

# Stroke in young women: an interpretive phenomenological analysis.



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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 M.Sc. is entirely my own work 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.

Signed: \_\_\_\_\_

ID Number: 60611298

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## **Abstract**

A comprehensive picture of the psychosocial consequences of stroke in young adults, that is grounded in the experience and perspective of stroke survivors, is currently lacking in the literature. The aim of this research was to explore the experience and psychosocial consequences of stroke amongst young women through semi-structured interviews and qualitative analysis. Individuals who were between 18 and 50 years old, who had experienced a mild to moderate stroke and were at least six months post-stroke were eligible for inclusion. Individuals with persistent dysphasia, a communication disorder which would result in difficulty in taking part in an interview, were excluded. Accounts of participants' experiences were analysed using interpretative phenomenological analysis (IPA). Four super-ordinate themes emerged from the analysis: (1) Stroke as a disease of the elderly: participants' struggled to come to terms with experiencing a disease normally associated with old age. Their shock was mirrored by the reactions of others including medical staff who were reluctant to diagnose stroke in the young. (2) Post-stroke selves: describes the complex task of trying to adapt to a new post-stroke physical and emotional self. Upon reflection on pre-stroke lives more able-bodied physical and cognitive selves were mourned. (3) A desire for peer support: experiencing a disease normally associated with old age made participants' feel isolated after their stroke. Participants' described their desire to relate to somebody similar with similar, specific concerns. (4) The impact of stroke on relationships: following stroke, patients need a considerable amount of social support, however, too much support can feel suffocating. While some relationships were strengthened, others became problematic. The findings suggest the importance of addressing the specific needs of young stroke patients through provision of age adapted facilities, services and advice.

## Chapter 1: Introduction

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A stroke is a sudden and devastating event, which usually happens without warning “striking” the person out of the blue (Horgan, Hickey, McGee, & O'Neill, 2008) and confronting the survivor with a variety of physical and psychosocial challenges. Physical effects can include weakness or paralysis, communication difficulties, difficulties swallowing, disturbed vision, incontinence and fatigue. With various degrees of severity and constellations of symptoms, the consequences are diverse and can extend to encompass numerous facets of life.

Stroke typically occurs in older adults, four out of five people admitted to hospital with stroke are over the age of 65 and therefore stroke is normally associated with old age (Banks & Pearson, 2004). The greater incidence of stroke in older adults is reflected in the research literature; samples are typically comprised of individuals aged 65 years and older. However, approximately one in five cases of stroke occur in adults of working age and 5 percent of all strokes occur in adults under the age of 45 (Johansson, Norrving & Lindgren, 2000). Research suggests that stroke among adults of working age is increasing (Johansson et al., 2000; Pessah-Rasmussen, Engstrom, Jerntorp, & Janzon, 2003; Medin, Nordlund, & Ekberg, 2004). Although research effort has been directed toward establishing the incidence, etiology, risk factors, neurological and functional outcomes of stroke among young adults (e.g. Lu, Ye, Adami, & Weiderpass, 2008; Rasura, Spalloni, Ferrari, & De Castro et al., 2006; Putaala, Metso, Metso, & Konkola et al., 2009) much less is known about the subjective experience and meaning of stroke for these individuals (Stone, 2005). The present study aims to extend this knowledge by exploring the experience and



psychosocial consequences of mild stroke amongst young adults to provide an account grounded in the perspectives and experiences of young stroke survivors.

In the sections that follow literature on physical and psychosocial challenges associated with stroke will be reviewed. While younger stroke patients are the primary focus of the current research, studies including older samples will be referred to in this review as there are commonalities in stroke experience among older and younger patients. Importantly however, differences between older and younger stroke survivors and issues of greater salience to younger stroke patients will be highlighted. It must be noted that the term 'young' is used to denote a variety of age ranges in the stroke literature and consensus in terms of the definition of 'young' in this context is lacking. In many instances retirement age (i.e. 65 years) serves to distinguish between young (< 65 years) and older (> 65 years) stroke patients, this convention will be adopted throughout this introductory literature review. The review will begin by examining the classification of stroke and its physical impact, followed by the psychological consequences of stroke for younger people. This section concludes with the rationale for the current study.

### **1.1 Stroke symptoms, types and risk factors**

The symptoms of a stroke include rapid disruption of normal brain functioning, as evidenced by weakness of, or a cramp in, one half of the body, headache, disorder of speech and eyesight, difficulties in swallowing, memory deficiencies and altered perceptions of space and the body (Gibbon, 1994). Stroke is a heterogeneous disease with more than 150 known causes (Amarenco, Bogousslavsky, Caplan, & Donnan et al., 2009). In contrast to their older counterparts, younger stroke patients tend to have a wider variety of etiologies. A

primary cause cannot be determined for up to one third of younger stroke cases (Rasura et al., 2006). Clinical categories of stroke include cerebral infarction or ischemic stroke, intracerebral hemorrhage and subarachnoid hemorrhage (McDowell, 1998). Cerebral infarction, the most common type of stroke accounting for approximately 80% of stroke cases, occurs when blood supply to part of the brain is restricted resulting in death of brain tissue. Cerebral hemorrhage involves the rupture of a blood vessel inside the brain and bleeding inside the brain. Subarachnoid hemorrhage occurs when a ruptured blood vessel causes blood to spill over the surface of the brain (McDowell, 1998). Data regarding the most common type of stroke in young people are conflicting, some research indicates cerebral infarctions are most common (Meyer, Oreneia, & Biller, 1994; Awada, 1994; Mehndiratta, Agarwal, Sen & Sharma et al., 2004), high rates of hemorrhagic strokes are reported elsewhere (Hop, Rinkel, Algra, & van Gijn, 1998; Lai, Chen, Lee, & Ro et al., 2005; Ruiz-Sandoval, Romero-Vargas, & Chiquette et al., 2006).

Stroke severity is typically graded in terms of basic motor function ability and an individual's ability to perform personal activities of daily living (P-ADL) (Numminen, Kaste, Aho, Waltimo, & Kotila, 2000; Jamrozik, Broadhurst, Lai, & Hankey et al., 1999). Mild stroke is characterised by no or slight motor impairment and high levels of independence in P-ADL, moderate and severe strokes are categorised on a gradient of impairment in these domains (Carlsson, Moller, & Blomstrand, 2004). However, diagnosed severity does not necessarily equate with subsequent disability and impairment (Wade & Halligan, 2004). Kapelle, Adams, Heffner, Torner and Gomez (1994) found that 92% of their study sample of younger stroke survivors had nearly perfect scores on the Barthel Index (BI) (>95), indicative of mild stroke, but half of the participants reported a deterioration in quality of life

(QoL) and only 42% returned to work. In a sample heterogeneous for age, Edwards, Hahn, Baum and Dromerick (2006, p.154) noted that 35% of mild stroke survivors “were discharged home with no post acute rehabilitation services” despite the fact that 87% of the stroke survivors had residual symptoms. Symptoms of mild stroke can include fatigue, concentration difficulties, poor short-term memory, emotional lability, stress resistance, anxiety and uneasiness, aphasia and visual impairments (Carlsson, Moller, & Blomstrand, 2003; Stone, 2005). Amongst individuals with mild stroke long-term decrements in social functioning and activity limitations have been documented (Carlsson et al., 2003). Previous authors have noted a failure to detect and address *hidden dysfunctions* (particularly domains of cognition and social dysfunction) associated with mild stroke because of the ceiling effects that occur with commonly used scales in stroke care (Carlsson et al., 2003; Hommel, Trabucco-Miguel, & Naegele et al., 2009).

Smoking and hypertension are major modifiable risk factors for stroke in young adults (Redfern, McKeivitt, Dundas, & Rudd et al., 2000; Putaala et al., 2009). Additional risk factors include: alcohol or drug use, use of oral contraceptives, hyperlipidemia (raised or abnormal levels of any or all lipids and/or lipoproteins in the blood), elevated plasma homocysteine levels, migraine, diabetes mellitus, and hypertension (Kruger, Graham, Kruger, Teasell, Foley, & Salter, 2010; Das, Bandyopadhyay, Paul, & Singh, 2010). Non-modifiable risk factors include family history (particularly strokes occurring < 65years), previous stroke, mitral valve prolapse, patent foramen ovale, pregnancy and postpartum, and race (research has shown elevated levels of risk for the occurrence of stroke in young black individuals) (Kittner, McCarter, Sherwin, Sloan, et al., 1993; Hassan, Sham, & Markus, 2002;

Nedeltchev, der Maur, Georgiadis, & Arnold et al., 2005; Rasura et al., 2006; Jones, Liu, Colangelo, & Yaan, et al., 2007; Kruger et al., 2010; Tang & Jeng, 2010).

### **1.2 Incidence of stroke in young adults**

Estimates suggest that one-fifth of all strokes world-wide occur in individuals under 65 years of age (Jette, Keysor, Coster, & Haley, 2005; Teasell, Mc Rae, & Finestone, 2000). Figures from the Economic and Social Research Institute of Ireland indicate that stroke affected 9,235 people in Ireland in 1999 and 27.4% of these were between the ages of 16 and 65 years (O'Connor, Cassidy, & Delargy, 2005). In the countries of Western Europe less than 5% of stroke patients are under the age of 45 years (Marini, Totaro, De Santis, Ciancarelli, Baldassarre, & Carolei, 2001). In general incidence is higher amongst men (Adams, Kapelle, Biller, & Gorden et al., 1995; Kristensen, Malm, Carlberg, Stegmayr, & Backman, 1997; Naess, Nyland, Thomassen, & Aarseth et al., 2002; Leys, Bandu, Henon, & Lucas et al., 2002; Lee, Hsu, Chen, & Chen, 2002; Varona, Guerra, Bermejo, & Molina et al., 2004; Nedeltchev et al., 2005). However, among those aged less than thirty years females usually outnumber males (Bougousslavsky & Pierre, 1992; Adams et al., 1995; Naess et al., 2002; Rasura et al., 2006).

### **1.3 Stroke outcomes**

Stroke can result in impairments of neurological functioning, such impairments vary according to the extent and location of damage. The most prevalent deficits are impairments in the motor domain including some degree of paralysis on one or both sides of the body and changes in ability to control and co-ordinate movements. Impairments in vision, cognition (e.g. memory, attention) and language,

and changes in sensation (e.g. numbness, tingling) and affect (e.g. post-stroke depression and anxiety) may also be evident. Post-stroke depression (PSD) is the most common affective disturbance following stroke affecting approximately one-third of all stroke patients (Hackett, Yapa, Parag, & Anderson, 2005). Younger age has been highlighted as a risk factor for PSD (Robinson, Starr, Kubos, & Price, 1983) although the evidence is inconclusive (Horgan et al., 2008; Hadidi, Treat-Jacobson, & Lindquist, 2009). The incidence of PSD in young stroke patients ranges from 11% to 55% (Hindfelt & Nilsson, 1992; Kapelle, Adams, & Heffner et al., 1994; Neau, Ingrand, & Monille Brachet et al., 1998; Cassidy, O'Connor, & O'Keane, 2004; Naess, Nyland, Thomassen, Aarseth, & Myhr, 2005).

In general, younger stroke survivors tend to have better prognoses, make a better neurological recovery (Manimmanakorn, Arrayawichanon, Wattanapun, & Nuntharuksa et al., 2008) and are more likely to be discharged home compared to older patients (Adunsky, Hershkowitz, Rabbi, & Asher-Sirron et al., 1992). However, young stroke patients will typically have experienced little age-related deterioration in health and functional abilities. Physical and cognitive impairments and the extent of restructuring necessary following stroke, for example in terms of employment and family responsibilities, can contribute to adjustment difficulties and affective distress (Robinson et al., 1983; Robinson, 1997; Verdehlo, Henen, & Lebert et al., 2004). Wade and Halligan (2004) suggest the need for medical staff to go beyond the physiological aspects of stroke and implement specific strategies aimed at dealing with psychological and social issues experienced by younger stroke survivors.

#### **1.4 Adjustment following stroke**

In tandem with its physical manifestations and associated affective distress, stroke brings about a variety of psychosocial challenges and transitions. Changes may occur in the individual's capacity for social functioning, in self-concept and in patterns of social relations and interactions. The trajectory of stroke experience has been described in terms of three phases: an acute and frequently crisis-like onset, an improvement (rehabilitation) phase and a stable post rehabilitation phase (Roland, 1994; Becker & Kaufman, 1988; Kaufman, 1988). The first stage is characterised by dysfunction and discontinuity; the stroke patient struggles to reconcile the person they once were with the person they have become as diagnosis and impairment become reality. The second stage entails facing transition, which for Becker (1993) and Bendz (2000) occurs when the stroke survivor returns home. Not until this point are the full implications for survivors'/carers' lives made real; the experience has been likened to being 'aliens in their own land'. Bury (1991) dubbed the third stage one of treatment and adaptation. Following stroke, patients are challenged to cope with a variety of often complex changes in their lives, the process of psychosocial adaptation to stroke is an evolving one (Livneh & Antonak, 2005). A number of studies have explored the personal experience of stroke (amongst older adults and in samples heterogeneous with respect to age) highlighting its transformative role in self-concept, themes of loss, uncertainty, social isolation, and adaptation (Salter, Hellings, Foley, & Teasell, 2008). Amongst young adults experiences of hospitalisation and rehabilitation (Röding, Lindström, Malm, & Öhman, 2003; Banks & Pearson, 2004; Stone, 2005) issues relating to stigma, identity and self-concept (Stone, 2005), changes in close relationships and social support (Hindfelt & Nilsson, 1977, 1992; Teasell et al., 2000; Leys et al., 2002; Banks & Pearson, 2004; Stone, 2005) and

return to work (Koch, Egbert, Coeling, & Ayers, 2005; Lock, Jordan, Bryan, & Maxim, 2005; Medin, Barajas, & Ekberg, 2006; Alaszewski, Alaszewski, Potter, & Penhale, 2007; Lindström, Röding, & Sundelin, 2009) have received research attention. Research in each of the above domains will be reviewed in the sections that follow.

### **1.5 Hospitalisation**

Organised stroke care enhances patient outcomes in terms of physical ability and quality of life (Stroke Unit Trialists' Collaboration, 1997; Sulch, Perez, Melbourn, & Kalra, 2000). However, Traberg-Kristensen (1998) questioned whether the needs of younger stroke patients were taken into consideration in the planning and implementation of their rehabilitation. The relative rarity of stroke in young adults means that the stroke rehabilitation environment is predominantly populated with older adults. Qualitative studies with young stroke survivors highlight dissatisfaction amongst young patients accommodated in wards with older people where the association between stroke and geriatric medicine is apparent (Röding et al., 2003; Banks & Pearson, 2004; Stone, 2005; Medin et al., 2006; Ch'ng, French, & McLean, 2008). In a Swedish study, Röding and colleagues (2003) used grounded theory to develop an account of how young stroke patients experienced the rehabilitation process. Participants vented their frustration at the narrow focus of rehabilitative strategies and expressed frustration at the lack of consultation, information, and age-adapted rehabilitation. The manner in which patients are informed about their condition and the provision of relevant, individualized information are pivotal issues for younger stroke patients (Kersten, Low, Ashburn, & George, 2002; Röding et al., 2003; Low, Kersten, Ashburn, & George, 2003). Research focusing on the unmet

needs of younger stroke survivors suggests that a significant proportion have ongoing needs in terms of age-appropriate, personalised information, financial assistance, non care activities and intellectual fulfilment (Kersten, et al., 2002; Low et al., 2003; Röding et al., 2003).

## **1.6 Self-concept and identity**

In their meta-synthesis of qualitative studies on the effects of stroke in samples that were heterogeneous for age, Salter and colleagues (2008) point to an ongoing process of re-interpretation of the self post-stroke, to a discontinuity between pre and post-stroke selves and to a difficult process of reconciling these discrepant selves. Changes in appearance, physical abilities, established roles and patterns of interactions, and the reactions of others can challenge the individual's capacity to maintain satisfactory self-concept.

Individuals create a sense of their past, present and future by telling life narratives (Gergen & Gergen, 1983; Sarbin, 1986), however when an individual experiences a chronic illness certain life stories can be disrupted resulting in a flawed sense of coherence referred to as "*biographical disruption*" (Corbin & Strauss, 1987, p.249). Pound, Gompertz, and Ebrahim (1998, p.489) describe stroke as an "illness that shatters lives", in particular "the lives of relatively young, professional people are turned upside down by stroke...as a bolt from the blue". Faircloth, Boylstein, Rittman and Young (2004) draw distinctions between stroke in young and older adults and challenge the inevitability of biographical disruption associated with stroke suggesting that rather than "an invader of everyday life" for older adults stroke is often "part of an ongoing life story" (Faircloth et al., 2004, p244). Findings from their qualitative study suggest that many older adults normalise stroke as part of the



ageing process. Age is thus an important mitigating factor in the experience and implications of stroke. Pound et al. (1998) suggest that for the young adults stroke is experienced as stigmatizing because of its strong associations with old age, which is a stigmatizing condition in itself. Stroke in younger individuals may represent premature aging, such identification can impact on self-concept as individuals feel 'old before their time' and robbed of plans and aspirations for the future (Röding et al., 2003; Stone, 2005).

Researchers have described the world of the stroke survivor as "one grounded in a world of loss" (Secret & Thomas, 1999, p240) associated with the "loss of a normally automatically smoothly functioning body" (Doolittle, 1992, p.122). An extreme but poignant example of such loss is illustrated in the work of Jean Dominique Bauby who suffered a stroke to his brain stem in December 1995 at the age of 43 that left him with locked-in syndrome. In his memoir "The Diving Bell and the Butterfly" written by blinking his left eye when the alphabetic letter he wanted was spoken aloud by his assistant, Bauby describes two different selves shaped by two different bodies one before and one after stroke (Dudzinski, 2001). He describes his body as inescapable; he is stuck "in a limited physical body". He also experienced his body as an alien presence fearing how he may be perceived by others including his young children (Dudzinski, 2001). Even subtle changes to the body can be problematic (Stone, 2005). Parts of the body might lose their normal effortless ability to function changing body language, gestures, facial expressions, mobility, personal style and appearance (Brauer, Schmidt, & Pearson, 2001; Flick, 1999; Hafsteinsdóttir & Grypdonck, 1997; Häggström, Axelsson, & Nordberg, 1994; Sisson, 1998). Sacks (1991) suggests that the body is the first definer of self, in the same vein Gadows (1982) argues that after illness or disability the self stands in conflict with the body.

Murray and Harrison (2004) highlighted loss of part of the self and continued estrangement as a result of changes in the body following stroke.

### **1.7 Interpersonal relationships**

The physical, psychological, and social implications of stroke extend beyond the individual patient to their family members, friends and beyond. Good family functioning after stroke is associated with better health outcomes and greater patient satisfaction with rehabilitation (Clark, Rubenach, & Winsor, 2003). Young stroke survivors' with caring, understanding, and able partners or carers have more positive rehabilitation outcomes (Teasell et al., 2000; Banks & Pearson, 2004; Buschenfeld, Morris, & Lockwood, 2009). However while moderate levels of social support from family members and friends in terms of assistance can be effective for functional and emotional recovery, over-protectiveness can result in feelings of helplessness, disempowerment and poor functional outcomes (Glass & Maddox, 1992).

As family members often take substantial responsibility in post-stroke care and recovery many will experience significant changes in their own lives, taking on tasks and roles previously performed by the stroke survivor (Buschenfeld et al., 2009). In some instances, the parents of young stroke survivors resume care giving roles for a previously independent child, in others a spouse may become a caregiver. Such changes can be problematic both for the patient and the carer. Amongst couples, individuals with multiple roles, such as responsibility for young children or employment, in addition to caring for their spouse tend to experience greater difficulties (Banks & Pearson, 2004). Across studies of young stroke patients the prevalence of marital problems, separation and divorce ranges from 5 to 54% (Hindfelt & Nilsson, 1977, 1992; Teasell et al., 2000; Leys et al., 2002; Banks &

Pearson, 2004; Stone, 2005). Parent-child conflict, difficulties associated with childcare and the burden of care giving experienced by children have also been highlighted as significant issues amongst young stroke patients (Teasell et al., 2000; Low et al., 2003; Röding et al., 2003; Banks & Pearson, 2004).

