highlights that HS is a life-altering, dramatic event. Young adults and their families may benefit from access to community supports and psychological supports, such as psychotherapy, as part of a holistic rehabiltiaiton process, which may provide support as they engage in an arduous journey of re-purposing the self over an extended period of time. This study can potentially bridge the gap between psychotherapy research and practice (Goldfried, 2010).

Implications for Psychotherapy Practice

This study highlights the key struggles of young adult HS survivors. The issues of loss of self, existentialism and meaning-making could be specifically addressed in psychotherapy. The findings of this study indicate that these young adults try to re-purpose their selves by integrating the stroke into their lives and resolving the biographical disruptions caused by the stroke.

This study provides a substantive theory for understanding how the participants engage in a dynamic and fluid process of re-purposing their self that spans three phases and re-purpose themselves by integrating their pre-stroke and post-stroke selves in order to function successfully and live with meaning in everyday life. The re-purposing process is about the extent to which the participants overcome their post-stroke challenges and adapt to discover a self that is meaningful and purposeful and situate themselves in the world as someone who survived a stroke.

Psychotherapy, as part of a wider psyschosocial reahabilitative process, could potentially be of value in supporting functional and emotional outcomes at different time points after stroke. Recognition of these key phases of recovery may support psychotherapists to individualise and contextualise therapy and empower psychotherapists to reflect upon how they may be able to become change agents, assisting young adults with validating their experiences and adjust to their lives after stroke.

The study also provides a theoretical framework that synthesises the recovery process which may help to bring about a clearer understanding of dynamic perceptions of the self and how young adults and their families reach a stable equilibrium. An empathetic understanding of this will enhance psychotherapists' expertise and enable them to deliver provide invaluable support to these families. The findings of this study may help psychotherapists to individualise and contextualise therapy and help them to reflect upon how they may be able assist these young families to adjust and re-purpose the self after stroke.

Understanding realities from the stroke survivors' perspectives are pivotal in developing psychotherapeutic services which may support their future needs. In some respects, working with a young adult stroke population is unique, given the multiple sequalae associated with stroke. The re-purposing process after a HS can support psychotherapists to contextualise therapy in terms of the recovery phases identified in the re-purposing process and adapt their approaches accordingly, if necessary. The phased model in this study can be integrated into any therapy model. For example, person centred psychotherapists could contextualise therapy and support young adult HS survivors to externalise problems associated with their stroke in a safe, non-judgemental environment, leading to a renewed sense of self. The person centred approach may support the fluidity of the self, associated with the re-purposing process of this study. Collaboratively exploring the existential concerns could potentially support this population to grieve for their losses and adjust to their new life situations in an effort to generate a new worldview that is meaningful and purposeful post-stroke. Cognitive-behavioural psychotherapists could contribute to adopt the 'here and now' approach, which could assist with the grieving process while the young adults face many challenges in their new life situation. The psychoeducation tool used in cognitive behavioural therapy could support this population to normalise their feelings regarding the stroke and the fear of a recurring stroke. Brief psychotherapy could support these young adults to engage in psychotherapy for short periods of time at varying intervals to cope with the new challenges or setback they may face over an extended period of time. Narrative psychotherapists could gently support young adult HS survivors to create new narratives which would assist with the re-purposing process and reduce emotional distress. In keeping with the association that HS affects the whole family, couples and family therapy and educational supports could also provide invaluable support to family members / partners to cope with the may feelings associated with supporting a loved one who survived a HS.

As a result of this study, psychotherapists now have a greater understanding of the psychosocial and emotional needs of young adult HS survivors and, by extension, their family members.

Implications for Psychotherapy Training

Inadequate attention is paid in training to work with people living with a disability which can make working with this population challenging. Therefore, knowledge of the consequences of ABI and in particular, stroke, and using these insights to identify effective therapeutic interventions could be critical to the advancement of psychotherapy for this population (Gideon, 2009). Attending a variety of workshops, seminars, conferences about working with disabilities may enhance knowledge and skill sets when working with the disabled population and specifically with young adult HS survivors and their families. Educators could use this model to educate psychotherapists on the issues of grief and loss and the skills that are needed to support such issues. Psychotherapists may also gain a greater understanding of stroke and this could increase the quality and availability of the psychotherapeutic care to this unique population and their families. This could ensure psychotherapists obtain optimum competence and which could increase the quality of the psychotherapeutic care given. .

Implications for Policy and Service Planning

Future policy and initiatives should include the development of community-based rehabilitation services as an integral component of the existing rehabilitation process and should not be treated as a separate process. Judd and DeBoard (2009) recommend that those involved in rehabilitation services planning should review community-based rehabilitation services for people living with disabilities. Young adults stroke survivors are considered a distinct group who have specific rehabilitation needs (Morris, 2016; Royal College of Physicians, 2016). The findings of this study identified that the available stroke services did not wholly meet the needs of this specific cohort.

Easily accessible and available access to rehabilitative services that are tailored to survivors' individual needs and their families' needs could reduce the stroke burden associated with this population. It could be of potential benefit to integrate psychotherapy supports with rehabilitation in the community. In line with best practice guidelines, service providers may benefit from reviewing the collective Irish research in this area, from the perspectives of stroke survivors, to gain a greater understanding of their needs and enhance service development.

The data revealed in this study, the re-purposing process is an ongoing and dynamic process and ongoing support over an extended period may be helpful to young adult HS survivors. Additionally, interactions with different professionals, services and agencies could holistically address the needs of this population. Access to relevant professionals to support the multiple difficulties associated with living with HS as a young adult is recommended, particularly, available psychosocial and emotional support. Healthcare professionals must be cognisant of the importance of providing information regarding stroke recovery, stroke symptoms, stroke prevention and support services that could assist with the adjustment process. Peer support groups targeted specifically towards young adult stroke survivors could create a platform to share experiences with other stroke survivors, reduce stigma and raise awareness.

Implications for Future Research

The emergent substantive theory and phased recovery model was grounded in the data collected. There was some suggestion of gender differences in the recovery process which warrants further attention. As noted in Chapter 4, the female participants were inclined to conceal their post-stroke difficulties when compared with their male counterparts and future research in this area could identify differences in recovery between male and female HS survivors that could influence future service provision.

Future research with a larger representative group of young adult HS survivors could modify the theory and expand theoretical transferability, for example, including young adults who have experienced an ischaemic stroke and / or live with significant impairments. This would provide an opportunity to explore further how the loss of self and the re-purposing process relate to the stroke sub-type and severity.

Future research could also investigate family members and caregivers' experiences supporting the participants as they were identified as influencers and, thus, influenced the participants' recovery. Their perspectives on needs and challenges associated with caring for/living with someone who survived a HS could enhance psychotherapy and the wider service provision for this group also.

Strengths and Limitations of the Study

A strength of the study was that in recognition of the fact that stroke implications are diverse and residual symptomology can extend over many years or even a lifetime, no participants were excluded with regards to the upper limits of time since stroke. In adopting a qualitative approach, the study provided a platform for this marginalised and vulnerable population to have their voice heard. The theoretical transferability of the study findings may inform practice and understanding of working with other vulnerable populations.

The methodology employed in this study provided insights into the unknown area under study. Through adopting a CGT methodology, the aims and objectives of the study were fulfilled. The study aimed to develop a theoretical understanding of how community-dwelling young adults live with HS in Ireland. Specifically, what processes they engaged in to move on from the stroke onset and how these processes unfolded over time. A unique strength of the study is that a substantive theory emerged, grounded in the intricate and complex real-life accounts of participants who are solely living as young HS survivors

The homogeneity of the participants regarding stroke type (HS) is a strength of this study. As discussed in Chapter 2, the majority of qualitative studies pertinent to young adults conducted to date recruited ischaemic stroke participants only or mixed stroke samples, making it difficult to distinguish recovery differences between the stroke sub-types. Therefore, this study recruited only young adults, between the ages of 18-55 years, who experienced a HS. As a result, the specific concerns and the recovery trajectory of this specific sample of stroke survivor's, whose risk factors for stroke differ from other cohorts, have now been identified.

This study is, however, not without limitations. The exclusion criteria were stringent and prevented stroke survivors with severe cognitive impairment or dysfunction limiting ability to participate in the study. Thus, the specific needs of those with significant cognitive impairments have not been considered.

The current study relates to the experiences of a specific group of young adults between 18-55 years who experienced a HS more than six months before participating in this study. They were living in the community and were recruited anonymously with the support of stroke and acquired brain injury organisations. The study was dependant on the stroke survivors contacting the researcher, and as such, these particular participants were likely to be more actively engaged in family, community and social settings. Consequently, the transferability of the findings to other young adult stroke contexts, for example, in patients who are experiencing initial stroke difficulties, is unknown.

The findings are based on a sample of six participants. This sample size is, however, considered adequate for a grounded theory study and is not substantially smaller that the first qualitative study of young adult stroke survivors to adopt a grounded theory analytic procedure (Roding et al., 2003). More importantly, the data contained in the six interviews contained rich information, and theoretical saturation of the core category was achieved which has, hopefully, ensured the rigour of this study. Recruitment challenges, coupled with the small sample in this study, do, however, mean that theoretical saturation of the core category and the findings should be approached with some degree of caution.

Quality of the Study

As mentioned in Chapter 3, the criteria as set out by Glaser (1978) evaluated the quality and rigour of this CGT study. However, Yardley's (2000) quality framework was also adopted to further measure the quality of the study. This study has been considered under the four principles described by Yardley (2000): - 1) sensitivity to context, 2) commitment and rigour, 3) transparency and coherence and 4) impact and importance. An overview of these principles was described in Chapter 3.