Previous literature has noted the problematic impact of stroke on sexual relationships and the deterioration of sexual relationships in younger stroke survivors (Neau et al., 1998; Teasell et al., 2000; Kersten et al., 2002; Low et al., 2003; Röding et al., 2003; Banks & Pearson, 2004). Sexual dysfunction can be attributed to an interplay between physical and psychological factors, however, researchers (e.g. Buzzelli, Francesco, Giaquinto, & Nolfi, 1997; Visser-Meily, Post, van de Port, & Heugten et al., 2008) suggest that psychological factors play a dominant role in the disruption of sexual functioning in stroke survivors. Various psychological factors contribute to post-stroke sexual dysfunction including fear of precipitating another stroke (Muller, 1999), lowered self-esteem and bodily changes which may make an individual with stroke feel less desirable or unattractive (Edmans, 1998; Murray & Harrison, 2004).

Single people face different challenges compared to those in relationships in terms of sexuality after stroke (Murray & Harrison, 2004; Ch'ng et al., 2008). For single individuals trying to meet partners, visible disabilities mean little control over the disclosure of their disfigurement or impairment. On the other hand, if impairments are not visible anxiety and anticipation regarding the timing and style of disclosure may result (Kent; 2003; Clarke-Henshaw, 2007, in Kennedy, 2007). Clarke-Henshaw (2007, in Kennedy, 2007) noted that in couples illness may have an impact on the dynamics of the relationship. Adopting care-giver/care-receiver roles can mean a profound shift within a partnership, the partner often plays a custodial role

which may resemble that of a parent. Such changes in roles may negatively impact sexual relationships (Caplan & Moelter, 2002, in Kennedy, 2007).

Stigma associated with disability can also affect sexual functioning and relationships as societal myths create false stereotypes, for example the belief that sexual life belongs to healthy people (Buzelli et al., 1997). As Renshaw (1975, p.68 in Redding, 1998) observed, “Stroke indeed is an emotional word, conjuring up visual images of wheelchairs, walkers, catheters, canes, splints, speech problems and drooling facial paralysis”. This image of stroke does not acknowledge the possibility of returning to work, engaging in social activities, and re-establishing sexual relationships (Chadwick, Saver, Biller, & Carr 1998, in Redding, 1998).

### **1.8 Quality of life after stroke**

There are few studies of QoL based specifically on young stroke patients (Naess, Waje-Andreassen, Thomassen, & Nyland et al., 2006) despite the acknowledged importance of QoL assessment in this patient group (Hamedani, Wells, Brass, & Kernan et al., 2001). Previous research has indicated that older stroke patients have lower QoL compared to younger patients (Kozielec, Rotter, & Karakiewicz, 2005; Madden, Hopman, Bagg, Verner & Callaghan, 2006). Naess et al. (2006) reported low levels of Health related QoL (HRQoL: in the SF-36 domains social functioning, physical functioning and role limitations due to physical health) in a group of younger stroke patients (aged 15-49 years) at a mean follow up of 6 years after stroke. (The authors did not specify whether participants had received rehabilitation). Röding, Glader, Malm and Lindström (2010) noted that less than half of their sample (n=1068) (aged 18-55 years) were satisfied with life as a whole and that deterioration in levels of concentration had negative consequences on their

overall perceived quality of life. Additional factors effecting QoL for younger stroke survivors include changes in work, driving ability, recreational activities and social functioning (Teasell et al., 2000; Vestling, Tufvesson, & Iwarsson, 2003; Naess et al., 2006; Grenthe Olsson and Stibrant Sunnerhagen 2007; Röding et al., 2003, Röding, Glader, Malm, Eriksson, & Lindström, 2009; Hommel et al., 2009).

In studies assessing the impact of rehabilitation, improvements in QoL have been noted. For example, Grenthe-Olsson and Stibrant-Sunnerhagen (2006) documented significant improvements in all 8 domains of the SF-36 following 6-8 weeks of day hospital rehabilitation. These improvements were maintained at two year follow-up (Grenthe Olsson & Stibrant Sunnerhagen, 2007). Manimmanakorn et al. (2008) assessed functional and psychological outcomes in addition to QoL in stroke survivors across three different age groups (<44, 45-64 and > 65 years) after a rehabilitation program. Greatest improvements in functional outcomes and QoL scores in both physical and social domains were documented in the youngest patient group. Similarly, O'Connor et al. (2005) documented improvements in QoL following late multidisciplinary rehabilitation.

### **1.9 Returning to work after stroke**

Individuals tend to regard work as a meaningful and purposeful activity that can contribute significantly to their life satisfaction, wellbeing, self-worth, social identity and ability to maintain independence (Vestling et al., 2003; Banks & Pearson, 2004; Medin et al., 2006); thus it is not surprising that many young stroke survivors express great concern about returning to work (Isakson, Mettavainio, & Ahlgren, 2004). Reported rates of return to work range from 19 to 74% (Neau et al., 1998; Wozniak, Kittner, Price, Hebel, & Sloan et al., 1999; Teasell et al., 2000; Vestling et

al., 2003; Varona et al., 2004). Unspecific symptoms such as headache, tiredness, irritation, anxiety, depression, emotional vulnerability and memory problems are common factors contributing to younger stroke survivor's inability to return to work (Glozier, Hackett, Parag, & Anderson, 2008; Tyerman & Meehan, 2004). Wolfenden and Grace (2009) noted that even high functioning stroke survivors with minimal impairments may struggle to return to work because of invisible cognitive limitations such as fatigue (Banks & Pearson, 2004), reduced concentration (Edwards et al., 2006) and memory lapses (Kersten et al., 2002). Radford and Walker (2008) identified social barriers preventing younger stroke survivors from returning to work including the benefits system, realities of the job market, travel to and from work, societal attitudes towards stroke and lack of understanding about hidden impairments after stroke. Factors that enable successful return to work for younger stroke survivors include provision of vocationally directed rehabilitation, employer flexibility, social benefits, positive attitudes towards return to work and support from family or coworkers (Corr & Wilmer, 2003; Koch et al., 2005; Lock et al., 2005; Medin et al., 2006; Alaszewski et al., 2007; Lindström et al., 2009).

Individuals who do not return to work after stroke report significantly more unmet needs than those who have reduced hours or changed jobs (Kersten et al., 2002). Failure to return to work has been associated with negative impact on family relationships, decreased sexual relations, financial difficulties, decline in leisurely pursuits and reduced quality of life (Kersten et al., 2002; Vestling et al., 2003; Röding et al., 2003; Daniel, Wolfe, Markus, & Busch, et al., 2008). In contrast, successful return to work can enhance recovery and life satisfaction by consolidating self-esteem, confidence and social identity (Wolfenden & Grace, 2009).

## **1.10 Setting and rationale for the current study**

Stroke among young adults is relatively rare. There are substantial differences between older and younger stroke survivors in terms of etiology, prognostic factors, extent of functional recovery and comorbidities. Although many young stroke patients will make a good physical recovery, the psychosocial impact can be significant. Younger stroke survivors are “at a different stage of the life course” (Stone, 2005, p.293), many will not have previous experience of health problems, are active in the work force, have financial needs and family responsibilities such as childcare (Snorgen & Stibrant Sunnerhagen, 2009). Research based on the stroke experiences of older adults may not be applicable to young stroke survivors.

Developments in organised stroke care have reduced both mortality and institutional care requirements after stroke (Collins, McConaghy, McMahan, Howard, & O’Neill et al., 2000). However, research highlights gaps in stroke care for young adults and patient dissatisfaction (Röding et al., 2003; Banks & Pearson, 2004; Stone, 2005). In Ireland access to rehabilitation and follow-up services for patients under the age of 65 years remains severely limited. The recent national audit of stroke services (Horgan et al., 2008) noted that: (1) only five hospitals routinely accept patients under the age of 65 years to their rehabilitation units; (2) day services and community stroke services for younger patients are underdeveloped; and that (3) limited entitlements to rehabilitation and home care can result in inappropriate long-term nursing home placement for young adults. There is a dearth of evidence regarding the experience of young stroke patients in the Irish healthcare system and in the longer term after stroke.

While there are an extensive number of quantitative studies in regards to the incidence, etiology, neurological and functional outcomes associated with stroke in

young adults, qualitative studies in which young stroke survivors provide their own accounts of the experience are lacking. The available qualitative studies exploring the personal experience of stroke have highlighted its transformative role in self-concept, themes of loss, uncertainty, social isolation, and adaptation (Salter et al., 2008; Bendz, 2000; Burton, 2000; Murray & Harrison, 2004). However, with the exception of qualitative studies addressing experiences of hospitalisation and rehabilitation (Roding et al. 2003; Banks & Pearson, 2004), return to work after stroke (Medin et al., 2006; Alaszewski et al., 2007) and identity and self-concept (Stone, 2005) most of the samples included in the qualitative stroke studies are comprised of individuals aged 65 years and older. The current research project will break new ground by using IPA to provide a comprehensive picture of the experience and psychosocial consequences of stroke in young adults.

In recent years there has been an increasing emphasis on the inclusion of user perspectives in the design and delivery of health services (Pollitt, 1988). Gaining insight into the subjective meaning and experience of illness is critical to furthering understanding of health and illness behaviour and can lead to more efficient and appropriate health services (Burton, 2000; Lawrence & Kinn, 2010). The Irish Heart Foundation's Stroke Manifesto (Stroke Manifesto, 2010) highlights the need to eliminate age-related discrimination in service provision. Improved understanding of the complex issues faced by young patients in the aftermath of stroke would serve to aid such developments. Providing a rich or 'thick' interpretive account of individual subjective experiences necessitates use of qualitative methods which are sensitive to the unique personal experiences, perceptions and meanings of individuals. The main objectives of the current study are to provide such an account by exploring younger patient's experiences of stroke, rehabilitation and life after stroke.



## Chapter 2: Method

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### 2.1 Aims and objectives

The aim of the current study was to explore the experience and psychosocial consequences of stroke amongst *young adults* (aged < 50 years) from an idiographic, phenomenological perspective using Interpretive Phenomenological Analysis (IPA, Smith, 2004).

The main objectives were to:

- Investigate the subjective accounts of young adults' experiences of stroke with specific regard to self-concept, emotional experience, interactions with others and adjustment over time.
- Increase our understanding of the psychological and social needs of young adults with stroke within both the medical setting and the wider community.

### 2.2 Design

Data for this qualitative study was collected via face-to-face semi-structured interviews and analyzed using interpretive phenomenological analysis (IPA) (Smith, 2004). The philosophical foundation of Interpretive Phenomenological Analysis (IPA) is phenomenological and ideographic and is concerned with the uniqueness of individual experience (Smith & Eatough, 2007; Smith & Osborn, 2008; Smith, Flowers, & Larkin, 2009). IPA has been informed by three key areas of philosophical knowledge: phenomenology, hermeneutics and idiography, and draws on the theorising of Husserl, Heidegger, Merleau-Ponty and Satre (Smith et al., 2009). Phenomenology which literally means the “science of phenomena” (Moran &

Mooney, 2002, p.5) is concerned with the nature of how things appear to us in experience (Eatough and Smith (2001 in Willig & Stainton-Rogers, 2001). “The founding principle of phenomenological inquiry is that experience should be examined in the way that it occurs” (Smith et al., p.12). Phenomenology is understood to have two distinct phases: transcendental and hermeneutic/ existential phenomenology. Transcendental phenomenology suggests that we should reduce our understanding of experience to its core. Husserl developed phenomenology as a philosophy and adopted a transcendental approach (Clarke, 2009). Concerned with ‘zuden sachen’ (‘the things themselves’), Husserl believed that the world is formed and experienced through conscious acts (Eatough & Smith, 2001 in Willig & Stainton Rogers, 2001). Husserl suggested that individuals should step outside of their daily experiences/ ‘*natural attitude*’ in order to be able to examine that experience (Smith et al., p.12). Therefore, to be phenomenological we need to ‘bracket’ off the taken for granted world and concentrate on our perception of that world via a series of ‘reductions’ where each reduction offers a different perspective, in order to reach the universal essence of a given phenomenon (Smith et al., p.13).

Heidegger and Merleau-Ponty adopted a hermeneutic/ existential phenomenological viewpoint and believed that Husserl’s suggestion of ‘bracketing’ isn’t always possible because our observations are always made from a position of our own, thus we can only offer an interpretation at best (Smith et al., 2009). Heidegger focused on the ‘Dasein’ (literally, ‘being there’ but more often referred to as “being in the world”) (Spinelli, 1989, p.108) and suggested that our bodies were unravelling in a world that was unique to each individual and thus different to the world which is experienced through a fellow human being’s body (Eatough & Smith, 2001 in Willig & Stainton-Rogers, 2001). Therefore, how does the researcher study another person’s

experience if we cannot connect with their experience directly? Heidegger proposed that we access the “factual existence” which means the experiences as they appear to another individual in his/her own way (Eatough & Smith, 2001 in Willing & Stainton-Rogers, 2001).

Merleau-Ponty shared Husserl and Heidegger’s interests in understanding our being-in-the-world (Smith et al., 2009), and proposed that the body is caught up with our sense of self, our surrounding environment and our relationships with others (Eatough & Smith, 2001 in Willig & Stainton-Rogers, 2001). Similar to Heidegger Merleau-Ponty emphasised the need for a more “contextual phenomenology” and he described our relationship to the world as ‘body-subjects’, which suggests that we feel and experience the world initially with our bodies (Smith et al., 2009, p.18). Thus every individual has their own unique relationship with the world and while we can be empathetic towards one another, we cannot share the other’s experience, because their experience is unique to their individual position in the world (Smith et al., 2009).

Similar to Heidegger and Merleau-Ponty, Sartre comes from an existential phenomenological viewpoint suggesting that human beings are consumed with projects in the world. In other words we are always becoming ourselves, thus an individual is always in the process of becoming rather than “a pre-existing unity to be discovered” (Kierkegaard, 1974 in Smith et al., 2009, p. 19). Similar to Heidegger, Satre explores the significance of the worldliness of our experience, in respect to the various relationships people have with their life worlds and “the interpersonal, affective and moral nature of those encounters” (Smith et al., 2009, p.21).

Phenomenology is both a philosophy and a research tool that enables the researcher to explore the nature and meaning of phenomena that appear to other human beings (Finlay & Ballinger, 2006). The philosophical concepts of Husserl,

Heidegger, Merleau-Ponty and Satre have all contributed to the foundation of IPA. Husserl's 'bracketing theory' is considered to be a very important component of the research process and Heidegger, Merleau-Ponty and Satre's exploration of each individual's unique and direct relationship with their life world emphasises the complex process that is necessary in trying to understand the lived experience of another human being (Smith et al., 2009). The second major theoretical underpinning of IPA comes from hermeneutics, the study and theory of interpretation, originally used to provide more definitive interpretations of biblical texts (Smith, 2007). Hermeneutics are concerned with the route that the researcher employs to understand another individual's experience (Smith et al., 2009). Heidegger found that interpretation was necessary to extract meaning from texts and thus linked phenomenology with hermeneutics (Moran, 2000). The hermeneutic circle has 3 main phases: 1) the fore-understanding/ prejudgement phase; 2) resistance/interrogating experience; and 3) interpretative revision of fore-understanding relationship between the part and the whole at a series of two levels (Smith, 2007) e.g. "to understand any given part you look to the whole; to understand the whole you look to the parts" (Smith et al., 2009, p.22). The third major influence of IPA is idiography. Concerned with the particular, rather than the general/universal, idiography operates on two levels; firstly, there is a focus on the level of detail and depth of analysis and secondly, IPA has a specific focus on how experiential phenomena have been understood from the "perspective of particular people, in a particular context" (Smith et al., 2009, p.29).

IPA has already been applied widely across a range of sub-disciplines in psychology particularly in health psychology (Smith, 1996) where considerable efforts have been made to move away from the simplistic confounds of the medical

model that merely mapped observable bodily processes onto a predictable illness experience (Brocki & Wearden, 2006). Healthcare professionals understand the importance of employing user perspectives in service delivery and thus recent research efforts in health psychology have been based on patient's perceptions and interpretations of their bodily experiences (Brocki & Wearden, 2006). IPA, a meaning focused qualitative method, facilitates researchers in their efforts to understand these subjective experiences and is committed to understanding the first person perspective from the third person position through inter-subjective inquiry and analysis (Smith et al., 2009). It is therefore committed to situating personal meaning in context. IPA with origins in phenomenology and symbolic interactionism would suggest that human beings are not passive perceivers of an objective reality, but rather that they interpret and comprehend their world by formulating their own biographical stories into a structure that makes sense to them (Brocki & Wearden, 2006).

In the current research the use of IPA gave a voice to participant accounts which facilitated the researcher to understand the meaning of their experience with stroke. Participants are seen as experiential experts; story tellers rather than respondents (Smith et al., 2009). IPA aims to explore in-depth the processes through which individuals make sense of their experiences; its origins lie in phenomenology and symbolic interactionism. IPA is phenomenological in that the primary focus is on individuals' subjective accounts of their experiences and on attempting to access 'the participant's personal world' (Smith, Jarman, & Osborn, 1999, p. 218). The researcher is central to the process in attempting to make sense of that other personal world through a process of interpretive activity; the analytic account is formed by the joint reflections of both participant and researcher (Smith, 2004), referred to as a 'double hermeneutic' (Smith & Osborn, 2003). The researcher is making sense of the

participant, who is making sense of x, thus illustrating the dualistic role of the researcher as being both like and unlike the participant. On one hand the researcher is similar the participant in terms of being a human being relying on everyday human resources to make sense of the world, however on the other hand the researcher only has access to the participant's experience, through what the participant reports about it, thus the participant's meaning making is first order and the researcher's sense making is second order (Smtih et al., 2009).

Semi-structured interviews provide an opportunity for the researcher to hear the participant talk about a particular aspect of their experience. The researcher's questions steer the interview to obtain the kind of data which will answer the research question. Therefore maintaining balance between controlling the direction of the interview and allowing the interviewee to contemplate and redefine their thoughts during the interview is essential (Willig, 2001). An interview schedule (see Appendix 1), consisting of 12 open-ended questions incorporating four different styles of questions, as recommended by Willig (2001), was used:

- Descriptive questions encourage the interviewee to present a general account of what happened e.g. "In your own words please tell me about the onset of your stroke?"
- Contrast questions enable participants to make comparable relations between events e.g. "Can you tell me a little bit about your life before your stroke (e.g. work socialising, relationships)?"
- Structural questions facilitate the organisation of the participant's thoughts where categories are identified in an effort to make sense of their world e.g. "In terms of the different types of staff in the stroke unit e.g. Doctors, OTs, Physiotherapists, Nurses etc. was there a certain staff member that you felt

most comfortable with if you had any questions or concerns that needed to be addressed?”

- Evaluative questions relate to the interviewee’s opinions towards someone or something e.g. “Could you tell me how your stroke affected you?”

However, a deliberate effort was made to avoid applying the interview schedule too rigidly as such an approach could have hindered the participant’s opportunity to elaborate on aspects of key importance to them (Hopf, 1974 in Flick, 1998). IPA is dedicated to fore-grounding the subjective experience of the participant and provides a means to describe and understand the participant’s account of the processes by which they make sense of their experiences (Brocki & Wearden, 2006). Smith (2004) suggests that IPA is particularly useful where the focus of study is relatively under-researched and where issues relating to identity, the self and sense-making are central. By using IPA to provide an in-depth, idiographic analysis of the participant’s personal experiences of stroke this study will add to the small number of qualitative studies concerning the perspectives of young stroke survivors that have been conducted to date.