Sensitivity to context involves considering in detail the prior relevant literature, empirical data, in so far as it exists, sociocultural settings within which studies took place, participant's perspectives and ethical issues. ABI was a particular area of interest for the researcher, who has been working in this field for the past eight years. In her local context, she was meeting an increasing number of young adults who experienced a stroke and was, because of this experience, motivated, to research this topic, particularly young adult HS, which was a neglected area.

An expansive review of literature relevant to stroke and, specifically, HS identified what was known in the area, and this provided the rationale for the current study. The researcher was interested in the experiences of young adult HS survivors, and she explored multiple methodologies to fit the study aim with the relevant methodology. Exposure to these methodologies was facilitated through reviewing the relevant literature and attending research modules, qualitative research workshops and research supervision. Classic grounded theory emerged as the suitable methodology that fit with the aim and objectives of the study.

Working in the field of ABI made the researcher vulnerable to insider researcher biases. Due care was taken throughout the research process to ensure the researcher remained objective at all times and the participants were not exploited in any way. Notably, being an insider researcher was a strength when interviewing the participants. The researcher was cognisant of a number of physical, cognitive and emotional difficulties that are associated with this population and was mindful of these challenges during the recruitment and interview process. These considerations are discussed in Chapter 3.

Commitment refers to the in-depth engagement with the topic and demonstrating dedication to develop research skills. This researcher undertook a classic grounded theory study of young adult HS survivors, based on a critical review of the available literature. Reviewing the literature enabled the researcher to make an informed decision regarding the chosen methodology that fit with the aim of the study.

To become more knowledgeable as a grounded theorist, the researcher engaged in an online mentorship with a grounded theorist and had several sessions together. Additionally, the researcher attended an international grounded theory seminar.

The rigour of the study is demonstrated in Chapter 3 whereby detailed descriptions of the systematic procedures regarding data gathering, handling and analysis are provided, highlighting the evolving research process from inception to completion. Chapter 4 provides an in-depth description of the data analysis. Additionally, the research supervisors closely monitored the study process and discussions regarding researcher biases, and analysis procedures were discussed in research supervision.

Transparency refers to the transparent methods and data presentation. Chapter 3 outlines the detailed accounts of how the study was conducted in line with classic grounded theory. As semi-structured interviews were the main source of data gathering, the interview schedule required significant consideration. Several adaptations to the schedule were made, with the research supervisors, to ensure the schedule was objective and free from researcher biases.

Field notes were prepared post interviews by the researcher that documented thoughts and reflections about the participants, the interview process and the potential analysis (see Appendix H for sample field note). Theoretical memos were maintained during the analysis phase to document ideas about the emerging categories and the relationships between these categories (see Appendix J for an example). A mapped presentation of the theory is presented in Chapter 4 (see Figure 3) and highlights the core category, the major categories and the associated sub-categories that were used to resolve the participants' main concern. Participant quotations were included in Chapter 4 to provide a clear description of their experiences.

Coherency is synonymous with believability. The core category succinctly captures how the participants resolved their main concern and is interconnected with the major categories as depicted in Chapter 4. The study provides a novel contribution to the neglected area of HS, the extant stroke literature and contributes to the field of psychotherapy by enhancing understanding of the needs of young adult HS survivors.

The impact and importance of the study refers to the benefit of the findings. The research was undertaken to investigate the experiences of living with HS from the perspectives of community-dwelling young adults. The aim of the study was not to verify a hypothesis but develop a substantive theory that captured the participants' experiences of living with HS and how they managed the implications associated with HS. The study identified a substantive theory for understanding how the participants engage in a process that spans three phases of re-purposing a self that is meaningful and purposeful as a young adult HS survivor. This may support psychotherapists individualise and contextualise therapy at different time points after stroke to support long-term functional and emotional outcomes of this vulnerable population.

The implications for psychotherapy practice, psychotherapy training, service planning and policy and future research are highlighted earlier in this chapter, which demonstrates the relevance of this study to the psychotherapy field and the wider service provision.

The findings have been discussed with colleagues who have found they fit with their experiences of therapeutically working with stroke survivors. They have begun to consider how they can proactively tailor their approach or pool resources with other colleagues to incorporate the interventions proposed in this study.

Additionally, the findings have been discussed with colleagues who work with clients of other neurological conditions, for example, Multiple Sclerosis (MS). They found the findings resonated with their experience of working with MS clients and related it to experiencing a biographical disruption when an MS diagnosis was received and a subsequent disruption when MS symptoms emerged. The findings provided them with a framework from which to work from when supporting someone who may require support at varying intervals, for example, support after the MS diagnosis and / or support as the condition progresses. This suggests the study findings are theoretically transferable beyond young adult HS.