### **2.3 Sample**

In keeping with IPA guidelines the current sample was selected purposively (as opposed to employing probability methods), thus “offering a research project insight into a particular experience” (Smith et al., 2009, p.48). Therefore participants were selected on the basis that they facilitated the researcher with the opportunity to gain further insight into the specified phenomena under study and as Smith et al. (2009, p.49) noted, participants in IPA studies “represent a perspective rather than a population”. Participants were recruited through the William Stokes Unit, the Stroke

Service at the Adelaide and Meath Hospital Tallaght, Dublin. The William Stokes Unit was the first purpose-built unit in Ireland providing age-related health care, with acute assessment, rehabilitation and day services for stroke patients. The unit is staffed by three consultant physicians, three registrars, one senior house officer and two interns. The specialist nursing staff are led by clinical nurse managers and specialist nurses in domiciliary assessment, stroke and falls. Services provided by the age-related health care team include physiotherapy, occupational therapy, social work, clinical nutrition and speech therapy. The unit caters for patients residing within the Southwest and South-Central Dublin catchment areas. Individuals who were between 18 and 50 years old, who had experienced a mild to moderate stroke and were at least six months post-stroke were eligible for inclusion. Fifty years of age was chosen as the upper age limit rather than 65 years in order to achieve a more homogeneous group in terms of work, childcare and family responsibilities. Individuals with persistent dysphasia, a communication disorder which would result in difficulty in taking part in an interview, were excluded. An interval of at least six months between the stroke and research participation was considered appropriate to allow participants time to reflect upon the event and its place in their lives. There was no upper limit in terms of time since stroke because the purpose of this study was to investigate the experience of stroke in young adults. Thus, allowing for varying intervals between time since stroke enabled the researcher to determine the broad patterns of adjustment and potential long-term implications experienced. Sixteen potential participants, identified from the Stroke Service database, received a preliminary information sheet outlining the nature of the study and an invitation to participate. Twelve females and one male agreed to participate in the study. Although the male participant was interviewed his data was excluded from the current



analysis with a view to obtaining a relatively homogeneous sample. Smith et al. (2009) noted the importance of making participant groups as uniform as possible in terms of obvious social factors or theoretical issues that are relevant to the phenomena under study, to determine psychological variability, or the pattern of convergence and divergence that may emerge within the group. Smith and Osborn (2003) note that in studies employing IPA sample size depends on a number of factors and that there is no 'right' sample size (p. 54). However, small sample sizes tend to be the norm in IPA as the analysis of large data sets may result in the loss of 'potentially subtle inflections of meaning' (p. 626) (Collins & Nicolson, 2002) and a consensus towards the use of smaller sample sizes seems to be emerging (Smith, 2004; Reid, Flowers, & Larkin, 2005). Table one outlines participants' characteristics.

**Table 1: Participants' Characteristics**

Pseudonym	Current age	Age at stroke onset	Time since stroke	Marital Status	Children	Return to work/change of job/career	Persistent Symptoms
1. Alison	23	21	2 years	Cohabiting	—	Returned to work p/t	None
2. Kate	41	39	2 years , 4 months	Married	1	Returned to work p/t	Occasional bouts of pins and needles and numbness
3. Angela	48	45	10 months since the second stroke	Married	—	Returned to work	Short-term memory loss, weakness in left arm and blurred vision
4. Tanya	31	27	3 years, 3 months	Married	2	Returned to college now working f/t	Slight right sided weakness affecting the foot
5. Miriam	25	23	2 years, 3 months	Single	—	Returned to work f/t	None
6. Emma	41	40	1 year	Married	4	Returned to work f/t	None
7. Fiona	48	47	1 year	Married	2	Housewife pre and post-stroke	Slight left sided weakness and occasional mild speech impairments and facial droop
8. Sarah	36	34	2 years, 6 months	Cohabiting	1	Housewife pre and post-stroke	Speech and reading deficits
9. Aoife	36	35	1 year, 8 months	Married	2	Housewife pre and post-stroke	Right sided impairments affecting hand and foot
10. Siobhan	30	29	1 year, 9 months	Married	3	Worked p/t pre and post-stroke	10% weakness in left hand
11. Jessica	20	18	2 years	In a relationship	—	Student pre and post –stroke	None
12. Jane	34	33	7 months	Cohabiting	—	Returned to work (reduced hours)	Mild speech deficits

**P/t = part-time; f/t = fulltime**

## 2.4 Procedure

Participants were initially contacted by their Consultant in the stroke unit to determine their interest in taking part in the study. Full written information on the content and conduct of the study, consent forms and contact sheets were sent out to all potential participants (see Appendices 2, 3, & 4 for copies of the information sheet, consent form and contact sheet, respectively). Subsequent to participants' initial agreement to participate, interview times and locations were arranged. Face-to-face interviews were conducted at the convenience of participants; 8 participants were interviewed in the consultant's office in the stroke unit and 4 participants were interviewed in their own homes.

On initial meeting a general preamble between the researcher and participant facilitated a relaxed atmosphere and provided participants with an opportunity to express any concerns they may have had at that point. Participants were reminded that the interview would be audio recorded and that they were free to withdraw from the study if feeling uncomfortable or distressed. Participants were debriefed after the interview and remaining questions or concerns were addressed. Copies of individual interview transcripts were made available to the participants on request.

Interviews ranged in duration from 30 minutes to an hour and a half, the average interview time was one hour. Efforts were made to ensure that a relaxed and comfortable atmosphere had been created thus enabling participants to speak openly about their experiences. Participants were asked to tell the story of their stroke and the way it had affected their lives, beginning with the question, 'Can you tell me about the onset of your stroke?', this question opened the way for dialogue. The content of the interview followed the participants through their account of experiences in relation to stroke from life before stroke, to stroke onset and hospitalization, and

life after stroke. Participants were asked to talk as widely as possible about the different ways in which their stroke affected or influenced their sense of self, emotional experiences and interactions with others. These topic areas served as a guiding framework for the interview rather than a prescriptive line of questioning, consistent with IPA.

## **2.5 Ethical considerations**

The "SJH / AMNCH Joint Research Ethics Committee" the Adelaide and Meath Hospital, incorporating the National Children's Hospital, Tallaght and the National University of Ireland Maynooth (NUIM) Ethics Review Committee, approved the study protocol (see Appendix 5 and 6 for copies of the ethical approval letters). The research was carried out in accordance with NUIM ethical policy and the Psychological Society of Ireland's Code of Ethical Conduct. The Director of Stroke Service (a Consultant Physician in Older Adult and Stroke Medicine) agreed to make timely referrals to the clinical psychology service at the Adelaide and Meath Hospital Tallaght in the event of participants becoming distressed by issues raised in the interview. Additional ethical issues considered to minimise the stress and negative effects of the study on the participants were as follows:

(1) *Confidentiality*: Participants were informed that their identity would remain confidential and pseudonyms would be used in any publications including the current report.

(2) *Information*: Participants received an introduction about the nature of the study and were told that the aim was to explore the meaning and experience of stroke in young adults.

(3) *Informed Consent*: All participants read a consent form and had the opportunity to consider and discuss participation in the study before signing a consent form prior to participation in the research study.

(4) *Withdrawal*: Participants were informed that if they felt uncomfortable at any stage, the interview could be terminated and a reason for the termination from the interview was not necessary.

(5) *Debriefing*: At the end of the interview participants were thanked for their participation and were debriefed. All questions regarding the study were explained to the participants by the researcher.

## **2.6 Data analysis**

All the interviews were transcribed verbatim and a case-by-case analysis of themes emerging from the interviews was conducted. Participants' were given pseudonyms for the purposes of anonymity. Interview transcripts were analysed using IPA guidelines articulated by Smith (1996). The four-stage process of analysis is initially carried out on a case-by-case basis and is subsequently followed by a case comparison across transcripts. The analysis is premised on a close interaction between the analyst and the text (Brocki & Wearden, 2006); hence initial familiarisation begins with a detailed reading of the transcript to obtain a holistic perspective of the participant's account. Initial themes are then identified, clustered and checked against the data. The emphasis is on meaning rather than the frequency of occurrence of particular themes. Emergent themes are refined, condensed and examined for connections and form the basis for development of a narrative account of the interplay between the interpretive activity of the researcher and the participant's account of their experience. Presentation of this account is supported by excerpts

from participant's actual discourse to allow the reader to assess the reliability and validity of interpretations. Table 3 illustrates the analytical process.

The initial stage of the analysis involved noting points of interest identified in the interview transcripts. For example, descriptive comments such as key words, phrases and explanations used by the participants' to highlight the issues of importance derived from their experiences. Paying attention to language use including repetition, tone, hesitation, articulate or inarticulate use of language, pauses and laughter, can add to the depth of exploratory analysis and "it opens out the potential for discussion for a range of more conceptual meanings" (Smith et al., 2009, p.88). Table 2 outlines examples of descriptive, linguistic and conceptual comments taken from the transcripts. Descriptive comments are in normal text, linguistic comments are italicized and conceptual comments are underlined.

**Table 2: Exploratory comments**

<b>Stage: Exploratory comments</b>		
<b>Analysis</b>	<b>Findings</b>	<b>Example</b>
Descriptive Comments	Reflections on former active self	“I was always up in the morning straight out...never...spending lots of time in the house...”
	Disbelief of initial stroke symptoms	“I couldn’t lift my arm but I was kind of saying...no I’ll be fine in a few minutes...”
	Loss of social support	“I had lots of friends which I find out now were really only acquaintances...”
Linguistic Comments	Hesitant repetitions	<i>“I’m...I work...work...I worked full time...”</i>
	Questioning self	<i>“I never smoke...I’m not a drinker...I don’t know...so basically if you looked for reasons why...I have no idea...maybe it was just a freaky accident...”</i>
	Sarcastic undertone	<i>“Dr. X...gave me the results of...the cardio echogram...he found a small...hole in the back of my heart...I was going...ah sure another thing there great, blood pressure, stroke and now this great you know (laughs a little) so at this stage noting was going to phase you...”</i>
Conceptual Comments	Age-related stigma associated with stroke	<u>“cause people think stroke is an old person you know in a wheel chair...there’s no like role model...it’s not what I’d call a sexy disease...”</u>
	Isolation as a younger stroke survivor	<u>“I don’t think I have ever met anyone who has been through the same as me...”</u>
	Hidden psychological effects of stroke	<u>“when I used to...tell people I had a stroke...they’d say god you wouldn’t notice you look grand...but the damage...is in...my mind...”</u>

The next stage involved developing the emergent themes. Once familiarized with the interview content, the researcher derives key or super-ordinate themes from the data. Themes emerge by reviewing exploratory comments in an interpretative manner whilst staying close to the initial data. Table 3 provides an example of the development of emergent themes.

**Table 3: Developing emergent themes**

Exploratory Comments	Original Transcript	Emergent Themes
	<p><b>Interviewer: Yeah...and you were saying as well it affected your self confidence can you tell me a little bit more about that?</b></p>	
<p>Ashamed of post-stroke self <u>Loss of social confidence</u></p>	<p>Am...I didn't like going out like...to the shops or for shopping because I was afraid that if I met somebody I wouldn't be able to have a proper conversation with them</p>	<p>Fear/Social withdrawal</p>
<p><i>Hesitation here emphasizing her personal struggle</i>  <u>Inner conflict caused by stroke- double edged sword- explain cognitive deficits or admit to being a young stroke patient</u>  Lack of awareness regarding younger cases of stroke</p>	<p>and then I thought well if I tell them I had a stroke that'll explain for me getting tongue tied and saying the wrong sounds but then I was embarrassed to tell them...that I had a stroke because I was only 34...they'd always say, "God your very young to have a stroke", of course I'd start crying then (laughs a little)</p>	<p>Unwanted new post-stroke self</p>
<p>Too young for stroke <u>Reactions of others made her feel abnormal, thus confirming her own fears</u>  <i>Reluctance to say the word confidence? Self-esteem...still unsure of herself</i></p>	<p>and am...that was where the psychology helped me...she kind of helped build up my...she kind of helped me to think of positives instead of negatives and try and build up my self-esteem.</p>	<p>Age-related stigma associated with stroke</p>

Developing super-ordinate themes requires identifying connections between emergent themes. Smith et al. (2009) advised printing out a list of identified emergent



themes and cutting them up into separate pieces of paper. Using a large space the pieces of paper can be moved around to try “to explore spatial representations of how emergent themes relate to each other” (Smith et al., 2009 p.96). Box 1 illustrates the sub-themes contributing to the super-ordinate theme *‘Stroke as a disease of the elderly’*.

**Box 1: Developing a super-ordinate theme**

<p><i>‘Stroke as a disease of the elderly’</i></p> <p>Normalising symptom onset</p> <p>Age as a diagnostic barrier</p> <p>Too young for stroke</p>
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The final stage of analysis involved looking for patterns across the interview transcripts. However, it is important when moving to the next transcript, “to do justice to its own individuality” (Smith et al., 2009, p.100). Therefore it was necessary to separate ideas and themes emerging from the initial transcript to allow for the development of new concepts in the transcripts that followed. Finally the merging of shared themes across cases was carried out by laying out a list of individual themes for each participant on a large surface to determine super-ordinate themes for the group. The final result should illustrate super-ordinate and subordinate themes that encapsulate the participants’ shared experiences (see Box 2).

**Box 2: Group analysis for the super-ordinate theme “Stroke as a disease of the elderly”.**

**Stroke as a disease of the elderly**

Normalizing symptom onset

**Jane:** and I'd even jokingly said to her that I think I'm having a stroke this is ridiculous because I was just...but it was totally just a joke...**p1/14-17**

**Kate:** Saturday I felt very tired unusually tired but then I suppose when you're away with nine girls I suppose there wouldn't be anything that unusual about it. But on the Saturday I didn't feel well way you know but I didn't pass any heed I just you know didn't feel well...**P1/11-15**

**Tanya:** I thought that's it...yeah the headache is going to go away...**p1/41-42**

Age as a diagnostic barrier

**Tanya:** it looked like I was just drunk because I was talking you know weird things “I was saying where is my hand have a look my hand doesn't work”, it felt like you know a drunk person so they were asking him “did she drink anything” (laughs) and he said no “she didn't drink anything she was driving you know, she is sober” ...**p3/119-129**

**Kate:** I must have been 13 hours and at that stage your getting very tired and...you really don't know what's going on and there's 2 or 3 doctors coming to look at you and nurses coming their taking bloods and... and you still don't really know what's going on...**p2/72-77**

**Emma:** but yeah I think it's quite nerve wrecking because your being brought for this test...that test and the other test...and you kind of don't know what end their going to look at next...**p4/177-180**

Too young for stroke

**Fiona:** I just burst into tears but I kept saying it couldn't be because I could walk...you know it was just the hand... **p2/64-78**

**Siobhan:** No they got it wrong...obviously it's for older people...still couldn't kind of believe it...**p3/119-121**

**Jessica:** a few people actually though which am...was a bit upsetting at the time were saying “oh it couldn't have been she's too young to have a stroke what else was it like?” and there was kind of rumours going around...like its...I live in a very small village like and there was a few farmers going around saying “Yeah she's probably on drugs” ...**p8/354-360**

## Chapter 3: Results

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### 3.1 Introduction

In the sections that follow a discussion of the super-ordinate and sub-ordinate themes will be provided. Four super-ordinate themes were generated from the transcripts, which are outlined in brief in Table 4 below.

**Table 4: Description of themes generated.**

<b>Super-ordinate and Subordinate Themes</b>	<b>Description</b>
<p><i>‘Stroke as a disease of the elderly’</i></p> <p><b>Subordinate themes</b></p> <ul style="list-style-type: none"> <li>• Normalising symptom onset</li> <li>• Age as a diagnostic barrier</li> <li>• Too young for stroke</li> </ul>	<p>Participants’ struggled to come to terms with experiencing a disease normally associated with old age. Their shock was mirrored by the reactions of others including medical staff who were reluctant to diagnose stroke in the young.</p>
<p><i>‘Post-stroke selves’</i></p> <p><b>Subordinate themes</b></p> <ul style="list-style-type: none"> <li>• Adapting to new post-stroke selves</li> <li>• Aging effects of stroke</li> <li>• The deceptive nature of mild stroke</li> <li>• The lost self</li> <li>• Coping with Stroke</li> </ul>	<p><i>Post-stroke selves</i> describes the complex task of trying to adapt to a new post-stroke physical and emotional self. Upon reflection on pre-stroke lives more able-bodied physical and cognitive selves were mourned.</p>
<p><i>‘A desire for peer support’</i></p> <p><b>Subordinate themes</b></p> <ul style="list-style-type: none"> <li>• Isolation of younger stroke patients in an older stroke environment</li> <li>• Need for relevant information</li> <li>• Shouldering the burden alone: isolation of younger stroke patients</li> <li>• Desire to talk to somebody similar</li> </ul>	<p>Experiencing a disease normally associated with old age made participants’ feel isolated after their stroke. Participants’ described their desire to relate to somebody similar with similar, specific concerns such as anxiety regarding reproductive decisions, a common dilemma faced by young female stroke survivors.</p>
<p><i>‘The impact of stroke on relationships’</i></p>	<p>Following stroke, patients need a considerable amount of social support,</p>

<p><b>Subordinate themes</b></p> <ul style="list-style-type: none"> <li>• Social support: how much support is too much?</li> <li>• Removal of support systems</li> <li>• Concern regarding impact of stroke on the family</li> </ul>	<p>however, too much support can feel suffocating. While some relationships were strengthened, others became problematic.</p>
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### 3.2 Stroke as a disease of the elderly

The occurrence of stroke in young adults can be traumatic not only because of the seriousness of the event itself but also because of its stereotypical association with old age and associated barriers to diagnosis. Initially, participants sought to downplay or normalise their unusual symptoms. On presentation at Accident and Emergency (A&E), these symptom reactions were mirrored by uncertainty and a failure to recognise the significance of the symptoms amongst medical staff. Medical staff were reluctant to diagnose stroke, a condition that seemed “impossible” for those at ‘younger’ ages. Consequently, participants’ experienced lengthy and anxious waiting periods in A&E prior to their eventual stroke diagnosis. Shock and distress were characteristic responses to diagnosis of a condition normally associated with old age. Reactions from others regarding their diagnoses reaffirmed participants beliefs that stroke at a young age is “abnormal”.

#### 3.2.1 Normalising symptom onset

In the early stages participants tended to minimise and normalise their unusual symptoms, interpreting them as minor ailments such as “headache” or a “trapped nerve”. And yet despite efforts to minimise, symptoms were also recognised as being “different” or “unusual”. In some cases sudden loss of physical function was experienced but dismissed as transitory: *“I couldn’t lift my arm but I was kind of*

saying no I'll be fine in a few minutes". Jane, a healthcare worker, briefly contemplated the possibility of stroke but considered it jokingly in light of her age:

**Jane:** and I'd even jokingly said to her that I think I'm having a stroke this is ridiculous because I was just...but it was totally just a joke...p1/14-17

### 3.2.2 Age as a diagnostic barrier

The constellation of symptoms presented by the participants together with their relatively young ages proved problematic for medical staff in determining a diagnosis. Upon initial investigation the medical staff in A&E shared the dismissive attitudes of the participants regarding their unusual symptoms. Tanya's description suggests she understood why doctors interpreted her symptoms as intoxication:

**Tanya:** it looked like I was just drunk because I was talking you know weird things "I was saying where is my hand?... have a look my hand doesn't work" ... they were asking him "did she drink anything" (laughs) and he said no "she didn't drink anything she was driving you know, she is sober" ...p3/119-129

Some of the participants were initially misdiagnosed with conditions such as migraines, viral meningitis and panic attacks. Miriam was sent home without diagnosis but with the observation that it was "not possible" for her to have a stroke at such a young age. Lengthy periods awaiting confirmation of a diagnosis, accompanied by fear of the unknown, resulted in negative appraisals of A&E experiences:

**Kate:** I must have been 13 hours and at that stage your getting very tired and...you really don't know what's going on and there's 2 or 3 doctors coming to look at you and nurses coming they're taking bloods and... and you still don't really know what's going on...p2/72-77

Participants were confronted with a "constant barrage of tests" many of which were inconclusive but all of which held the possibility to reveal life-changing outcomes.

The intensive medical scrutiny marked the beginning of an unexpected transition to

patient-hood for participants and recognition of the possible seriousness of the situation by medical staff:

**Emma:** *but yeah I think it's quite nerve wrecking because your being brought for this test...that test and the other test...and you kind of don't know what end their going to look at next...p4/177-180*

The unfamiliarity and complexity of medical terminology enhanced feelings of disempowerment and compromised control but the sheer quantity of tests in the absence of answers was the key source of distress:

**Kate:** *there were loads of investigations going on. I had every test imaginable...constant ah bloods being taken. I had...the CAT scan, MRI, a thing called a TOE something they put a tube down they look at the back of the valves or whatever at the back of your heart...I had a lumbar puncture all the tests like they were basically ruling out everything and I think it's just the constant barrage of...of ahhm ...tests and your not really sure what they are for and to be honest I'm the sort of person I wouldn't really ask...p4/182-192*

Numerous misdiagnoses of serious illnesses emerged in the diagnostic process including “multiple sclerosis”, “brain tumour” and “vascular meningitis”. The changing diagnoses seemed to advance possibilities on the severe end of the disease spectrum. Consequently, participants found themselves deciding between preferences for one health condition over another. Emma recounted her surprise when a doctor ruled out the likelihood of a brain tumour, a diagnosis she had not considered, and her reluctance to relinquish an earlier diagnosis, the better of two evils:

**Emma:** *Dr. X actually came to me “you'll be glad to know it wasn't a brain tumour”...I hadn't even thought...I suppose in my naivety or whatever I hadn't even considered...oh it could be a brain tumour...I knew there was something serious but what I didn't know...I suppose I was still clinging to the MS diagnosis that had been given by a doctor earlier...p2/92-100*

Conversely, Emma considered her misdiagnosed conditions to be worse than stroke and a sense of relief was evident when stroke was confirmed:

**Emma:** *there was relief there...that it wasn't MS...I just remember crying saying...to Dr. X like when MS had been mentioned “I can't end up in a wheelchair...I can't you*

*know because I have young children” ...so it was a sense of relief that yeah it wasn’t a brain tumour...it wasn’t MS...it was just a stroke you know...while I knew it was kind of serious enough territory it was kind of the preferred option I suppose...so it was kind of surprise and relief I think...were the two major emotions I suppose that kind of came at that point you know...p3/112-124*

### 3.2.3 Too young for stroke

Reactions of extreme shock, disbelief and distress were common as participants struggled to accept a diagnosis normally associated with old age, “*I have to be completely abnormal cause like who on earth at the age of...I think I was 22...23 gets a stroke?*”. The word *stroke* conjured images of severe paralysis and significant loss of function “*when you think of a stroke...I always imagine a vegetable type*”. Some of the participants’ doubted the confirmed diagnosis because they did not match the stereotypical prototype of stroke:

***Fiona:*** *I just burst into tears but I kept saying it couldn’t be because I could walk...you know it was just the hand... p2/64-78*

***Siobhan:*** *No they got it wrong...obviously it’s for older people...still couldn’t kind of believe it...p3/119-121*

The reactions of others reaffirmed participants’ feelings of abnormality and embarrassment about having a stroke at a young age. Kate describes the nurses’ disbelief as they questioned the idea of her having a stroke so young; their astonishment was illustrated in the low, surprised whisper they used to talk about this taboo subject “*you couldn’t have had a stroke*”. Participants feared that the unknown cause of their stroke would lead others to speculate on their lifestyles in an effort to pinpoint the cause. They were anxious and concerned about how they might be perceived and judged by others. Sarah describes her concern regarding how others might question her lifestyle after experiencing a stroke at 34 years of age, speculation might suggest that she brought the stroke upon herself. Sarah’s fears were confirmed

by Jessica who found that others were ruminating on why she would have experienced stroke so young, and suggestions were made that she must have engaged in an activity that would cause a stroke:

***Jessica:** a few people actually though which ahm...was a bit upsetting at the time were saying “oh it couldn’t have been she’s too young to have a stroke what else was it like?” and there was kind of rumours going around...like its...I live in a very small village like and there was a few farmers going around saying “Yeah she’s probably on drugs...”p8/354-360*

The problematic stereotype of stroke being a condition of old age resulted in some of the participants feeling “different” and ‘old before their time’. Miriam’s description of stroke being associated with a “granny” would imply that she felt separated from her own age group. She suggested altering the current stroke adverts by replacing the person experiencing a stroke with a younger individual to raise people’s awareness of stroke in the young, thus decreasing the level of age-related stigma associated with stroke:

***Miriam:** I see those ads on the TV of the signs...they are actually quite good...but they could...stick a younger person in to the ad (laughs)...I suppose it probably is not as common for younger people but it could happen so at least...when people look at ads they relate to it as in “oh God I saw it on the ad” where if there’s somebody younger at least it’s not something different...and I suppose it makes people aware I just don’t think that people are aware that it can happen to younger people at all really it’s something you associate with your granny or your granddaddy you know...p15/730-748*

Stroke was perceived as an “injustice” not only due to the participants’ age but also because the aetiology could not be identified. The cryptogenic nature of the stroke contributed to the participant’s struggle to make sense of their experience. Reflection and questioning of pre-stroke lives and behaviours ensued, however, the main risk factors for stroke were generally absent from their lives:

***Kate:** Out of all 8 of us if you asked anybody in our family...I would be the healthiest...I’m a vegetarian...I would be the active one like I’d go to the gym...I’ve*



*never smoked...I would have had what I would have considered a very healthy life style and out of all 8 of us I said the injustice of it all... p3/136-146*

**Angela:** *I just thought it was unfair that I wasn't old and this was happening to me like...why? I'm not a smoker...I'm not a drinker like I would have an occasional drink maybe twice three times a year do you know what I mean I wouldn't be out every weekend drinking...p5/208-213*

**Jane:** *It was quite...just really surreal cause I had no history...no nothing ...quite healthy...don't smoke was on the pill...that was the only thing I suppose I was logically going maybe that's what happened...p3/139-141*

For some of the participants a reoccurrence of their stroke symptoms resulted in similar negative experiences in A&E. The participant's former stroke diagnosis was queried by medical staff as their age posed as a diagnostic barrier for the second time. Disbelief of medical staff contributed further negativity to an already stressful and upsetting situation for Kate. It made her feel angry as she was doubted by the doctor in A&E and she had to fight to be taken seriously as a stroke patient:

**Kate:** *it was almost like as if I was being told well your making it up you know you're too young you couldn't have possibly had a stroke. I said at one stage, I said to one of the doctors well then go and ask Dr. X...about his diagnosis because he told me I had I...didn't decide I had one type of thing...p14/658-663*

Angela's previous treatment in A&E resulted in efforts to avoid attending hospital when her stroke symptoms reoccurred:

**Angela:** *I can't go through that casualty effort again I'd rather die I think than go through that again like cause when it happened to me before like the way I was treated in casualty was unreal they told me I was taking up a bed I was wasting casualty time...p2/3-95-102*

### **Summary – Stroke as a disease of the elderly**

*Stroke* is not a word that is normally linked with young individuals thus, reactions of extreme shock, disbelief and distress were common as participants struggled to accept a diagnosis normally associated with old age. Participants' shocked reactions were mirrored by the reactions of medical staff both in A&E and the staff on the stroke unit who struggled to diagnose and accept that stroke was

possible in the young. Some participants felt ‘old before their time’ when diagnosed with a condition associated with older patients. There was also a feeling of ‘injustice’ amongst participants because the majority of them did not exhibit the standard risk factors for stroke.

### **3.3 Post-stroke selves**

Life after stroke was marked by feelings of anxiety and loss as more able bodied pre-stroke selves were mourned. Adapting to new and in most cases unwanted post-stroke identities, proved to be a difficult struggle for the majority of participants. Experiencing stroke had both physical and emotional repercussions on participants’ perceived sense of self. Participants’ ventured on an emotional journey in a quest to both accept and comprehend their experience.

#### *3.3.1 Adapting to new post stroke selves*

Some of the participants were apprehensive about hospital discharge and the future because they were in a body that no longer resembled their former self. Adapting to a new physical self within such a brief time period proved to be a struggle for Aoife, “*you’re going around grand and then it’s very hard to accept that you can’t walk out to the toilet*”. Some of the participants had to relearn basic physical skills that would normally have been taken for granted, “*I remember how hard it was to figure out...how to make...the index finger do what you need to do*”. Feelings of vulnerability and fear were invoked by recognition of the fact that their bodies were not invincible:

***Emma:*** *I think it makes you feel very...very vulnerable and frightened I suppose of the things that can happen to you...you know I’m human and things can go wrong...p11/594-514*

***Siobhan:*** *Just the fact that your paralysed do you know that kind of way...your body could actually do that...p10/11-497-499*

Anxiety regarding a recurring stroke caused participants to become more in tune with their bodies so that they might be more aware of the warning signs indicating another stroke. Tanya and Alison developed more cautious attitudes towards their bodies due to their recognition of the body's ability to malfunction:

**Alison:** *I'm more cautious now, like if I get 'stuttery' at all or anything, I think to myself oh god am I alright? Is that another little clot gone somewhere? Or if me eyes go a bit tired I'd be thinking to myself oh god has that clot gone to me brain I'll be blind. Like I'm more aware now of like you know of what me body is telling me...p6/275-281*

**Tanya:** *If I'm walking I'm walking more careful I'm trying to kind of watch out, slow down if I need to...p15/749-751*

Participants experienced feelings of vulnerability and anxiety in the early stages after stroke. Apprehension about hospital discharge and the future were apparent in Tanya's and Sarah's accounts, their eagerness to return home was darkened by fear of a reoccurring stroke. The fear of leaving hospital with a new unfamiliar physical self, without the hands-on support from medical staff, made the transition from hospital to home difficult:

**Tanya:** *I wanted to go home but I was scared a little bit to go home...p12/553-554*

**Sarah:** *I was kind of delighted to be leaving hospital but kind of frightened as well that I was kind of going to be out on my own like...vulnerable and if anything went wrong...the hospital was kind of far away...p3/100-103*

After discharge from hospital some of the participants experienced symptoms similar to those during their initial stroke onset. Heightened levels of anxiety ensued and in some cases an impending doom resulted from feelings of uncertainty and anguish:

**Jane:** *quite nervous as well at home cause your just get like funny feelings in your head and your like oh...is that another stroke...don't know...p7/320-323*

**Fiona:** *it's like people you often hear about...they have a stroke and they're ok and then you hear about them having a second one and it finishes them...p12/13-595-601*

Physical impairments had negative repercussions for body image and self-esteem. Fear of how they would be perceived by others was evident for Fiona, Aoife and Siobhan. Fiona and Aoife made efforts to conceal their impairments from others:

**Fiona:** *sometimes if I'm tired I notice my mouth kind of goes a little bit...so I... feel people are staring at me...my sister says to me one day, "what are you putting your head down for?" I says "no I'm not", she says "you are", "I says No I'm not" but am...I would say I kind of hold me head up now...I used to feel people were looking at me...you know...p10/465-471*

**Aoife:** *Say bringing my son to school...I'd be trying to hide my walking stick...p17/807*

Upon reflection on her stroke Siobhan frets about the possibility of negative reactions from onlookers. *"He probably saw my horrible face coming out in that wheelchair...."* Her negative perception of her physical self image at the time was evident in her description of *"my horrible face"* accompanied by her emphasis of the fact that she was in a wheelchair, thus bringing more attention to her. Both Miriam and Tanya highlight the negative impact that stroke can have on one's physical image. Miriam felt fortunate that her face had not been affected, prioritizing the importance of this region over other areas of her body. Tanya believed she had less to offer in social situations because of her physical impairments and felt isolated by her peers as a result:

**Miriam:** *I was lucky...it didn't affect my face...p15/727-728*

**Tanya:** *if you are healthy...if you are successful...if you are good looking everybody's your friend...and then if you have a stroke like that and you start dragging your foot your are just lagging behind...you know your just left alone as simple as that...p15/720-725*

Aoife's negative perception of her physical state after stroke mirrors an internal change towards her emotional self. A negative attitude towards her new unwanted post-stroke self is reflected in the loss of interest in her physical appearance:

**Aoife:** *when I look in the mirror I'm different because as I said I don't bother doing anything with myself my hair probably do no makeup...p13/635-637*

### 3.3.2 Aging effects of stroke

The occurrence of stroke led to feelings of premature aging for most of the participants. Kate, Jessica and Jane struggled to accept that they had a medical condition normally associated with old age. Jane's description of the stereotypical prototype of stroke, i.e. an older individual in wheelchair with severe paralysis, emphasises the age-related stigma associated with stroke. She also highlights the lack of younger role models or celebrities with stroke, suggesting that it is not a youthful disease. Jane's observation of the lack of younger celebrities with stroke, suggests her need to associate her illness with somebody relevant to her age. The idea of experiencing a disease similar to a young celebrity might also make it more socially acceptable for her:

**Kate:** *...even saying the word stroke you know aged 39 (laughs) it's just ridiculous...p18/882*

**Jessica:** *it doesn't happen to many younger people...you don't hear of it that often and when you think even now if somebody says oh such and such a person had a stroke and you don't know them you automatically think of an old grey haired woman...p11/12-541-599*

**Jane:** *people think stroke is an old person...in a wheel chair not able to... you know that's the person they associate with strokes...there's no like role model you think of...it's not what I'd call a sexy disease...you don't see someone in the newspapers with it...p13/623-628*

Being on stroke medication and the quantity of tablets required were compared with actions of older individuals "Mam I'm on more tablets than you

now..." (Siobhan, p22/1089-1090). Kate's comparison of her former active self to a person in possession of large quantities of medication emphasises her perception of an aged self. Comparisons were made between the participants and their mothers because they were on medication, something that is not normally associated with young people:

**Kate:** *I went from being a very active healthy busy engaged person...to somebody who has a box with all my medication in it...you know everywhere I go I have to bring me box of tablets and my sister would be roaring laughing at me she said between yourself and me mother (laughs). p18/882-890*

Siobhan's appreciation of having a friend who works in the pharmacy, suggests that she would feel embarrassed accepting her stroke medication from a stranger. She also emphasizes that her friend always has her medication ready, presumably making an uncomfortable situation for her less difficult:

**Siobhan:** *my friend works in a chemist...I'd go up to her to get my tablets so it's grand so I know who I'm dealing with and... she'd always have them ready...p21/1017-1022*

Jane reflects on the alteration to her medication after stroke. She comments on the aging impact of changing from a contraceptive pill, associated with women of childbearing age, to taking stroke medication, normally associated with older individuals:

**Jane:** *I used to take my pill at night, now I'm taking my plavix and lipotoire instead...I kind of go...oh why am I on old people's tablets? P18/855-858*

The cognitive deficits resulting from stroke that mirror those normally associated with the elderly encourage reflection upon the aged self. Angela associates her memory impairment with that of the elderly Alzheimer patients that she works with and feels that she needs to readjust her lifestyle now that she is getting older and has become more aware of her age:

**Angela:** *that's one thing that I hate about what happened me is me memory loss...I work with elderly patients and I work with Alzheimer's cases and all and I look at them I say I'm going to end...I'm ending like this at 40 something like and they're like that at 90...p9/441-449*

Jessica recalls having to wear flight socks when going on holidays, one of the recommendations after stroke to prevent clotting while in the air. The idea of putting on flight socks and their appearance made Jessica feel like “an old granny” and she tried to conceal this practice from her young group of friends:

**Jessica:** *I have to wear do you know the...tights on the plane (laughs a little) which is a bit embarrassing... and my friends were like “where are you going?” and I was like “just going to the toilet to put on my tights like” and I didn't want to tell them this...the look of them they were just horrible looking (laughs) flight socks like I felt like an old granny...p11/12-541-544*

### 3.3.3 The deceptive nature of mild stroke

For the most part, participants' physical impairments were not visible, however this created a further struggle to explain the post stroke self. People normally tend to associate stroke with severe paralysis and loss of cognitive ability. Therefore individuals with mild stroke tend to be at odds with the stereotypical conceptualization of stroke. Hidden physical and emotional difficulties experienced in the aftermath of stroke went unnoticed by others, e.g. fatigue and minor speech impairments. Thus posing a challenge for participants' in the quest to resume their pre-stroke lives:

**Jane:** *I was asked the week I was back to do a presentation in like 3 weeks time to the hospital and I kind of looked at this girl going...I have had a stroke give me a chance...p15/733-739*

**Emma:** *I suppose there is different kind of...sense in everyone's head of what exactly a stroke is...I would say in the wider setting that some people are a little bit dismissive...the fact that your not going around kind of with a lame leg...it can't have been that bad...p8/375-383*

**Jane:** *people forgot...I think it was cause I physically looked ok...I had a friend call round and she stayed for ten hours and I was nearly crying by the end of it...p19/20-948-951*

The participants struggled to explain the rules of their new post stroke lives to others. Some of them feared being misunderstood because of their speech impairments and engaged in socially avoidant behaviour. Other people struggled to understand how an illness with no visible symptoms could still be affecting the participants. Tanya noted the difficulty in describing her experience, suggesting that only those who have had a similar experience would understand. Thus, the division between those within the world of stroke and those on the outside exemplifies the arduous task for stroke survivors in resuming normal life:

**Fiona:** *the first week or two I went home now...I was still kind of stuttering and I didn't want to kind of talk to people...p7/338-340*

**Tanya:** *it's unbelievable you can't describe it you can't feel it...and you know...ahhm...this is something very...I don't know how to even describe it...p11/511-514*

**Jane:** *I was getting stuck on words and that was annoying me and I was kind of embarrassed if people thought...I was quite happy for someone to know what had happened to me because then I was like ok if I couldn't find the words or I couldn't get a word out at least then they'd know...p9/427-432*

**Sarah:** *when I used be telling people I had a stroke...they'd say "God you wouldn't notice you look grand and everything", but...the damage that was done...it's in my brain more...like looking at me you wouldn't know and people would say "God you wouldn't notice when your talking and that" but I'm very conscious...I'm not as chatty as I used to be...p7/305-315*

Some of the participants began to doubt themselves, because of the lack of visible symptoms and sceptical reactions from others:

**Jessica:** *I felt like a hypochondriac sitting in hospital because...I felt there was nothing wrong with me and I...just wanted to go home and...all my friends were kind of saying "well yeah why are you here?" and that had me thinking about it as well and I was like, well really like, am I just a guinea pig, do I really need to have all these tests done?...p9/413-420*



**Kate:** *I still do feel a bit silly saying I had a stroke because I...I looked fine (laughs) do you know, there was no outward signs that...that I'd had a stroke p5/224-226*

### 3.3.4 The lost self

The world of the stroke survivor can be one grounded in loss, loss of former identity, loss of confidence, loss of independence and control. In the recovery phase participants struggled to accept the loss of their former abilities. Unfavourable comparisons to pre-stroke selves provoked feelings of loss and former able-bodied selves were mourned:

**Kate:** *I went from being confident and sort of comfortable in my own skin to being (whispers)...she had a stroke (laughs)...do you know like it does...it does effect you p19/902-905*

Aoife's physical impairments have altered her role as a mother. Because of her disability she feels physically restricted in her choice of outdoor activities with her children. Her reflections on her former active busy self compared to her current limited physical state, has jeopardized how she spends time with her children:

**Aoife:** *What really bugs me is not being able to go off with the kids...I was always up in the morning straight out...you know I was never one for spending lots of time in the house...p157-160*

Some of the participants' struggled to let go of items associated with their pre-stroke selves. Aoife recalls her reluctance to throw out her old shoes, despite the fact she can no longer wear them because of her impairment. However, for Aoife her shoes symbolize part of her pre-stroke identity, and throwing them out would suggest letting go of her pre stroke self:

**Aoife:** *I have all my old shoes that I would have worn and I know I'll probably never wear them again but I just can't throw them out do you know silly things like that...I just can't get rid of my old shoes...P10/475-478*