Summary

This study contributes to the field of psychotherapy by showcasing that the crux of the re-purposing process, over three phases, is how these young adults proceeded with re-purposing their damaged relationship with their selves. This study provides a theoretical understanding of young adults' experiences post-HS and serves as a guide to psychotherapists working with this population, particularly in the areas of loss of self, existential issues and meaning-making. The study was evaluated based on Glaser (1978) criteria, discussed in Chapter 3, and Yardley's (2000) framework for evaluating qualitative research. It highlights implications for psychotherapy practice, training, service provision and policy and future research. The study challenges us to think how a strong therapeutic relationship and flexibly psychotherapeutic interventions can support the re-purposing process after a HS.

Reflexive Statement

This statement outlines the cyclical nature of how I influenced the study from inception to completion and how the study has influenced me and my professional practice.

This study was based in the Republic of Ireland and explored the experiences of living with a haemorrhagic stroke as a young adult stroke survivor. I have been working with adults who live with an ABI for the last eight years. My personal belief about working in this field is that everyone deserves a voice and everyone deserves support to create a QoL that is meaningful and fulfilling to the individual.

Based on my experience, the vast majority of the people I have supported and colleagues I have liaised with, lack of emotional support was commonly cited as the major barrier to improving QoL after sustaining an ABI. Thus, my motivation for initially undertaking the Doctorate in Psychotherapy. I wanted to focus on brain injury services in Ireland and share my voice about the greater need for addressing the emotional needs of this population.

In my current role, I was meeting an increasing number of young people who experienced a stroke and evoked my curiosity to learn more about why this was happening and what life was like for them as a young adult stroke survivor. It was a topic of personal relevance for me also, as I was of a similar age to the people I was meeting. This personal and professional curiosity lead to the inception of this research study. However, my passion for improving service provision initially influenced the aims and objectives of the study rather than exploring stroke experiences from young adult perspectives. Considerable reflection and discussions with my supervisors encouraged me to recognise my biases towards service provision and park them so that I could flex my curiosity muscles about life as a young adult stroke survivor. Hence the aims and objectives of the study, identified on page 45, were written out on cue cards and stuck to the wall of my home office, my research notebooks, my literature folders, my analysis folders and placed in my laptop bag to constantly remind me of what research I was undertaking.

My initial analysis was conceptualised through a service provision lens. While coding the data, I initially focused on content pertinent to services received or services recommended by the participants. However, as analysis progressed, and I was gaining more experience in conducting research interviews and continuous memoing, I reminded myself that the main goal of my data analysis was to conceptualise a main concern and core category pertinent to the participants' life experiences post-HS across the interviews which was not specifically related to service provision.

The impact of the study was a cyclical process; I influenced the study as described above but also the study has positively influenced me and enriched my understanding of working with this group and my professional practice. The research interviews taught me that my active listening skills needed refining. My interpretation of this is that I have not been approaching my clients with the openness they deserve of late. Although it was challenging not to support the participants as a practitioner, it was insightful and eye-opening to sit and wholeheartedly listen to their stories without intervening. The participants confirmed they were relieved to share their story with someone who listened and who, they felt, understood them. This is something I have actively reintegrated in my practice, and I have upskilled my active listening skills through practice and supervision. Additionally, since the study has concluded, I have facilitated an active listening skills workshop with my colleagues in my current employment. to support them with developing and refining this valuable skill so they can act as powerful change agents with the individuals and families they support.

In my therapeutic practice, the findings of this study have increased my sensitivity to the re-purposing process after stroke. This framework has enabled me conceptualise clients' recovery points within these phases and have provided me with greater insight into their recovery journey. The outcomes of this have thus far, been successful in my practice.

Closing the Study

This study is novel because it explored the long-term recovery process of young adult haemorrhagic stroke survivors. The uniqueness of stroke is the sudden and unexpected nature of the event followed by devasting, life-altering impairments across a continuum. The stroke severely disrupts the life trajectory of haemorrhagic survivors, typically meaningful occupations, roles and social participation. This study contributed to the psychotherapy field by providing an understanding of the key struggles the participants experienced when living with haemorrhagic stroke and a phased recovery model which captured the key processes the participants engaged in to move onward. Widely accessible psychotherapy as part of a psychosocial rehabilitation process, could be useful at varying time points for this vulnerable population and their families. The study also contributes to the field by highlighting the central role of the loss of self as the impetus for psychotherapy. Psychotherapy provision has the potential to close the gap between the existing, yet limited, psychological services in the Irish stroke healthcare system and young adult haemorrhagic stroke survivors' unmet needs. Psychotherapy could have the potential to become an integral component of the rehabilitation process and beyond. As one participant in this study said *"Don't forget the strokeys…we're here too."* Our young adult HS survivors deserve no less.