The loss of physical and cognitive abilities had negative consequences for participants' self-confidence. Tanya's physical impairments have altered her levels of confidence in her physical ability, she experiences her physical self as unreliable:

**Tanya:** *I don't feel the same I don't feel if I need to run I will run, you know, fast and long...p15/746-748*

Sarah's cognitive impairments resulted in mild dyslexia and her reflection upon her pre-stroke self emphasized feelings of loss and reduced self-worth. Her post stroke impairments have compromised her numerical ability:

**Sarah:** *I used to have a job years ago at doing...book work and now if I don't have my phone or calculator with me I can't do numbers...p12/575-577*

Participants' were eager to return to their former lives despite not being physically or mentally ready. A combined need to resume normal life and fear of work-related disempowerment meant that some of the participants returned to work soon after their strokes. Participants' concealed physical complaints to avoid unwanted speculation from employers' and work colleagues in an effort to protect their work-related autonomy:

**Emma:** *I went back to work... and when I look back now I don't really know whether I was ready; in some ways I was ready to go because I wanted to go and I wanted to try to get a normality back in my life...p18/906-911*

**Angela:** *I felt me arm very weak I never said anything because...I wanted to be back at work...I felt very tired...p24/1159-1162*

**Miriam:** *I didn't actually..... tell too many people at work because I didn't want to be taken pity on either and I didn't want people to think that I couldn't do stuff...so I kind of let on that I was grand maybe if I wasn't...p27/1341-1345*

Some participants had to alter their working lives after stroke. Reduced working hours, concerned employers' and time off work, created feelings of

disempowerment. Some of the participants recalled being treated differently by their employers, Kate felt that her career progression had stopped and Angela was advised to reduce her workload. For younger stroke survivors alterations to their working lives can be quite traumatic, some of the participants were in the prime of their careers and suddenly had to face reduced responsibilities and working hours. Such alterations would seem more normal for somebody nearing retirement age:

**Kate:** *I've changed my hours totally I'm working half days now...the whole work thing altered completely because once you tell your bosses at work that you've had a stroke...game over...P11/ 504-507*

**Angela:** *actually my manageress called me into the office and she says "your going to have to slow things down"...p17/18-p850-851*

One's working life can be an essential aspect of a person's identity, thus the loss of work may involve a partial loss of the self. Disruption to her biographical narrative was evident in Siobhan's frustration with being off work because of her stroke. Her inability to work compromised a major aspect of her life. She described her struggle to readjust to a sudden and unwanted change to her lifestyle:

**Siobhan:** *What'll I do this morning like I should be in work and you know it kind of has stopped...p13/638-639*

Experience of an unexpected illness, without any specified cause, jeopardized feelings of control. Anxiety about a reoccurring stroke was heightened as participants were unable to identify factors to aid prevention:

**Kate:** *...the biggest question for me...before I left the hospital was how do I stop getting a second one...like I've gotten a first one and I...had no way of knowing it was going to happen but how do I prevent myself from having the second one...and there really was no answer to that it was just unfortunate... P4/161-166*

Stroke became the deciding factor for some of the participants when it came to making life altering decisions. Emma described stroke's restriction on her reproductive choices. The decision to have another baby was now made more difficult because of the increased risk:

***Emma:** if I do want another baby...I do think...there would be that issue, like is this causing a close on another phase of my life? do you know what I mean? ...is this going to put pay to any plans that we might have? ...I'm not saying that we would have...but it is making the decision for me ...p16/760-775*

Stroke had a knock on effect on other aspects of the participants' lives. The link between stroke and oral contraceptives meant that Sarah had to change to an alternative method of birth control. During an already life altering time, additional changes can heighten levels of stress and feelings of loss of control:

***Sarah:** I was on...the contraceptive injection and Dr. X advised me to come off that and get...the coil or my partner get a vasectomy but I got the coil and...that was just like another kind of not a problem but it was...something else that kind of...as a result of the stroke ...oh God like everything is happening it's not just a stroke...p9/415-424*

Needing assistance with daily living tasks made Aoife feel that her former role of authority over her household had been challenged. She felt that she lost control over her home because the boundaries between those who dwell in the house and houseguests were blurred:

***Aoife:** when I had my children I was very specific...stupidly...neurotic nearly about the way I ironed their vests and when they were younger the way I made their bottles and all and I kind of feel that control is taken away because people breeze around my house like it's their house...p4/175-180*

Experiencing a stroke and the physical deficits that ensued meant having to rely on family and friends for support, thus relinquishing independence as well as control. Miriam describes the immediacy of her transition from independence to becoming

dependent on her parents again. Her brief journey into adulthood was cut short because of her stroke:

***Miriam:*** *I moved out I'd say a year and a half later I bought my own place and moved out but in that period of time I had to revert from being independent to being back at home...p25/1205-1208*

Some participants perceived driving as the key to their independence. The inability to drive after stroke meant having to rely on others. Being able to drive again was a crucial aspect of the recovery process; this is evident in Fiona's account, she places specific emphasis on her ability to return to driving within a short time period.

***Emma:*** *I wasn't allowed drive until mid July which I found to be a huge handicap it was like my independence was totally gone so I was depending on a colleague to collect me in the mornings...p19/913-916*

***Fiona:*** *I'm back driving and all now I think it was about 6 weeks after when I went back driving.p5/225-227*

### 3.3.5 Coping with stroke

An emotional journey proceeded in the aftermath of stroke as participants' tried to adjust to this significant life altering event. Participants engaged in a variety of coping strategies during this time. For some of the participants the emotional toll of experiencing a stroke gave way to feelings of sadness and apathy. Some stroke survivors experience anhedonia (an inability to experience pleasurable emotions from normally pleasurable life events such as eating, exercise, social interaction or sexual activities) in the aftermath of their stroke. Participants' struggled with their emotional response to stroke and experienced an absence of positive feelings. In Sarah's case, medical staff felt the need to incorporate additional psychological support in her care plan:

**Sarah:** *I'm on antidepressants...my GP referred me to counselling and then Dr. X got me the psychology...p8/350-355*

**Tanya:** *I became sadder...I find it hard to laugh...p13/638-639*

Siobhan and Jessica experienced a post-stroke apathy, losing motivation to engage positively in life after stroke. Jessica describes her negative attitude change towards her studies. Her sudden disinterest in her studies was reflected in her changed life priorities after stroke:

**Siobhan:** *I was very more down in myself where I'd be like ah I don't want to do anything...p18/848-854*

**Jessica:** *I didn't study as much as I should have because I just...I didn't care to be honest...just...complete lack of interest when I got back... I kind of developed a new strategy on life after it...I kind of said ah 'feck' it like worse things can happen and I was like ah sure if I fail it...I fail it and I kind of had a real lackadaisical attitude afterwards p13/601-615*

However, participants' changed life priorities after stroke had dualistic implications; on one hand, a perceived positive revision of life's priorities, but also a reinforced awareness of one's mortality. For Jessica a newfound perspective on the fragility of the physical self had negative consequences for her academic motivation. Emma describes feeling more aware of the inevitability of her mortality:

**Jessica:** *I could have another stroke tomorrow I could have a massive one and die...why would I bother...studying...p14/693-695*

**Emma:** *it does make you think more about...mortality... you know it's ahead...of us all I suppose whereas before that I never really thought...you never think of dying or whatever...p11/525-529*

Participants also recalled that changed perspectives on life after stroke and revised priorities had positive consequences. This may be interpreted as positive reframing or accommodative coping. Despite her initial reluctance to reduce her

working hours and responsibilities at work, Kate realized the positive outcome that this would have for her daughter:

**Kate:** ...its not my priority anymore...I still love going to work but...the priority now for me is to make sure that I'm here...and...stay as healthy as I possibly can for my daughter, she's 4 now nearly 5...**p11/541-549**

A kinder attitude towards the self developed from Jane's changed outlook on her working life and her relationship with work colleagues. For Jane adopting a new found assertiveness with work colleagues had positive consequences for her physical and emotional wellbeing:

**Jane:** one of the girls was talking to me the other day and she was like you're so more chilled out... "You're just... saying no more often"...in a good way...not in a bad way...but I'm not the person that's going to do everything for everyone yeah and I'm enjoying my time not that I wasn't enjoying it I'm kind of just chilled out...booking holidays you know where before... I'd be like can I afford that...**p16/770-778**

Angela decided to prioritise health over wealth realising that without good health material possessions were of no real value:

**Angela:** ...it has taught me...you don't have to have the best of this...the best of that your health is your wealth at the end of the day as the old saying goes...**p19/944-947**

Some of the participants focused on the positives to help them to accept the experience, for Sarah this involved reflecting on her physical progress since her stroke:

**Sarah:** when I went into hospital first I couldn't...I didn't even know my name or ahhm...and...like she used to say to me "for every negative thing there's always a positive"...**p6/275-278**

Some participants' reported that stroke had been character building. Emma remarked on the strength of the human spirit in the face of adversity. Participants' found hidden strengths that enabled them to cope with the experience. Sarah and

Jessica (both 2 years since stroke) interpreted the complex physical and emotional journey of stroke as an accomplishment to be proud of rather than allowing stroke to be an on-going negative presence in their lives:

***Emma:** in some ways its character building...it makes you dig into yourself and pull out resources and things you didn't know...there's hidden depths...and I think...the human spirit...while it takes a few knocks...it will always come through you know...p21/22-1045-1051*

***Sarah:** I'm kind of...nearly proud to tell people that I had a stroke and I got through it...p10/471-472*

***Jessica:** it's my little heroic tale I don't mind relaying it...p9/443-444*

Downward social comparisons aided some of the participants to view their own situations from a more positive perspective. Being able to compare the self with those they deemed to be worse off, enabled participants to view their own health status in a more positive light. Kate and Angela reflected on those with illnesses they considered to be far more severe than their own and took comfort in the fact that things could have been a lot worse:

***Angela:** ...there are people out there with cancer that die don't have the choice...people with strokes are still alive...not to the lifestyle they'd like but still can get there...p20/972-975*

***Kate:** if my cholesterol had been higher or if I had been a smoker...maybe there would have been paralysis or loss of speech and...I shudder to think what those people go through it has to be horrific for them. P17/839-843*

Miriam and Alison's concerns about experiencing a disease that normally occurs in older individuals were reduced through downward comparisons with those younger individuals who had also experienced a stroke:

***Miriam:** I have to be completely abnormal cause like who on earth at the age of...I think I was 22...23 gets a stroke like...who (laughs) you know so ahhm...but then like even that reassurance from Dr. X who goes "oh well actually I had an 18 year old" and I was kind of going ok then I'm not so bad...p10/466-471*



**Alison:** *me Da, aged about 20 years, he got an...awful fright. I think he thought it couldn't happen to anyone as young even though it has happened to younger people than me like...p4/162-167*

Some of the participants engaged in forms of avoidant-coping. Siobhan's struggle to believe she had a stroke resulted in occasional denial of the event:

**Siobhan:** *I know I've had it but sometimes I go ah no I didn't...p12/589-590*

Emma became emotionally disengaged and socially detached, fearing that involving herself in life's daily stresses would provoke the onset of a second stroke:

**Emma:** *I suppose you cocoon yourself as well to some degree... you're kind of conscious oh if I get stressed will it bring on another stroke...so maybe if I'm more detached or if I don't engage as much that yeah...I can't become stressed...p13/606-611*

Releasing emotional responses to stroke and seeking emotional support from others assisted some of the participants to cope with their experience. Seeking emotional support from others including family, friends and hospital staff provided participants with some level of reassurance. Miriam and Sarah's appreciation of the emotional support received from medical staff, emphasises the importance of addressing patients emotional as well as physical needs:

**Miriam:** *Hospital A is a fantastic hospital like...I don't think I would have wanted to be anywhere else and I think that was pretty much down to who I had looking after me...I've been to people who...they may be good at their job...but their not good at dealing with people...they don't understand they don't really care for the other side of the situation, how you feel about it, its more just treating it, get it done...p10/11-493-504*

**Sarah:** *Ahmm Dr. X...I could kind of open my heart to him and cried in front of him and didn't feel embarrassed...p2/86-87*

The importance of requesting and accepting help is evident in Sarah's statement, and she suggests the importance of opening up emotionally about the experience:

**Sarah:** *I'd just tell them not to be too proud and take all the help that is offered to you...regards psychologists ah...anything...social workers...just take all the help out there and don't be proud because you need to talk about it...and don't be embarrassed about it. P10/455-459*

Problem-focused coping strategies were evident in the participant's efforts to regain control over their lives by improving their levels of physical functioning through engaging in exercise and attending physiotherapy sessions:

**Tanya:** *try to work it out...try to exercise as much as you can because exercises really work...no matter what your doing if your doing you know...really going to the physiotherapist or if your going to the gym or if your doing exercises yourself at home or just walking outside no matter but just being physically active it really helps...p20/21-995-1002*

**Miriam:** *the type of person that I am is that I'd go right this happened there's nothing I can do about this, what can I do to improve?... the physio... I would be insistent on doing that because I knew that was going to help...p22/1083-1088*

For Aoife goal setting became an important aspect of her life in hospital enabling her to monitor her progress and regain her independence:

**Aoife:** *I kind of set myself goals like I wanted to walk out to the toilet by myself I know it sounds so trivial now but that was really important to me when I was in hospital...p3/130-133*

Fiona altered her life style to decrease her chances of having a second stroke by reducing nicotine intake and adopting healthy eating habits:

**Fiona:** *I have cut down on the cigarettes...I only smoke about 3 cigarettes a day...I go out...most evenings...for my walk I did what they told me...I cut the butter out...cut the sugar... I got used to it and the brown bread and I grill everything I don't fry anything...p8/362-372*

## **Summary – Post-stroke selves**

Life after stroke incurred feelings of loss and anxiety as participants' reflected upon more able-bodied selves. Learning to live with new unwanted post-stroke physical and emotional selves proved to be a struggle for some participants. Feelings of anxiety and vulnerability were common in response to apprehension about hospital discharge and fear of a reoccurring stroke. Fear regarding how they would be perceived by others resulted in negative attitudes towards the self and some participants felt they aged prematurely due to the age-related stigma associated with stroke. Participants with impairments that were not visible struggled to explain the new rules of their post-stroke world and hidden physical and emotional difficulties went unnoticed by others. For some participants former identities were jeopardized after stroke for instance in terms of diminished maternal and domestic roles, reduced work related responsibilities and compromised physical and cognitive abilities. Participants engaged in different emotional journeys in their efforts to cope with life after stroke, for some feelings of sadness and apathy were experienced as the loss of former identities were mourned. However in time, the majority of participants had changed perspectives on life which had positive consequences in terms of the new found appreciation for aspects of life that were formerly taken for granted. These positive changes were associated with a variety of emotion and problem focused coping strategies and engaging in downward social comparisons with other patients perceived to be worse off than themselves.

### **3.4 A desire for peer support**

Due to the relatively rare occurrence of stroke in younger individuals stroke services are geared primarily towards older patients. Amongst participants feelings of

isolation were common during hospitalisation. Experiencing a disease not normally associated with young people and feeling segregated from their rehabilitative environment heightened feelings of loneliness and seclusion. A need to relate to and engage with somebody similar in terms of age and experiences was evident in participants' accounts. Specifically, participants wanted the opportunity to compare and discuss the physical and emotional consequences of their stroke with individuals of a similar age and to learn from others' experiences regarding reproductive decisions and issues relating to returning to work.

#### *3.4.1 Isolation of younger stroke patients in an older stroke environment*

Some of the participants described feeling out of place in an environment that seemed to be populated with mainly older patients. Sarah describes feeling like she “*didn't belong*” in her ward and Miriam referred to herself as the “*odd one out*”.

Being in a rehabilitative setting with much older patients enhanced Aoife's feelings of isolation because of her inability to relate to her older counterparts:

*Aoife: When you're down in physio and you don't see anybody your own age...you don't feel you could talk to somebody in their 70s...p22/1051-1056*

Some participants felt their needs were not being met in the recovery process because their symptoms did not fit the stereotypical stroke prototype. Both Miriam and Jessica felt more could have been done to meet their needs as younger patients with stroke. In Jessica's case the hospital staff acknowledged her symptoms as being unusual, but did not provide follow-up:

*Jessica: the physio...they didn't really know what to be doing with me because they were used to stretching older patients...they tested the muscle...power in both my hands and...they said that it was unusual that I was the same on both sides like I had perfectly normal strength on both hands but...more tests probably should have been done into that because I would have been stronger in my right hand...but I'd say because of the stroke that it was the same on both sides... and nothing else was done like there was nothing they could do about it I suppose but like because there weren't*

*used to that amount of strength I suppose (laughs a little) like they didn't really go into it...p3/134-160.*

Miriam compares the different approaches used by the different staff members on the multidisciplinary team during her recovery process. Her preference for the one approach over the other emphasises the importance of attending to individual patient needs as opposed to adopting a generalised approach:

**Miriam:** *the [mentions one group of health professionals (X)] were brilliant cause [X]...assessed me on what I was then, they didn't have this book saying well you've had a stroke your supposed to be like this...they assessed you on what you were and they helped you along which was good... [mentions another group of health professionals (Y)] was complete opposite... I found [Y] absolutely no benefit to me whatsoever...[Y] came in firstly and did all those tests on me...then I half felt that [Y] was there going no your too young...it's like[Y] didn't really take an interest because I was younger ...I didn't fit into this class of having stroke so there...was nothing [Y] could do about it basically... p9/410-417*

#### 3.4.2 Need for relevant information

Age relevant information was prioritised by the majority of the participants.

Kate and Sarah appreciated the information provided regarding their sexual lives, an issue neither of them would have felt comfortable discussing with medical staff had the issue not been raised by the staff:

**Kate:** *Nurse W...she was very ahm...very considerate of the fact that it was a bit of a shock obviously and sort of what do I do now and just like...you know like age 39 well don't go home now and be afraid to...to have sex with your husband (Laughs) you know there was no way I would have asked that in a fit but she brought it up and talked openly about things that you know I probably wouldn't...*

**Sarah:** *one of the nurses...gave me an information leaflet about...sex after stroke because I was afraid that I might do...more damage but she said that's an issue that a lot of people are too embarrassed to ask about and there is information out there about it...p9/405-413*

Apart from approaching medical staff with their queries and concerns, informational resources were limited. Finding relevant information proved to be

problematic, resulting in feelings of helplessness amongst the patients and their families. Miriam's description of *knowledge being equivalent to power* emphasises her struggle to regain control over her life after stroke by seeking relevant information. Seeking information and improving her knowledge of stroke may be interpreted as a means of problem-focused coping and a proactive approach to life after stroke:

**Miriam:** *my mother went and looked it up, she was the one, I was in hospital and she went and looked on the 'net about strokes in younger people and she came back with nothing...knowledge is power...you know what I mean and the lack of knowledge...didn't help the situation I think that if there's more things that you can read or you are informed about then you know...you know what to expect...you know what to do...p24/1883-119*

Miriam was dissatisfied with the information booklets presented to her while in hospital as they failed to address her individual concerns. Her repetitive use of "me" suggests the desire for information that was applicable to her specified needs:

**Miriam:** *a nurse came up ah...with this booklet on stroke... and I was going "please tell me what on this booklet actually applies to me, I'm not an old person" (laughs a little)...so I said "where does it tell me what I'm supposed to do with going back to work, where does it tell me about driving, you know where does it tell me you know about the things that actually effect me because none of this applies to me", it was more to do with kind of older people with getting stuff in their homes and things like that...p7/338-348*

Jane's anxiety about reoccurring symptoms after discharge fuelled her need for relevant information:

**Jane:** *On that Facebook page...there's people with...chronic pain and chronic tiredness and I'm like ok I don't have any of those, I kind of feel like a cheat being on that and then I'm kind of going am I going to get something cause then I thought if you have complications does that happen straight away or does it happen six months or a year later? It's to get an understanding of...is it done now and then you just recover can...yeah I can have other strokes but can other things come from this lesion ahhm...but...when the neurologist...goes yeah...don't really know...ok...so having to be happy with I don't know...p26/1261-1274*

However she struggled to find information specific to her requirements as a younger stroke survivor through Irish channels. On the discovery of relevant information Jane's relief and her efforts to make downward comparisons with other stroke survivors emphasises the importance being able to identify with similar others in times of anxiety and uncertainty:

***Jane:** got home ...was.... proper headachy and then...quite nervous as well at home cause you just get like funny feelings in your head and your like oh...is that another stroke?...started looking up stuff on the internet then about the British Stroke Association and that...they had a lot...Irish one none, so went for Irish first and it was like the heart foundation and there was nothing really specific so went to the British Facebook page... there's loads about young people... women and much worse off than me so I was like yeah ok...I got off lightly here...**p7/319-331***

#### *3.4.3 Shouldering the burden alone: isolation of younger stroke patients*

For most of the participants the psychological impact of their stroke far outweighed the physical consequences. However, when the physical signs of their stroke were no longer visible, the underlying psychological effects went unnoticed by others. Emotional isolation ensued as the participants struggled to resume previous roles e.g. wife, mother, employee. Tanya expressed her need for more support and reassurance from family and friends as she dealt with the psychological impact of her stroke. Tanya's struggle to cope with her feelings of doubt and uncertainty after stroke stemmed from her belief that family and friends had continued on with their lives despite her ongoing psychological struggle:

***Tanya:** psychologically it was very hard, ahm it is very hard even now... I would like to have more support first of all from the people I am close to...even my family...even my friends around here...just sometimes you need someone to tell you that everything is going to be alright you will be back and you will recover positive things you know...because everybody is busy with his own life ...nobody cares too much...**p16/778-792***

Emma's perceived obligation to shoulder the burden of stroke alone left her feeling isolated in her efforts to cope with her experience. Despite her differentiation between those outside her immediate social circle and her primary support network, Emma felt unable to rely on either party for emotional support. Normally in times of distress, family and close friends are preferable sources of support. Conversely Emma also wanted to avoid an over reliance on support from her primary care-givers for fear of being treated differently thus delaying return to normal life. Similar to Tanya, Emma felt obliged to resume pre-stroke roles (e.g. wife, mother, employee etc.) despite being unready psychologically to return to normal life:

*Emma: it is something that has happened to me and... I have to cope with it....people that wouldn't be as close to you...it's kind of a lack of understanding on their behalf ...they don't really know and you don't really want to go there with them and you kind of feel right...be it in the work place or whatever I'm the soldier and I have to kind of brave the elements myself...it's like you have this thing built around yourself... and then with people close to you... it's the... fear of...if I keep going on about this thing... it's going to keep it foremost in their minds and their going to start worrying and fretting and continue to wrap me in cotton wool...after a couple of days you know life is as normal and you just get on with it and it doesn't mean that all those emotions go from me you know so it's kind of...I think that's isolating in itself...p18/845-883*

#### 3.4.4 Desire to talk to somebody similar

Opportunities to communicate with similar others were lacking, both in the stroke unit and after hospital discharge. The majority of participants commented on their desire to talk to younger patients with mild stroke comparable to themselves. Stroke instigated feelings of abnormality and frustration for some of the participants. Being able to communicate with others who were similar in terms of age and experience might have reduced feelings of seclusion and bewilderment. Sarah describes her isolation and concern about the feelings she experienced after stroke and questioned whether it is a normal reaction:



**Sarah:** *if I had somebody to talk to...that had been through what I had been through, I would have been able to...not compare notes but ...but I would have known that what I felt was normal. Like the feelings, like frightened...p4/167-172*

Like Sarah, Miriam's inability to relate aspects of her illness to others' experiences led to self-questioning. She describes her frustration and struggle to accept her illness. Miriam highlights the benefits of having an illness common to other individuals to allow social comparison. Being able to measure the self against similar others would ease Miriam's sense of isolation and confusion and perhaps prevent her feeling 'abnormal':

**Miriam:** *...don't think I have ever met anyone who has been through the same thing as me, ... I know people who ...have illnesses who would have met other people with those illnesses and would have been able to relate to that going "God that happened to me...oh yeah did that happen you", ...you don't have anybody to bounce that off...so it...can be a bit frustrating cause sometimes you're going "God is this normal, is this?... ", and if you have something to relate it to you can accept it but if your kind of going well I don't know if this is part of this or if it's just me, do you know what I mean? then it can be a little bit kind of confusing too...p22/1055-1067*

The difficulty of decision making regarding having children after stroke was evident in the majority of participant accounts. Tanya and Emma expressed anxiety about having more children and neither of them felt they had anyone with whom they could discuss their concerns. The isolation experienced by both participants in their shared dilemma emphasises the need for the provision of services that would facilitate a social support network amongst younger stroke survivors:

**Tanya:** *it would be very interesting for me to talk to a person that had a stroke... that went through the same because at that time in the Stroke Unit all the patients were quite elderly patients...so there was no one young...and...and now at this stage say a few years even down the road I...I'd still like to talk to someone young ...that maybe had a similar stroke whether they found a definite reason...how is the person feeling now...are there any tips you know that we could give each other ...to recover better and...It's quite a personal thing...if I wanted to have another child...would I be allowed to?.... P10/446-465*

**Emma:** *I don't know whether it would be the same for other women ...but I suppose it's just that when you'd be in your late 30s anyway it would be something that I would be aware of as well that you know ahhm if you... and I don't know whether it's something that would hit other women in the same age group or not ...p16/17-776-817*

Jane felt isolated from those who she deemed to be worse off than herself and found comfort in talking to her friend's mother who had suffered a stroke twenty years ago:

**Jane:** *you'd love to talk to someone similar but there really wasn't...I kind of went on to that...the stroke Facebook thing but...no offence to some of the people on there but it's just like...there was no optimism like they were using it as their sounding board ahhm...and I kind of felt well...I'm actually not half as bad...you know I'm not like a real stroke compared to what these people have...p11/503-510*

Their discussion of shared emotions and the opportunity to talk about issues that could not be shared by those who had not experienced stroke provided her with some comfort. However, she still has an unfulfilled desire to communicate with somebody similar to herself in the present day:

**Jane:** *I actually ended up meeting my friend's Mom ah...a couple of weeks ago and it was really funny because she's like...even though it was like 20 something years ago the same things and even now the frustrations with people who didn't get it...it was funny actually we had a good laugh about it but even now that's the one thing I would say I would love to have met someone who was similar...p11/510-521*

The lack of follow-up services after hospital discharge left some of the participants feeling cut off from medical support. Aoife described feeling isolated after hospital discharge and suggested the necessity of a social support network. Her suggestion for an additional support network emphasises the extent of her loneliness and also a need to communicate with similar others. Adapting to life after stroke can be very challenging. Struggling to explain the changes and rules of their new world to those on the outside can make for a very isolating time:

**Emma:** *I suppose when you're having a bad day ... or everything goes wrong...when you get one of those days...when things go wrong and you kind of feel you know...if*

*people understood what happened to me maybe it would put things in perspective you know...p18/19-896-902*

### **Summary – A desire for peer support**

Experiencing a disease normally associated with old age meant that young patients with stroke often felt isolated in their rehabilitative environment. The desire to relate to similar others in terms of age and experience was a key issue for most of the participants. Given the predominantly older profile of patients in the stroke unit, it is not surprising that some participants felt like the ‘odd one out’ and others were disappointed because their rehabilitative needs as younger patients had not been met. The lack of opportunities to compare the self with similar others and limited sources of information for younger patients resulted in further feelings of isolation after stroke.

### **3.5 The impact of stroke on relationships**

Young stroke patients need a variety of supports (e.g. practical, emotional, and financial) in adjusting to their lives after stroke. However, inappropriate or untimely support efforts can be detrimental to the patients’ attempts to “*return to normal*”. While some relationships after stroke were strengthened, others became problematic.

#### *3.5.1 Social support: how much support is too much?*

Experiencing an illness which strikes suddenly can be a very traumatic and distressing event, therefore having strong support networks was very important for the participants. Miriam’s strengthened appreciation for her family, stemmed from the strong sense of continual support and security that they provide for her.

**Miriam:** *it's strengthened my relationship with my family because I appreciate them all now and I appreciate the support they've given me and I know no matter what happens to me I'll always have them there for me...p17/841-844*

**Kate:** *I'm very lucky he is incredibly supportive. You know he's a very strong person and very supportive...p16/772-774*

Some of the participants also received support from the other patients in the hospital.

Being in a hospital environment as a patient can be overwhelming therefore being able to relate to others in an unfamiliar environment provides a certain level of comfort. For Tanya receiving useful tips from other patients on the ward motivated her to improve her level of physical functioning:

**Tanya:** *people were very supportive as well even the other patients in the room you know they were saying "doing any movements, exercising anything doesn't matter just put your hand on the table you know and try to lift every single finger...p5/215-220*

**Emma:** *I must say like the people that I met in hospital were kind of a great source...the people in the ward were a great source of comfort to me...p4/173-175*

However, participants struggled with their need for support and the desire to return to normal life. The protective nature of family and close friends sometimes led to frustration as participants tried to reassert their independence. Being "treated differently" or "wrapped in cotton wool" prolonged the stroke-patient role. Continual concern and the expressed opinions of others regarding the participant's safety and well-being, led to feelings of suffocation and frustration:

**Alison:** *Yeah my mother is a real fusspot and I hate that and she was always all over me...anytime... I'd come back for a check up she was always with me and in the room and was asking questions and I hated that...but looking back now she was always there for me kind of and I kind of took her for granted a little bit.p3/103-109*

**Kate:** *Once... anybody finds out you've had a stroke you are...definitely ...definitely treated differently... everybody has a comment on it; like if you go to the gym somebody will say 'well should you be doing that now? Did you check with your doctor?' or you know go out with your friends and have an extra cocktail it's like 'should you be drinking those now? You should take it easy' ... it's always the take it easy mentality...p9/420-434*

### 3.5.2 Removal of support systems

Some of the participants witnessed the gradual reduction in their support networks after stroke. Relationships dissolved as lives had to be altered and the true nature of friendships were tested. Necessary lifestyle changes had negative consequences for some of the participants' relationships. Miriam's partner was not willing to accept her need to be more physically aware of her limits after stroke:

**Miriam:** *before that I was going out with somebody and afterwards I...wasn't and the reason I wasn't was just that...my life had changed an awful lot I suppose in perspective and in what I had to do for myself that kind of went from had to look after myself basically you know what I mean on certain things so when you get to be with somebody who couldn't understand that and doesn't fit into that then that's the end of that...p17/851-859*

For Aoife, requiring a lot of assistance with domestic tasks meant that the house was no longer confined to the family unit, an alteration her husband was struggling to cope with and she felt that he blamed her for the unwanted changes to their home environment:

**Aoife:** *my husband I think blames me for having the stroke in ways cause its after upsetting his life...he thinks it's very unfair that I had a stroke and he thinks I upset his whole life cause he doesn't like people being in the house either and he wants everything back to the way it was...p5/231-233*

Fickle friendships began to dissolve quite quickly for some of the participants, Aoife and Jane began to recognise the true nature of some of their friendships, when support was not available:

***Aoife:** I had lots of friends which I find out now were really only acquaintances...p18/871-873*

***Jane:** ...at that time see you kind of found out who your good friends are and then you find out the people you thought were your friends actually, you know, they're not really, you know their not keeping in touch or any of that...p22/1062-1066*

Tanya's friends failed to make any allowances for her physical disability, leaving her feeling isolated from her social circle:

***Tanya:** you have 2 or 3 friends whatever that you go with so say you expect them to...understand that you cannot walk so fast and you expect them to slow down a little bit so that you...but they don't...you know what I mean...it's a real life nobody takes into consideration nobody needs you if you are sick and its...its very painful...its very painful (becomes tearful) ...p15/697-705*

Stroke not only affects the patient but also casts others in the role of caregivers. Emma describes the emotional impact of the hospital experience on her husband, as they awaited confirmation of a diagnosis. During a time of emotional anguish, participants were concerned about their caregivers in addition to coping with their own issues:

***Emma:** I just remember that morning in Hospital A when we didn't know what we were being faced with...he'd been...he was being really strong for me and then he just broke as well you know and then I think you've all that worry as well you've worry about other people...p15/704-709*

Miriam and Jane describe their concerns regarding the lack of social support available for their caregivers; while their own needs were being addressed in the hospital environment, the loneliness, concern and isolation of family members tends to go unattended:

***Jane:** I'd say he felt more alien in here than me ...ok he doesn't like hospitals but it is kind of...you know he wasn't being catered for if you know what I mean...p23/1132-1135*

**Miriam:** *what I found difficult was for...I still do a bit...was for my parents for them to see me in that position (laughs a little) I even well up about it now (gets a little emotional at this point) but ah I couldn't imagine watching your child go through that and I think like its great for them to see me on the other end of it as well...but I do think my mother was particularly upset...but for them I don't think there was any support for them...to actually have to look after me...like there was nothing on that end of things nobody told them... I suppose because I was 23 at the time ah...the doctor talked directly to me but...ah sorry...p24/1152-1163*

The negative impact of stroke for most participants was not only devastating for them but for their partners' and families. Reduced working hours, meant an unwanted role change for Alison, she felt guilty because her partner was struggling with their financial burden alone:

**Alison:** *it was just an awful lot of strain cause I was out of work and that and we were only after buying a new house and he was out working all the hours God sends and I couldn't be... p4/194-197*

For Kate her stroke's restrictions on future plans to have children, resulted in feelings of concern for the impact this would have on her husband's life. She compared their circumstances to those of their own immediate social circle:

**Kate:** *...it has to be difficult for him to be told 'well you know your not having any more kids' and his friends are all having kids or whatever but he just...he just blows that sort of thing off, well that's just the way it is...he looks at the bright side of life sort of thing...p16/776-781*

Angela and Emma describe their own personal sense of isolation in dealing with their circumstance due to their efforts to avoid burdening others with their problems:

**Angela:** *I'm sure people are sick of hearing that ah Angela's in hospital... other people have enough of their own problems without listening to other peoples. p12/554-569*

**Emma:** *cause I'd be very independent and I think its, that kind of I think its, probably from trying to be independent that you build up this isolation I suppose... you know its me that this happened to and its me that has to come through it at the end of the day and you kind of feel yeah everybody else has their own life to lead as well that they don't want to be listening to you...p18/863-875*

Fiona and Sarah's sense of uncertainty about their futures led to anguish about being a burden on their families. Sarah and Fiona felt that it would be an injustice to expect their partners to stay with them, should their health problems deteriorate. To avoid being a burden they both tried to push their partners away:

***Fiona:*** *I was just thinking of the...the two kids well they are teenagers, I was thinking of them, are they going to have to look after me for the rest of their days? Or...like my husband is he going to have to give up his job?...p4/170-184*

***Fiona:*** *I said to me husband one night "if you want to go and find someone else you can, cause I don't know if I'm going to have another ah...", I says "I wouldn't expect you to look after me" p9/427-431*

***Sarah:*** *and am I remember when I was up here at the very start...I turned around to my boyfriend and told him to dump me because it wasn't fair (very emotional at this point).p8/350-359*

For younger patients fear about how stroke may affect their children and concerns about long spells of time in hospital away from their children can also add to an already emotional experience:

***Emma:*** *I suppose with young kids and everything I was just kind of conscious that they'd be worried like because I'd never really be...I wouldn't be absent for long spells at all...p6/286-289*

Aoife did not want her physical impairments to have an impact on her children's lives, fearing that her own resentment of her condition would be transferred onto her children, particularly when activities are restricted due to her limited physical ability:

***Aoife:*** *I want them to have a good childhood and not be always ah Mammy's stupid leg or we can't do this you know.p15/701-702*



## **Summary – The impact of stroke on relationships**

Life after stroke requires a certain amount of emotional, social and in some cases financial support. Some relationships were strengthened after stroke as participants were reassured of the reliable support networks they had available to them in times of distress. However, inappropriate or untimely support efforts can hinder stroke patients in their efforts to resume ‘normal’ life. In some cases participants’ witnessed a break down in relationships due to unwanted household role changes and fickle friendships dissolved because of the lack of awareness in regards to a stroke survivor’s reduced physical ability and associated lifestyle changes. The majority of participants in the current study also had concerns for the impact of their stroke on their family members, partners were often left with the sole care of the person with the stroke in addition to family and work related responsibilities. Parents of adult children with stroke became carers again and witnessed the loss of their child’s short-lived independence. Young stroke survivors with teenage children worried about becoming a burden on them in the future.

## Chapter 4: Discussion

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This research adds to the literature on younger stroke through its novel focus on the meaning and experience of stroke for young females through the application of IPA. The current study is unique because it is the first qualitative study based on the experiences of younger female stroke patients in Ireland. The key issues emerging from the current study include: age-related stigma and associated repercussions of such stigma in terms of experiences within the Irish healthcare services; the transition between the pre and post stroke selves; and changes in interpersonal relationships. Issues relating to the current provision of stroke services for young adults also emerged as a key concern in the current study. This chapter will discuss the findings in regards to: (1) the consequences of experiencing a stroke for a young female adult; and (2) the implications for the stroke services available to young adults within the Irish healthcare setting. Findings emerging from the current study will be reviewed in relation to previous research on young stroke, the limitations of the current study will be considered, and this section will conclude by offering recommendations for future stroke service planning.

### **4.1 The consequences of experiencing a stroke for a young adult**

The aftermath of stroke at a young age is characterised by change, change in physical and emotional functioning, changes in identity, roles and relationships. The sudden and unexpected onset of stroke serves as a discrete marker separating life before stroke and life after stroke into distinct periods. Many of the changes experienced after stroke are negative, previously young, healthy females experience their bodies as unreliable and are confronted with limitations and treatment regimens

which are alien for their age and developmental stage. Incorporating these changes and experiences into self identity and reconciling the discrepancy between past and current selves can be challenging. Such changes do not occur in a vacuum they extend beyond the individual stroke patient to their families and friends and wider social and professional circles. For the young female stroke survivor, stroke impacts on their role and responsibilities in the family and changes the dynamics of interaction. Where the individual has a spouse and/or children concerns about becoming a burden are evident. In situations where parents re-establish a caring role after their adult child experiences stroke, independence is lost, at least temporarily. In the work context, few allowances are made for individuals with *hidden impairments* after stroke and stroke survivors are often expected to resume work related tasks despite their post-stroke difficulties. It is clear that stroke has multiple and potentially devastating consequences for the young adult. However, it is not exclusively experienced in negative terms, in some cases stroke survivors reassess their life situation and express gratitude for the positive aspects of their life that may have been taken for granted prior to stroke.

#### *4.1.1 Stroke and identity*

Stroke is not a word that is normally associated with young and healthy adults. Low et al. (2003, p.1056) described younger individuals with stroke as an “invisible group” because of its strong association with old age. Findings from the current study reiterate the link between stroke and old age; this link was evident from participants’ efforts to normalise their initial stroke symptoms, dismissing the possibility of stroke, and also in their shocked reactions on diagnosis. Stroke is not unique in this regard; age-related stigma associated with specific diseases has been documented elsewhere.

For example, Bury (1991) noted the distress felt by young arthritis patients in relation to their diagnoses because of the cultural belief that arthritis is a disease of old age and that to have arthritis at such a young age is suggestive of premature aging. Both participants and medical staff in the current study struggled to acknowledge the possibility of stroke in young adults suggesting the need to improve awareness regarding the occurrence of stroke in younger individuals. The age-related stigma associated with stroke extended beyond participants' initial reactions and hospitalisation experiences to their lives after stroke. For some participants stroke had an ageing effect in terms of self-concept and identity. The lack of younger role models with stroke, the requirement to take stroke medication and the experience of stroke related impairments, such as memory loss which is normally associated with old age, contributed to perceptions of an aged self. Similar findings were noted by Stone (2005). Together these findings highlight current attitudes to stroke in young people in terms of the associated stigma and perceptions of an aged self.