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Appendix A - Evidence of Ethical Approval from DCU

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

Ms Michelle Murphy
School of Nursing and Human Sciences

11 November 2016

REC Reference: **DCUREC/2016/170**

Proposal Title: **An investigation of the experiences of community dwelling young adults following stroke**

Applicant(s): **Michelle Murphy, Dr Evelyn Gordon, Prof Teresa Burke**

Dear Michelle and colleagues,

Further to a full committee review, the DCU Research Ethics Committee approves this research proposal.

Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee.

Should substantial modifications to the research protocol be required at a later stage, a further amendment submission should be made to the REC.

Yours sincerely,

Donal O Gorman

Dr Dónal O'Gorman
Chairperson
DCU Research Ethics Committee

DCU
Research & Innovation

Taighde & Nuálaíocht Tacaíocht
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Appendix B - Evidence of Approval from Acquired Brain Injury Ireland

ACQUIRED
BRAIN INJURY
IRELAND

National Office:
64 Mulgrave Street
Dun Laoghaire, Co. Dublin

T. 01 280 4164
E. info@abiireland.ie
www.abiireland.ie

Michelle Murphy
DCU

13.12.2017

REF: **Ethics application for approval:**
An investigation of young adults' experiences following haemorrhagic stroke

Dear Michelle

The ABI Ireland Research Ethics Committee has approved your application for the above-named study.

I wish you every success with the work.

Yours sincerely

Lorraine Crawley
____

Dr. Lorraine Crawley
Chairperson REC

cc Grainne McGettrick, REC Administrator

Appendix C – Call for Volunteers

CALL FOR VOLUNTEERS

Volunteers needed to take part in a research project exploring young adults’ experiences of haemorrhagic stroke.

Did you suffer a stroke and are you between 18 and 55 years?

If you experienced a haemorrhagic stroke at least 6 months ago, and have now been discharged from hospital, you are invited to participate, on a volunteer basis, in a research study exploring young adults’ experiences of stroke.

If you volunteer to participate, you will be invited to take part in an interview in your locality, at a time and date that suits you. The interview will take one hour and will be audio-taped. You will be asked about your thoughts and feelings about your stroke and your life experiences since your stroke.

For more information or to volunteer for this study, please contact:

Michelle Murphy,
Doctoral candidate of Psychotherapy at the School of Nursing and Human Sciences,
Dublin City University at
089499063 or email michelle.murphy244@mail.dcu.ie

This study has been approved by Dublin City University Research Ethics Committee.

Appendix D - Study Information Sheet/Plain Language Sheet

Study Title: An investigation of the experiences of community dwelling young adults following stroke

Research Team: This study is being carried out by Ms. Michelle Murphy, Doctoral candidate of Psychotherapy, under the supervision of Dr. Evelyn Gordon and Prof. Teresa Burke, School of Nursing and Human Sciences, Dublin City University.

Introduction: You are being invited to take part in a research study entitled *"An investigation of the emotional and support needs of young adults post-haemorrhagic stroke"*. This study invites you to talk about your experiences of your stroke. It aims to help inform stroke services of the emotional needs and experiences of younger patients with haemorrhagic stroke Before you decide whether or not to take part, it is important that you understand why the study is being carried out and what it will involve. Please read this information carefully and discuss it with others, if you wish.

What is the purpose of the study? The aim of this research is to investigate your life experience of haemorrhagic stroke as there has been very little research in this area in Ireland.

Why have I been invited? You have been invited to take part in this study as you have experienced a haemorrhagic stroke and you expressed an interest in obtaining more information about the study.

Do I have to take part? No, it is completely up to you whether you take part or not. If you decide to take part, you will be asked to sign a consent form to show you have agreed to take part. You are free to withdraw from the study at any time.

What do I have to do? Participation in the study will involve taking part in a one-to-one interview. The interview will take approximately one hour and will take place in private room in a conference centre in your locality. The interview will be tape recorded and will be treated in strictest confidence at all times. You will be asked about your thoughts and feelings about your stroke and your life experiences since your stroke.

What are the benefits of me taking part? There are no direct benefits from taking part in this study. However, your insights may provide more understanding of the implications of stroke for young adults and inform clinical practice and service provision in this area.

What are the risks of me taking part? Talking about your experience of stroke may lead you to memories that could be upsetting or distressing for you. If you think talking about your stroke experience would be too upsetting for you, you should not volunteer to participate in this study. If you do participate and if you feel uncomfortable or distressed at any stage, we can pause the interview and/or you can withdraw from the study if you so wish. A copy of telephone numbers of support services will be provided at the interview and you can arrange any further support you may need.