In addition to the perception of an aged self, life after stroke proved to be a challenge for most of the participants in terms of adapting to new and unwanted post-stroke identities. Similar to findings based on younger stroke survivors in Lawrence's (2010) study, physical impairments following stroke had negative consequences for some participants' body image and self-esteem and efforts were made to conceal their impairments, this was a particularly poignant issue for the young female participants in the current study. According to Goffman (1963) the socially acceptable management of one's body is important in terms of how one is perceived by others. For individuals with visible disabilities their compromised ability to manage the physical self can result in social withdrawal (Murray & Harrison, 2004). Feeling unattractive and self-conscious about visible disabilities after stroke has been

documented elsewhere (Ch'ng et al., 2008). Clarke-Henshaw (2007, in Kennedy, 2007) noted the greater social pressure on women to appear attractive and suggested that women may be more vulnerable to body image disturbance compared to men. Disability can threaten one's sense of femininity and social value making it more difficult to fulfil previous roles (for example, the roles of wife and mother). However, for many participants in the current study, the struggle to adjust to new, post-stroke selves was complicated by the relatively hidden nature of their impairments. The absence of visible impairments created a separate array of problems because hidden emotional and physical difficulties in the aftermath of stroke went unnoticed by others. Participants in the current study experienced difficulties in return to work because of unseen cognitive impairments resulting from stroke such as fatigue, memory disturbances and minor speech difficulties. This led to decreased levels of confidence and self-esteem in the workplace; this is consistent with findings from other studies based on younger stroke survivors with mild stroke (Banks & Pearson, 2004; Roding et al., 2003; Lock et al., 2005). According to Stone (2005), the assumption of an unproblematic divide between disabled/abled renders difficult the recognition of those who appear to be able bodied but have disabilities that are not visible to others. Stone (2005) suggested that her participants' experiences were mediated by the belief that disabilities worth taking seriously are readily visible and that social convention dictates that we may not expect as much from those with visible impairments compared to individuals who do not appear to be disabled. Similar to participants in Murray and Harrison's (2004) study, participants in the current study suggested that having a visible disability might lead to more understanding responses from others. This position contrasts with the commonly reported stigmatization of individuals with visible disabilities (Kelly, 1992).

In the absence of culturally accepted markers for disability, stroke survivors with mild impairments face dualistic implications in regards to how they present themselves (Stone, 2005; Goffman, 1963). Stroke survivors risk being perceived as lazy and incompetent if they keep quiet about their hidden impairments, however, on the other hand if they communicate their hidden dysfunctions they run the risk of not being believed, attention seeking and inappropriately looking for sympathy (Stone, 2005). Similar concerns were expressed by Roding et al.'s (2003, p. 870) participants who felt that their invisible handicaps were “not as legitimate as other forms of handicap”. Being young with hidden impairments is even more difficult because others do not expect young, apparently healthy and physically fit individuals to have physical difficulties (Stone, 2005). This highlights the need for more awareness regarding the hidden physical and psychological impact of mild stroke.

Participants' experienced a profound sense of loss of their former identities after stroke and levels of self-worth and confidence decreased. Reflections on more active, busy and social pre-stroke selves enhanced feelings of loss. Similar findings were noted by Carlsson et al. (2004) who described participants' “harmed or threatened self”. Feelings of a loss of control, of chaos and of life being ‘turned upside down’ as they sought to regain a sense of structure in their lives were evident for participants as they perceived their former abilities to be impaired. Carlsson et al. (2004) interpreted the participant's perception of a threatened self as being a threat to their self concept. Mead (1934/1967 in Carlsson et al. 2004, p.1379) defined the self concept “as the totality of a complex dynamic system of learned beliefs, attitudes and opinions that a person believes to be true about oneself. It is a social construct and develops and changes many times during a person's lifetime”. Illness may also have an impact on an individual's life narrative. Concepts such as “biographical

disruption” have been employed to describe the consequences of illness on an individual’s “construction of a biography” (Bury, 1982, 1991 in Carricaburu & Pierret, 1995, p.65). According to Bury (1982 in Faircloth et al. 2004, p.243) “biographical disruption” ensues when “chronic illness constitutes a disruption or a discontinuance of an ongoing life, a critical situation”. Stroke was experienced as a biographical disruption by some of the participants in the current study, such disruption is illustrated in the effect of stroke on reproductive decision making. After stroke, decisions regarding having children became considerably more difficult because of the increased health risks. One of the participants described stroke as “*causing a close on another phase of my life*”, when she decided it was too dangerous to risk having another child.

In addition to difficult reproductive choices, work-related disempowerment, difficulties returning to work and reduced working hours created a sense of biographical disruption for participants in the current study. Return to work after stroke has been associated with the stroke survivor’s attempt to regain their formal social position or to adapt to the new social situation which is dependent on their interaction with people in their social context (e.g. family, employer, community, professionals and the general public) (Benz, 2000, 2003; Kersten et al., 2002; Low et al., 2003; Lock et al., 2005; Lawrence, 2010). For younger individuals work plays a pivotal role in their lives (Medin et al., 2006; Grace & Wolfenden, 2009); previous research suggests that individuals who do not return to work after stroke report significantly more unmet needs (Kersten et al., 2002). Teasell et al. (2000) indicated that 48% of younger stroke survivors expressed concerns about return to work as a critical issue after stroke. In the current study some participants were in the prime of their careers and the level of reduced responsibilities and changed attitudes of work

colleagues compromised their work-related autonomy. Fear of work related disempowerment was evident from participant's efforts to conceal their post-stroke impairments from employers and work colleagues. Wolfenden and Grace (2009) highlighted the need for employers to consider the stamina and endurance of the stroke survivor returning to work, thus allowing stroke survivors to regulate their workload and hours in times of stress or unpredictable fatigue (Medin et al., 2006; Different Strokes, 2007).

Previous research on return to work after illness has suggested the necessity to alter the misconceptions that people need to be fully fit to return to work (British Society of Rehabilitation Medicine, 2003). Wade (2005) suggests that the question of an individual's capability to work cannot be restricted to medical data alone. An individual's qualifications, competence and experience in addition to having the capacity and power to work should be taken into account. Wadell and Aylwood (2005 in Radford & Walker, 2008) noted the additional health risks associated with the inability to return to work (e.g. loss of fitness, mental and physical deterioration and low mood). Overall this theme would suggest that the importance of returning to work for younger stroke survivors goes beyond the basic monetary gains. Stroke for younger individuals can be a time of uncertainty especially in regard to perceptions of the self, therefore opportunities for returning to work may be valuable in regaining aspects of the former self. Increasing employer's levels of awareness regarding the complexities associated with mild stroke could aid return to work for younger stroke survivors.



#### *4.1.2 Coping with stroke*

Participants employed different types of coping strategies in the aftermath of their stroke. These coping strategies can be categorised in terms of five different dimensions of coping: (1) emotion-focused strategies, aimed at changing the emotions caused by the stressful event; (2) problem-focused coping; involves making efforts to change the situation causing the distress; (3) avoidant-coping which includes denial and mental disengagement (Folkman & Lazarus, 1980); (4) benefit finding, is a form of coping that involves viewing one's life situation from a more positive perspective (Tennen & Affleck, 2002); and (5) downward social comparison, is a technique individuals employ to compare themselves with others who are worse off (Bennenroek, Buunk, Van der Zee & Grol, 2002). Participants employed emotion-focused coping strategies, in terms of seeking emotional support from family and friends and in some cases professional psychological support. Problem-focused coping strategies included making healthy life style changes and participating in rehabilitative therapy etc. Avoidant forms of coping were also apparent as participants' described losing motivation to engage in tasks that had taken priority in their lives pre-stroke and some participants became socially withdrawn after stroke. Additionally several participants had a changed perspective on their lives after stroke. For example, reduced working hours were viewed from a positive perspective in terms of spending more time with family and kinder attitudes to the physical self were adopted. Similar findings were reported by Roding et al. (2003), younger participants felt a sense of relief that the stroke did not have a more devastating impact. Efforts to view changes in the aftermath of stroke from a more positive perspective can be interpreted as form of benefit finding or positive reframing (Tennen & Affleck, 2002; Gillen, 2005). Tennen and Affleck (2002) described benefit finding as identification

of benefit from adversity and suggested that it serves as a method of regaining lost control. Research based on other illnesses has noted that participants reported some experiences related to their illness experience to be positive or beneficial (Katz, Flasher, Cacciapaglia, Nelson, 2001; Antoni, Lehman, Kilbourn, & Boyers et al., 2001; Stanton, Danoff-Burg, Sworowski, & Colins, et al., 2002). Gillen (2005) documented benefit finding in stroke noting that 63% of the patients interviewed (n = 16) were able to identify positive consequences of their stroke including improved social relationships, increased health awareness, change in religious life, personal growth and altruism.

In the current study engaging in downward social comparisons allowed some participants to view their own situation from a more positive viewpoint. Downward social comparison tends to occur when individuals feel threatened by a negative aspect in their lives and take comfort by comparing themselves to others who are less fortunate. Engaging in downward social comparisons allows individuals to regain a positive perspective on their own experiences. Some of the participants in the current study took comfort in the knowledge that there were younger individuals who had similar experiences to themselves. The variety of coping strategies utilised by participants suggests that flexibility in coping styles is necessary to deal with the multitude of evolving challenges after stroke. Coping in the aftermath of stroke, whether at young or older ages, has not been extensively studied and should be a fruitful avenue for future research.

#### *4.1.3 The impact of stroke on social networks*

The impact of stroke not only affects the stroke survivor, family members and friends may also be affected. Altschuler (1997) likened the family to a machine

which relies on all of its parts for smooth functioning, disturbance to any specific part alters the operation of the machine. For some participants interpersonal relationships became problematic after stroke. While social support was appreciated by participants in the initial phase after stroke, participants' struggled to return to their normal lives because of untimely and inappropriate levels of support received from family and friends. For example continual expressions of concern from others regarding the participant's safety and well-being, resulted in feelings of suffocation and frustration. Similar findings were reported by Carlsson et al. (2004, p.1378), stroke survivors felt that too much support from their spouses or children "hindered" them and the imbalance between spouses caused relational problems. In a study based on the experiences of partners of young stroke survivors, Buschenfeld et al. (2009) noted that feelings of protectiveness towards the stroke survivor persisted over many years. In addition to feelings of work-related disempowerment, participants' in the current study struggled to accept reduced levels of responsibilities in the home and in some cases requiring additional domestic support with household chores resulted in marital problems. Palmer and Glass (2003) noted that an overabundance of task-orientated support was associated with poorer functional outcomes and increased risk of post-stroke depression.

Baikie (2002) has highlighted the absence of attention to marital relationships in the abundance of literature concerning caregiver burden in chronic illness. The impact of illness can have negative repercussions for marital relationships in terms of a reduction in shared activities, loss of emotional support and decreased verbal communication (Baikie, 2002). The majority of participants in the current study were either married or in relationships and had young children. Participants expressed concern about the impact of their stroke on their partners and the lack of support

available to them during the acute phase. Life after stroke can be difficult for partners in terms of providing appropriate levels of support without appearing over protective. Younger couples are often faced with additional challenges in regards to balancing work and family responsibilities as well as providing support for the stroke survivor. Buschenfeld et al. (2009) stressed the importance of providing age-appropriate services for partners of young stroke survivors and suggested that stroke services should aim to involve the partners in the stroke survivor's care plan. Living with illness may not be a typical occurrence for younger couples, thus additional support in terms of adapting to illness and managing family responsibilities may prove to be beneficial.

In contrast to the unwelcome over-abundance of support provided to some participants, others noticed a reduction in their support networks after stroke. In some cases participants experienced a changed self in addition to an altered lifestyle (e.g. being more aware of physical limitations, requiring assistance with household tasks etc.) and participants' friends and families had difficulty in adapting to these changes. Banks and Pearson (2004) noted similar findings in their interviews with younger stroke survivors and their carers. Loss of work with associated loss of income, depression, lack of social life, and general changes in lifestyle had a negative impact on their relationships. Participants' struggled with the fact that their partners were unable to relate to their experiences with stroke and, similar to the current study, some of the participants' partners were struggling to accept their physical impairments after stroke (Banks & Pearson, 2004).

Parent-child conflict has been highlighted as an issue experienced by younger stroke survivors (Teasell et al., 2000; Low et al., 2003). In the current study however, conflict was not evident rather mothers expressed a variety of concerns which differed

depending on the age of their children. Participants with young children were concerned about the possibility of not being present to continue their maternal roles, conversely those with adolescent children expressed concerns about becoming a burden should their children have to adopt the role of caregiver for their ill parent. Participants also voiced concerns about the negative impact their stroke would have on their elderly parents in terms of the distress and anguish they might endure watching their adult children cope with a disease that normally occurs in older individuals.

Participants reported feeling isolated in their efforts to cope with the psychological consequences of their stroke and felt pressured to resume previous pre-stroke roles (e.g. wife, mother, and employee) despite their psychological difficulties. Findings from studies including older age samples have indicated that many of the changes following a stroke are invisible to others, e.g. frustration, depression and irritability (King, 1996; Andersen, 1997; Clark & Smith, 1998) which can lead to feelings of isolation and difficulties within families. Some of the participants' tried to conceal the psychological impact of their stroke from families and friends to avoid having the topic of stroke as the primary focus in their lives. However, as Altschuler (1997) noted in trying to protect one another by not voicing negative feelings, people unintentionally create the very barriers to communication that they are trying to avoid. Participants in the current study described feeling isolated by hidden psychological concerns within their family unit; however, the majority of them expressed a preference to communicate their concerns with people (e.g. with other young stroke survivors) outside of their immediate social circle. The lack of opportunities to relate to somebody similar in terms of age and experience during and after hospitalisation resulted in further isolation. Participants' questioned whether their feelings were

normal. The inability to share their experiences with similar others resulted in feelings of confusion and anxiety. Previous research suggests a greater need for younger stroke patients to communicate with similar others in contrast to older patients (Glader, Stegmayr, Johansson, Hulter-Asberg, & Staaf et al., 2001). Ch'ng et al. (2008) conducted focus groups with stroke support group members', including a group targeted at younger stroke survivors, to explore the benefits arising from support group participation. Responses indicated that stroke support groups were beneficial in terms of providing opportunities to relate to similar others in a manner that was not possible with family members, normalising experiences and sharing practical tips for living with disability (Ch'ng et al., 2008). In addition to communicating with similar others Caplan (1993) suggested that young stroke support groups may assist young stroke survivors to overcome self-image problems in relation to their physical impairments through contact with others who have managed to achieve a satisfying post-stroke lifestyles despite experiencing some residual cognitive and/or physical deficits. Furthermore, Low et al. (2003) documented increased levels of awareness in Stroke Association members in regards to the availability of resources and how to access them. Despite evidence for the benefits emerging from stroke support group participation, there appears to be a gap between expressed desire to participate in a stroke support group and actual participation. Banks and Pearson (2004) noted that 75% expressed the desire to communicate with other stroke survivors, but only one participant had attended a stroke support group however, it was not stated whether support groups were available to all of the participants. Thus, barriers to stroke support group participation warrant further investigation.

In addition to participants' own desires to communicate with others after stroke, they also had concerns regarding the lack of support for their families. While participants' needs were being addressed during the hospitalisation phase, concerned family members were isolated from this process. This is consistent with findings reported by Banks and Pearson (2004) who noted that carers have also been found to feel inadequately supported in tackling their emotional and personal problems. Banks and Pearson (2004) likened the experience of stroke as a parallel journey for stroke survivors and their carers; stroke survivors adopt a career in stroke and carers adopt a career in caring. In a study based on the psycho-social functioning of spouses during the chronic phase after stroke, Visser-Meily et al. (2008) reported high levels of life dissatisfaction and care-giver burden one year, and in some cases up to three years, after stroke. The sample in Visser-Meily et al.'s (2008) study was heterogeneous in terms of age however the authors noted the increased risk of deteriorated psychosocial functioning in spouses with young children. Based on their findings Visser-Meily et al. (2008) suggested the importance of empowering spouses during the rehabilitation phase with a view to managing the psychosocial consequences of caring. Partners of young stroke survivors in Buschenfeld et al.'s (2009) study expressed the social benefits of meeting people through young stroke support groups for carers. Therefore, communicating with similar others after stroke may also be helpful for the primary caregivers. Young carers may also have specific concerns that would suggest the potential benefits of communicating with other young carers (e.g. having sole responsibility for family activities, emotional adjustment to their partner's stroke, and employment in addition to care giving) (Buschenfeld et al., 2009). Younger stroke survivors and their primary caregivers can become isolated from one another in terms

of having separate concerns in the aftermath of stroke, therefore both parties might benefit from having access to formal social support outlets.

#### **4.2 Implications for stroke service planning**

Improved understanding of the lived experience of stroke and the biopsychosocial consequences of stroke in young adults can inform efforts to enhance rehabilitative outcomes and promote a fuller return to health and participation in society after a stroke. There are five key issues emerging from the current research they may be understood in terms of a trajectory of stroke experience from symptom onset to diagnosis, hospitalisation and rehabilitation and reintegration to community life after discharge. Many of these key issues are located at the interface between the health service and the individual patient. They can be addressed via: (1) increasing awareness of the incidence of stroke in younger patients amongst medical staff and the wider community to prevent the dismissal of initial symptoms and delayed medical intervention. (2) Facilitating patients with opportunities to communicate with similar others (for example informing patients about relevant social networking websites) may combat feelings of isolation and anxiety both during and after hospitalisation. (3) Younger patients with stroke may feel less isolated in their rehabilitative setting if facilitates and services were age-adapted e.g. information booklets and rehabilitative programmes designed to cater for younger patients' needs. (4) Younger stroke patients reported feeling cut off from medical support because of the lack of follow-up services. While it may not be possible to restore follow-up services for those with mild impairments, efforts to assist patients in terms of their transition back into the community may reduce their level of dependency on medical



services. (5) Medical staff need to address the issues of younger patients with hidden mild impairments that may hinder them from returning to the work-place.

Participants' efforts to normalise their initial stroke symptoms, followed by their shocked reactions at being diagnosed with a disease that is normally associated with old age highlights the need for more awareness regarding stroke in younger individuals, to avoid delays in seeking immediate medical intervention. Banks and Pearson (2004) also noted the normalisation of initial stroke symptoms in a younger sample of stroke survivors (aged 18-49 years). Symptoms were confused with other conditions and thus delayed calling for medical help. Banks and Pearson (2004, p.419) suggested that the "reluctance to bother GPs or call out emergency services can be misinterpreted by health professionals who may not appreciate how difficult these decisions are for people who have no previous experience of ill health". Increasing general public awareness about the possibility of stroke in the young may reduce the level of delay in seeking medical assistance. However the dismissive attitudes of medical staff in A&E, regarding the possibility of stroke at a young age, led to further delays in treatment. Once stroke symptoms start, there is a very brief window of time for individuals to receive beneficial treatment. Participants in the current study were relatively fortunate as they had experienced strokes of mild to moderate severity. Delays in treatment for those with more severe strokes could prove to be detrimental in terms of the permanency of residual physical disabilities. Similar findings were noted by Stone (2005), participants felt that their young age was an issue that got in the way of others (including medical staff) taking them seriously. The apparent reluctance of medical staff to consider the possibility of stroke in young adults resulted in participants being sent home without a diagnosis or having their symptoms misdiagnosed for other conditions. The shared disbelief of medical staff in regards to

their stroke diagnosis heightened participants' feelings of abnormality and embarrassment at having a stroke so young. Increasing awareness of the possibility of stroke in young people amongst medical staff could contribute to reducing the level of apprehension and confusion experienced by younger stroke patients during their initial admittance to the hospital. The perceived unwillingness of A&E staff to consider stroke in the young may also suggest the potential for further staff training in recognising and diagnosing stroke in younger adults. The unusual occurrence of stroke in younger individuals led to feelings of seclusion and isolation during hospitalisation. Opportunities to engage with and relate to similar others in terms of age and experience during hospitalisation were lacking. This is consistent with reports from participants in Roding et al.'s (2003) study, in which a key theme was termed '*outside and invisible*'. Participants were frustrated with the lack of age-adapted rehabilitation, insufficient rehabilitation, lack of information and lack of participation. Further evidence of the anxiety and isolation experienced by younger stroke patients during hospitalisation was demonstrated in participants' accounts in Banks and Pearson's (2004) study. Participants described the distinctive link between stroke and geriatric medicine despite the allocation of designated stroke units. For many, being admitted to a ward with older people caused considerable anxieties. Rehabilitative strategies in stroke care tend to be aimed predominantly towards older patients, thus the needs of younger patients (e.g. individually tailored rehabilitation programmes aimed at returning to work) are neglected (Roding et al., 2003; Medin et al., 2006; Treger, Shames, Giaquinto, & Ring, 2007; Lindstrom et al., 2009). Stone aptly noted the problematic nature of experiencing a stroke at a young age when she stated that "in popular consciousness, the virtually exclusive focus on the elderly regarding the potential for suffering stroke means that young survivors are largely

invisible” (Stone, 2005, p.302). Prospects to communicate with similar others are not always available therefore facilitation of social support groups specific to younger individuals with stroke may prove to be beneficial. Some of the participants underwent a phase of self doubt after stroke and questioned their emotional response to the event. Opportunities to share such concerns may help to combat feelings of isolation and feeling ‘abnormal’. However, given the low numbers of young adults with stroke ‘in-person’ stroke support groups specifically for younger patients may not be feasible, an online forum may be a practical alternative to assist younger stroke survivors in communicating and sharing information.