Legal requirements There are some legal limitations in relation to data confidentiality and information may be shared for the following reasons 1) requirements for mandatory reporting of child abuse, 2) requests submitted under Freedom of Information legislation and 3) court subpoena. Additionally, any information you may share that suggests there is a risk to yourself or to others will be forwarded to the relevant services.

What information will be held on me? If you agree to take part, information regarding your identity and contact information will be anonymised and stored in a safe and confidential manner. All interviews will be initially recorded on an audio recorder (Dictaphone). These recordings will be numbered (to ensure anonymity), transcribed and removed from the recording device immediately. The transcripts will be coded and stored on an encrypted file and in a locked filing cabinet for the duration of the study and five years thereafter (July 2023) as per Dublin City University 'Data Handling Guidelines' and the Data Protection Act, 1998 & 2003. Reports may include direct quotations from you however your identity will be protected with the use of a pseudo-name.

What happens the results of my interview? The results of this study will be included as part of a thesis. The results of the study will be used to contribute to the small but growing amount of research regarding young adults' experiences of haemorrhagic stroke. Direct quotations will not include any names or any other personal information. The results may also be published in scientific journals and presented at seminars but no personal information will be included. We can forward you a brief copy of the final report if you so wish once the thesis is complete in October 2018. Your interview may be stored securely on file until October 2023 for future research purposes.

What if I have a complaint? If during your participation in this study you have any concerns and wish to contact an independent person, please contact The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail rec@dcu.ie.

Voluntary participation You have volunteered to take part in this study and will not be paid. You may discontinue participation or withdraw at any time. If you decide not to participate or if you withdraw, you will not be penalised and will not give up any benefits which you had before entering the study. Participation is voluntary and without prejudice.

Permission This study has been approved by the Research Ethics Committee of the Dublin City University.

Further information If you would like more information or answers to your questions about the study, your participation in the study and your rights, please feel free to ask them now or at any time throughout the study to the researcher, Michelle Murphy, 0892403931 or michelle.murphy244@mail.dcu.ie

Many thanks for taking the time to consider this proposal. I hope that by you sharing your experiences and from me learning from your experiences that together, we will be better able to benefit other young adults living with stroke.

Best wishes,

Michelle Murphy

Doctoral Candidate of Psychotherapy

Dublin City University

Appendix E - Consent form

Title: Young adults’ experiences of haemorrhagic stroke

Research Team: This study is being carried out by Ms. Michelle Murphy, Doctoral candidate of Psychotherapy, under the supervision of Dr. Evelyn Gordon and Prof. Teresa Burke, School of Nursing and Human Sciences, Dublin City University.

You are being invited to take part in a research study entitled *“An investigation of young adults’ experiences following haemorrhagic stroke”*. Participation in the study will involve taking part in a one-to-one interview. You will be asked about your thoughts and feelings about your stroke and your life experiences since your stroke. The interview will take approximately one hour and will take place in private room in a hotel or conference centre in your locality. The interview will be tape-recorded and will be treated in strictest confidence at all times.

Please read the following statements and tick the boxes provided:

1. I confirm that I have read and understand the information sheet for the above study and that I have had the opportunity to ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I understand all information I provide will remain confidential between the research team.	
4. I understand there are some legal limitations in relation to data confidentiality including 1) requirements for mandatory reporting of child abuse, 2) requests submitted under Freedom of Information legislation and 3) court subpoena. Additionally, any information I may share that suggests there is a risk to myself or to others will be forwarded to the relevant services. These limitations have been discussed with me in advance of this interview.	
5. I agree to the use of quotes from my interview on the understanding that neither my name nor any other identifying information will be used.	
6. I consent to my interview data being used by the research team for the purpose of this research project.	
7. I consent to my interview data being used by the research team for related research projects by the same research team but only on the understanding that I will not be identifiable and that the research has received ethical approval from DCU.	

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 F - Interview Schedule

Opening: "Again, thank you very much for answering those questions, which is very helpful. Now, I would like to talk with you about your experience of living with a stroke. I will turn on the recorder now, are you ok with this? Do you need anything before we start the interview?"

1. ***Tell me what life has been like for you since your stroke. You may want to begin with what the initial stages after your stroke such as being in hospital and move towards what life is like for you now.***
   <<prompt>> time in hospital, what was that like?

   <<prompt>> initial stages after stroke

   <<prompt>> now

   <<prompt>> day-to-day/relationships/emotionally/physically/cognitively-Have any or all of these changed since your stroke?

   <<prompt>> life – financially /vocationally/occupation-Have any or all of these changed since your stroke?

2. ***Can you tell me about your experience of any services that you may have availed of following your stroke/that you mentioned earlier you received while in hospital/that you mentioned earlier you received when discharged from hospital?***
   <<prompt>> What was that like for you?

   <<prompt>> What was helpful? Unhelpful?

   <<prompt>> What do you think you need/needed? Service recommendations?

3. ***Has your thinking about life changed since your stroke?***
   <<prompt>>positive/negative impacts of life after stroke

4. ***In terms of your future plans/goals, have these changed since your stroke?***
   <<prompt>> Based on your experiences since your stroke

   <<prompt>> Have they been impacted?

Closing: "I have one question left, thank you very much for telling me about your experiences of living with a stroke, I really appreciate it and it was a pleasure to sit here with you and hear your story".

5. ***So, if you could give advice to other young adults living with a stroke, what would it be?***

Before we finish, are there any other comments you would like to make? Is there anything else you would like to add or if there is anything we may have missed?"

MEMO FOR INTERVIEWER

1) Are all the questions answered?
2) Did the participant discuss all aspects of their experience of stroke from initial stages to present, i.e. relationships/occupation/positive/negative impacts?
3) Did the participant discuss service provision?

"Thank you again for your time." Interview terminated.

DEBRIEF AFTER THE INTERVIEW-INTERVIEWER TO ASK PARTICIPANT

1) How are you feeling after the interview?
2) Provide participant with list of useful contact numbers
3) May I contact you again if I need clarification on something you said or if I missed out on asking you something?
4) Can you confirm your contact details for me?
5) Would you like to receive the findings of this study?
    a. Yes/No
    b. Dissemination-Via Post/email?

Appendix G - Helpline Contact Sheet

If you would like to talk about issues not directly related to the interview process, please consider the following services that provide a number of services including a listening service.

Aware	Tel: 1800 804848
The Samaritans	Tel: 116 123
Irish Heart Foundation	Tel: 01 668 5001
Headway Ireland	Tel: 1890 200278
Acquired Brain Injury Ireland	Tel: 1800 303556
BRI Ireland	Tel: 01 4824802
Volunteer Stroke Scheme	Tel: 01 634 6925
General Practitioner	

Appendix H - Field Note from P1 Interview

Initial question "tell me what life has been like for you since your stroke" seemed to be a very large question to answer. I asked for a timeline from experience in hospital to present day to try and anchor the participant. Participant was unsure she was answering the question correctly. This answer took 50minutes and I ticked the interview prompts as the participant answered them. Why did it take so long? The participant had no previous outlet to share their experience? I was getting quite concerned about time at this stage as I was not anticipating the question to take this long to answer. ***Key learning-this seems like it would be less overwhelming to answer if the participant only recently experienced a stroke, (as was the case with this participant). However, this may be more difficult to answer if the participant experienced their stroke a number of years previously. They may require more prompting from me or the question may need to be broken down. Additionally, the length of time it takes to answer this question may differ. Finally, I recongise, this question, of all the questions, is central to the research study and will endeavour to give the participants the time they need to answer this sufficiently, i.e. all the prompts are answered.***

There was a sense of urgency when the participant was referring to the time it is taking to 'recover'-participant wants to resume normal ADL?'s as quickly as possible for financial reasons as well as others. Participant speaks about guidance received post stroke for further education-catch 22-participant needs an income to fund further education and also has achieved highest level of education pre-stroke.

Participant spoke with sadness regarding current life situation. Participant spoke about a lot of changes, physical and social that have curtailed their life. Social isolation as a form of protection against others. Limited social engagements. Contradictorily, participant also acknowledged positive aspects of stroke, i.e. need to reduce stress and focus on priorities and also redirection in life goals, i.e. wants to be a writer more so than teacher. Participant spoke about life purpose all throughout the interview, i.e. what job will I have, what will I do?

Participant was curious about stroke and life post stroke and constantly questions life and the meaning of stroke and how to future proof life without getting a second stroke. Questions life direction going forward.

Participant requested a break after this question Participant went to the bathroom, confirmed they were a little fatigued but confirmed they were happy to proceed with the interview. I did not see any reason the interview could not continue at this time.

Appendix I - Sample Open Coding of P5 Transcript

Descriptive Codes	**Transcript**	**Researcher's Interpretation**
	R: So you do want to start by telling me what life has been like for you since you've had a stroke since you were in hospital to now?	
Symptoms Gratitude/ Appreciation Progress Progress Coping Awareness/ Impact Sadness	P: Ok eh the hospital part I I really don't eh recall or re ah remember em and even some of the home part is eh hazy but em right now em I am still sp eh or I'm speaking now which I couldn't do em I'm I have full movement which I couldn't do em when I had the stroke and I have eh limited em I suppose eh dexterity in my right hand again which I couldn't do initially when I had the stroke so that's something to be thankful for and I'm blessed for em I suppose eh day to day eh now em it's more a question of keeping on keeping on em and by that I mean just em consolidating what you've eh had to learn or relearn about em you know say just simple simple stuff like eh how to move your hand a certain way or how to to make your leg you know eh sit down and then eh rise up again em but it's just eh em learned to to kind of do simple stuff and then do gradually more eh complex eh em stuff you know em that that for me is is you know the hard part em I because I have been in hospital for so long and then been cared for eh for so long I have a kind of em semi eh kind of em not dependency but just you know I I I still in in my mind expect everything to be done for me	Speaks Progressively Possibly perseverance? New learning Learned helplessness to be explored further
	R: Hmm	
	P: and eh but that's just a mindset that I need to move away from but em yeah so like I said day to day I just you know eh obviously you know em my my life life is different eh since I've had the stroke but em it's not drastically different and actually what eh Mum and I recounted to you about the journey from eh the stroke to now pretty much sums it up that you know it's just like you you wonder if you're you're ever going to get to the place eh you once were in terms of like just eh physically em and it's there always is going to be a lack but at the same time em I I I'm grateful that I eh have what I have	Two lives-one past and current adjusted life Descriptive language- Journey is interpreted as travelling to a destination- time consuming
	R: Hmm	
	P: that's probably the the simplest but the the the best thing I can say	
Family Support	R: And when you came home from hospital what was that like for you?	
Future recommendations	P: I don't remember I honestly don't remember eh its em I mean you see initially there were so many visits up and down to to (name) and back eh actually looking back on it that possibly could be a contributing factor to like if if I put it to you another way if I had been closer physically to the hospital I mightn't have had as many say seizures as I ended up having eh because as as mum particularly when I was discharged initially and I was sent to the (name) like	

Appendix J - Theoretical Memo on Strategising Category

Strategising suggests a heightened awareness of limitations bestowed upon them post stroke but the adoption of strategies makes life manageable. Acceptance that life had to change. Matter of fact and proactive to make life easier. However, the strategies adopted highlights the significant changes they have had to make in order to live as well as they can at this point in time.

Strategies and progress seem connected. Strategies are used to make it easier, assume control and become more independent. Independence is the end goal and realising limitations is the category which creates markers in achieving this goal. Ergo strategies and limitations are related to each other.

Strategies can increase independence and further develop cognition. The P's want to be as independent as possible and use of strategies as these reduce the need for dependency on others, normalising way of life.

Resolving the rumination-As the participants reframed their thought processes about creating a life for themselves devoid of the stroke, they became braver at reintegrating in to society. They felt they were conquering and coping with the stroke simultaneously through strategising.

This suggests acceptance of difficulties and perhaps it shows perseverance with regaining autonomy and control.

Strategising now seems to be a major category rather than a minor category of realising limitations. Strategising was theoretically coded as a sub action of realising the implications of stroke P's continuously refer to strategising as a meaning making action-this creates a sense of purpose for the P's. Strategising has involved developing compensatory strategies, but also masking/concealing their difficulties, limiting their social experiences and changing their relationships with others. P's place a lot of emphasis on strategising as evident in the quotes, i.e. P5- "…heavy reliance on smartphone…", P6 – "step it out, step one, step two, step three…"-panic sets in if P6 does not do this-Strategising enables the participants to repair their sense of self by becoming more independent in their ADL's-they can learn to trust themselves with strategising.

Appendix K - Emotional Distress Interview Management Protocol

Draucker, Martsolf & Poole, (2009) two stage response protocol was adapted to this interview context and will be implemented to support participants who may become distressed during the interview, as outlined below: -

Stage One: The researcher is a Counsellor and will be cognisant of participants' verbal and nonverbal cues during the interview, i.e. being tearful, irritable, frequently sighing, crossing arms, distancing self from the table, non-eye-contact, nervousness, sudden change in persona, statements of distressing feelings etc. Should participants exhibit any of these signs, the researcher will: -

- Pause the interview; and/or
- Offer tea/coffee/water/tissues; and/or
- Take a break for a couple of minutes; and/or
- Discuss the issues arising for the participant (this will not be audio-recorded); and/or
- Resume the interview when the participant is ready; and/or
- Suspend the interview if the participant does not wish to continue; and/or
- Suspend the interview should the interviewer deem this appropriate; and/or
- Resume the interview at a later date, if applicable.

Stage Two: Should participants experience high levels of stress or emotional distress or exhibit behaviours suggesting that the interview is too stressful for them (uncontrolled crying, shaking, statements of harm etc.) the researcher will: -

- Suspend the interview;
- Encourage the participant to contact their next of kin; (or the researcher to do so if the participant is unable to); and/or
- Encourage the participant to contact their GP or mental health provider; and/or
- Contact the participant's next of kin, with the participant's consent; and/or
- Offer to contact the participant's next of kin, with participant consent, for the researcher to do so (should the participant be unable to do so); and/or
- With participant consent, contact a member of the health care team treating the participant for further advice/support; and/or
- Follow participant up with courtesy call (if participant consents).
- The participant will be removed from the study and their data will not be used.