For some stroke survivors the availability of peer support may suffice, however, for others the emotional distress associated with stroke calls for professional psychological intervention. Participants experienced lost confidence, decreased self-esteem and in some cases breakdown of their personal relationships. In the current study one of the participants described her new found ability to view her life situation from a more positive perspective and her increased level of self-esteem as a result of attending a psychologist. The psychological impacts of stroke need to be addressed in care planning. Barton (2007, in Kennedy, 2007) suggests the importance of counselling to assist stroke survivors with emotional adjustment, either in individual counselling sessions or within a group setting. Counselling sessions allow stroke survivors to address their experiences of loss, express worries and concerns and aid individuals to move forward emotionally. Barton (2007, in Kennedy, 2007) noted that psychological assessments and interventions can be delivered by members of the multidisciplinary team other than psychologists (e.g. screening assessments for mood and cognition can be carried out by medical, nursing and occupational therapy members of staff and more in-depth assessments can then be followed up by the

clinical psychologist). This strategy may be particularly useful in hospitals with limited resources (Barton, 2007, in Kennedy, 2007). Conversely, while the potential benefits of incorporating formal psychological intervention within stroke services have been highlighted in the current study, Immenschuh (2003) noted the stigma associated with seeking psychotherapeutic treatment and questioned whether younger stroke survivors would accept such help. Assessment of attitudes towards seeking psychological assistance amongst younger patient groups would be a necessary first step in service provision.

Similar to previous findings from qualitative studies on the unmet needs of younger stroke patients (Teasell et al., 2000; Kersten et al., 2002; Roding et al.'s 2003; Low et al., 2003) the lack of age appropriate and personalised information was a key concern for the participants in the current study. The participants struggled to accept their diagnoses because of the unusual occurrence of stroke in younger individuals and the cryptogenic nature of their strokes which resulted in feelings of distress. Various attribution theories suggest our human need to make sense of our surroundings and suggest that "we seek to understand our world" (Myers, 1993, p75). The limited and often inappropriate information made available to them contributed to their struggle to adapt. Participants in the current study echoed concerns expressed in Low et al.'s (2003) study, in terms of requesting information about stroke etiology, avoiding a second stroke and potential recovery. Efforts to adapt to life after stroke became more difficult in the absence of relevant information. Participants in the current study reported the need for more information and help with entitlements, information in relation to available services and general information based on what to expect after a stroke. The need for relevant information was also highlighted in the INASC report (Horgan et al., 2008). Kersten et al. (2002) noted that younger stroke

survivors wanted more information related to their stroke's specific consequences and implications as opposed to information about stroke in general. The need for relevant and more importantly age appropriate information seems to be even more significant for younger stroke survivors because of the rare occurrence of stroke in the young. Participants perceived age appropriate information as an essential stepping stone that could assist them to adjust to life after stroke.

The issue of sexual activity after stroke did not emerge as a key theme in the current study. However, participants were appreciative of the fact that medical staff initiated discussion on sex after stroke during hospitalisation. A number of participants had concerns regarding the physical risks involved in sexual activity after stroke but were too embarrassed to initiate discussion with medical staff. The proactive engagement of staff in facilitating discussion of sensitive issues such as sexuality may open lines of communication for issues of particular relevance to young patients and should be encouraged. Increasing medical staff's awareness of younger patient needs may reduce feelings of isolation during hospitalisation. Faircloth et al. (2004) noted that treating all stroke survivor's situations as universal will omit important aspects of the survival experiences thus resulting in inadequate interventions and negative outcomes.

Participants in the current study reported feeling "cut off" after being discharged from hospital. The lack of available follow-up services for younger stroke survivors left participants feeling isolated and worried about reoccurring stroke. For younger stroke survivors with limited financial resources, access to necessary rehabilitative support is not always possible. The Volunteer Stroke Scheme (VSS), one of the few community resources available on a nationwide scale may offer an avenue for filling this service gap (Tobin, Hevey, Horgan, & Coen, 2008). Tobin et

al. (2008) noted that the VSS was of pivotal importance to those who were unable to afford private physiotherapy sessions. Murphy, Chamberlain, Weir and Berry et al. (2006) noted the cost saving benefits of providing individuals of working age with disabilities (22% stroke) with rehabilitative training. At entry 92 % of the participants that took part in the training programme were in receipt of incapacity benefits, however at follow-up 41% were in paid employment, 16% engaged in voluntary work and 15% were in training or education (Murphy et al., 2006). Previous research based on samples that were heterogeneous for age noted the discrepancies between the unmet needs highlighted by stroke patients and healthcare professional's understandings of what patients need (McKevitt, Redfern, Mold & Wolfe, 2004; Olofsson, Anderson, & Carlberg, 2005). Faircloth et al. (2004) noted that a sample of older stroke patients tended to identify age as a causal factor in their physical ailments and lack of sexual drive. This resulted in limited availability of rehabilitation coverage from medical insurance providers and early discharge from hospital despite serious ongoing health issues. However, younger stroke survivors in Irish healthcare are also granted fewer privileges (e.g. age appropriate rehabilitation, follow-up services) because of their age (Horgan et al., 2008; Stroke Manifesto, 2010). Thus younger stroke patients' unmet needs highlight the importance of combating age related discrimination in the provision of stroke services.

In addition to increasing awareness regarding the possibility of stroke in young adults, the complex nature of mild stroke needs to be addressed. Previous authors have noted the inability of health professions to detect the hidden dysfunctions (particularly in the domains of cognition related to social dysfunction) associated with mild stroke because of the ceiling effects that occur with commonly used scales in stroke care e.g. the Barthel Index (BI), Mini Mental State Examination

(MMSE) and the Scandinavian Stroke Scale (SSS) (Carlsson et al., 2003; Hommel et al., 2009). Kapelle et al. (1994) found that 92% of their study sample of younger stroke survivors had nearly perfect scores on the Barthel Index (BI) (>95) but half of the participants reported a deteriorated QoL and only 42% returned to work. In a sample heterogeneous for age Edwards et al. (2006, p.154) noted that 35% of stroke survivors with mild stroke “were discharged home with no post acute rehabilitation services” despite the fact that 87% of the stroke survivors had residual symptoms. Rehabilitative strategies designed to address the specific needs of patients with mild impairments may assist their transition back into the community.

#### **4.3 Limitations and recommendations of the study**

The current study offers a novel insight into the meaning and experience of stroke in a young Irish female sample, however, some caution is warranted with respect to interpretation of these results. The study focused on the psychological impact of stroke from a female perspective. Consistent with IPA guidelines the purposive sample in the current study was chosen for its homogeneity. However, the gender-specific differences noted by Roding et al. (2003, 2010) with regard to decreased QoL after stroke warrants further investigation in regards to the psychological impact of stroke from the perspective of young male stroke survivors. Additionally, individuals with aphasia and other impairments that would result in difficulty in participating in interviews were excluded from the current study. It would be informative to explore the experiences of younger stroke patients with post-stroke aphasia via provision of communication support. “The localized nature of many qualitative studies means that their potential to influence wider clinical practice remains limited” (McKevitt et al., 2004, p.1502). Conversely by selecting an IPA

approach rich data emerged from participant's accounts, thus facilitating the potential to generate hypotheses that could be tested in larger populations. The current study is cross-sectional providing a snapshot of female patient's experiences, investigating patient experiences longitudinally, in both males and females, is necessary to assess the *process* of adjustment that younger stroke patients experience.

#### **4.4 Conclusion**

Experiencing stroke at a young age can result in stigmatization and perceptions of an aged self. Adapting to life after stroke proved to be challenging for most of the participants as they tried to negotiate new and in most cases unwanted post-stroke identities. Younger stroke survivors with hidden impairments experience additional complications in terms of fitting the prototype of a typical stroke survivor. In the absence of visible markers for disability, impairments go unnoticed and the stroke survivor is faced with the challenge of explaining the post-stroke self. Stroke created a sense of biographical disruption marked by difficult reproductive choices, decreased levels of responsibility at work and in some cases loss of employment.

The impact of stroke also affects family members. Young stroke patients need a variety of supports (e.g. practical, emotional, and financial) in adjusting to their lives after stroke. However, inappropriate or untimely support efforts can be detrimental to the patient's attempts to "*return to normal*". Partners of young stroke survivors can be faced with the complex task of trying to balance family and work related responsibilities in addition to caring for their partner with stroke. Additional support for partners of young stroke survivors may assist the entire family in their adjustment to life after stroke.

The incidence of stroke in young adults needs to be acknowledged by medical staff and the wider community to prevent delays in diagnosis and treatment. Younger



female stroke patients have specific needs that are not being addressed by the current Irish healthcare system. The absence of age appropriate care in addition to the lack of follow-up services for young stroke survivors are key examples of the inequitable nature of stroke services in Ireland. Age-adapted rehabilitative programmes and the provision of relevant information would combat feelings of isolation and seclusion currently being experienced by younger stroke patients during hospitalisation. Thus, the need to increase awareness of stroke amongst young adults across all divisions of the health service is vital to challenge the current barriers faced by younger stroke patients because of the strong link between stroke and geriatric medicine.

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## **Appendices**

Appendix 1: Interview Schedule

Appendix 2: Information Sheet

Appendix 3: Consent Form

Appendix 4: Contact Sheet

Appendix 5: Letter of ethical approval from the Adelaide and Meath Hospital  
Tallaght.

Appendix 6: Letter of ethical approval from the National University of Ireland  
Maynooth.



## Appendix 1 – Interview schedule

1. In your own words please tell me about the onset of your stroke?
2. Can you tell me about your time in hospital?
  - a. In terms of the different types of staff in the stroke unit e.g. Doctors OTs, Physios, Nurses etc. was there a certain staff member that you felt most comfortable with; if you had any questions or concerns that needed to be addressed?
  - b. Did you feel ready to go home when your time came to be discharged from the hospital?
3. What was the transition like for you from hospital to home?
  - a. What kind of support did you have?
  - b. How did other people react to you?
  - c. Can you think of any additional supports that would have helped you, when you returned from hospital after your stroke?
4. Can you tell me a little bit about your life before your stroke (e.g. work socialising, relationships)?
5. Could you tell me how your stroke affected you?
6. Do you see yourself differently since your stroke? If so, why do you think that change has happened?
7. How did you cope emotionally after your stroke? How was your mood?
8. How did your partner react to your stroke?
9. Were you able to return to work?
  - a. If so, can you tell me what returning to work after your stroke was like? How did others react to you?
  - b. In your opinion what kind of support would have helped you after your stroke, in your work place?
10. If you could give advice to other young patients with stroke what would it be?
11. Are there any other comments you would like to make?

## **Appendix 2 – Information sheet**

### **An investigation of the meaning and experience of stroke in young adults**

#### **Introduction**

You are being invited to take part in a research study entitled ‘An investigation of the meaning and experience of stroke in young adults’. About 10,000 strokes occur in Ireland every year about 1/5 of which occur in younger patients. This study aims to help inform stroke services of the needs and experiences of younger patients with stroke and assist in national planning and development of stroke services to specifically include younger patients.

The study is being supervised by Dr. Rónán Collins, Director of Stroke Service and Consultant Physician in Older Adult & Stroke Medicine at the Adelaide & Meath Hospital incorporating the National Children’s Hospital and Dr. Deirdre Desmond, Department of Psychology at the National University of Ireland Maynooth.

Before you decide to take part or not, 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. If you would like more information or would like to ask any questions, please contact Dr Rónán Collins at the Adelaide & Meath hospital Tallaght on 01-4144724.

The aim of this research is to investigate the meaning and experience of stroke amongst young adults (ages 18 to 45 years) and to identify areas where additional supports may be beneficial. There has been very little research in this area in Ireland. Participation in the study will involve taking part in a one-to-one interview. The

interview which will take approximately one hour will take place in private in the Adelaide & Meath hospital Tallaght (or at your home if more convenient). The interview will be tape recorded but will not contain any identifying information and will be treated in strictest confidence (as a medical record) at all times.

### **Procedures**

Individuals aged between 18 and 45 years who experienced stroke at least 6 months ago are eligible to participate. You will take part in an interview which will take about one hour. This interview will be audio-taped. You will be asked about your thoughts and feelings about your stroke and your experiences during and after rehabilitation. You will also have the opportunity to give some suggestions on what would help other young people who experience stroke.

### **Benefits**

There are no direct benefits from taking part in this study.

### **Risks**

Talking about your experience of stroke may lead you to memories that could be distressing. If you feel uncomfortable or distressed at any stage, you can withdraw immediately from the study. You can also contact Dr Rónán Collins, Age-Related Health care / stroke-service at AMNCH who will be happy to review matters with you and arrange any further support that you may need.

### **Confidentiality**

If you agree to take part your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the research team. Tapes of the interview discussions will be destroyed when the study is completed.

### **Voluntary participation**

You have volunteered to take part in this study. 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 Adelaide & Meath Hospital, Tallaght and the Ethics Committee of the National University of Ireland Maynooth. Participation in this study is covered by an approved policy of insurance in the name of AMNCH. In addition the medical practitioners involved in this study have current medical malpractice insurance cover. The sponsor will comply with the ABPI guidelines and Irish Law (statutory and otherwise) in the unlikely event of your becoming ill or injured as a result of participation in this clinical study.”

### **Further information**

You can get more information or answers to your questions about the study, your participation in the study and your rights, from Dr Rónán Collins, Director of Stroke Services Adelaide & Meath Hospital, Tallaght who can be telephoned at 01-4144724.

Many thanks for taking the time to consider this proposal. We hope that by learning from your experiences we will be better able to benefit other patients with stroke.

Best wishes,

Dr. Rónán Collins MD MRCP(UK)

Dr. Deirdre Desmond PhD

## Appendix 3 – Consent form

### National University of Ireland Maynooth Consent Form

**Title:** An investigation of the meaning and experience of stroke in young adults.

This study is being carried out by Ms. Dorothy Leahy, a postgraduate student, under the supervision of Dr Deirdre Desmond, Department of Psychology, National University of Ireland, Maynooth and Dr. Rónán Collins, Director of the Stroke Service, Adelaide and Meath Hospital Tallaght.

**Purpose of the research:** The aim of the research is to explore young patients' experiences of stroke, rehabilitation and life after stroke. Participation in the research involves taking part in a one-to-one interview, lasting approximately one hour. The interview does not constitute any kind of counselling or medical treatment. **The interviews will be audio recorded and transcribed.** During the interview you will be asked to describe your own personal experience of stroke. The interview will cover three broad areas: (1) the stroke onset and its immediate impact, (2) experiences while in hospital and during rehabilitation, and (3) experiences after hospital discharge.

Participation in the study is voluntary. **You are under no obligation to participate and if you feel unable to participate it will not affect your ongoing care.** You may also withdraw from the study at any time. If you agree to take part, all information collected will be kept confidential within the limitations of the law.

All data will be stored securely in the Department of Psychology at the National University of Ireland, Maynooth. All information that will identify you in any way will be removed to protect confidentiality. Tapes of the interviews will be destroyed when the study is finished.

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process please contact the Secretary of the National University of Ireland Maynooth Ethics Committee at [pgdean@nuim.ie](mailto:pgdean@nuim.ie) of 01 708 6018. Please be assured that your concerns will be dealt with in a sensitive manner.

**I have read all of the above information. I understand that my participation is voluntary and that I am free to withdraw without disadvantage. I understand that my name will not be identified in any use of these records. I am voluntarily agreeing that the data collected may be studied by the research team for use in the research project and used in scientific publications.**

Name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_/\_\_\_\_/\_\_\_\_

## Appendix 4 – Contact sheet

### **Contact details:**

Dr. Deirdre Desmond,

Lecturer, Department of Psychology,

National University of Ireland, Maynooth,

Maynooth, Co. Kildare.

Telephone: (01) 708 6479; E-mail: [Deirdre.Desmond@nuim.ie](mailto:Deirdre.Desmond@nuim.ie)

Ms. Dorothy Leahy,

Postgraduate research student,

Department of Psychology,

National University of Ireland, Maynooth,

Maynooth, Co. Kildare.

Telephone: (087) 6209343.

If you experience any kind of discomfort or distress as a result of participation in the study please contact:

Dr. Rónán Collins,

Director of Stroke Service,

Adelaide and Meath Hospital Tallaght.

Telephone: (01) 414 4724



**Appendix 5 – Letter of ethical approval from the Adelaide and Meath Hospital**

**Tallaght.**

THIS NOTEPAPER MUST NOT BE USED FOR  
PRESCRIPTIONS OR INVOICING PURPOSES

Dan Lynch Ph: 4142860 email: [Dan.Lynch@amnch.ie](mailto:Dan.Lynch@amnch.ie)  
Ursula Ryan Ph: 4142342 email: [Ursula.Ryan@amnch.ie](mailto:Ursula.Ryan@amnch.ie)  
Secretariat Fax 4142371



**SJH/AMNCH**  
**Research Ethics Committee**  
**THE ADELAIDE & MEATH**  
**HOSPITAL, DUBLIN**  
INCORPORATING  
THE NATIONAL CHILDREN'S HOSPITAL

TALLAGHT, DUBLIN 24, IRELAND  
TELEPHONE +353 1 4142000

Dr. Rónán Collins, M. D.,  
Consultant Physician in Older Adult and Stroke Medicine,  
Adelaide & Meath Hospital, Dublin,  
incorporating the National Children's Hospital,  
Tallaght, Dublin 24.

6 February 2009

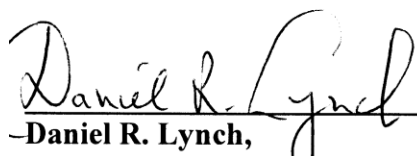
*Please quote this reference in any follow up to this letter: 2009/02/01 Chairman's Action*

**Re: Research proposal "An investigation of the meaning and experience of stroke in young adults".**

Dear Dr. Collins,

Thank you for your recent submission of the above proposal to the SJH/AMNCH Research Ethics Committee. The Chairman has given ethical approval to this proposal on behalf of the Committee.

Yours sincerely,

  
—Daniel R. Lynch,

**Appendix 6 – Letter of ethical approval from the National University of Ireland**

**Maynooth.**

NATIONAL UNIVERSITY OF IRELAND, MAYNOOTH  
MAYNOOTH, CO. KILDARE, IRELAND



NUI MAYNOOTH  
Ollscoil na hÉireann Má Nuad

Dr Carol Barrett  
Secretary to NUI Maynooth Ethics Committee

Ms. Dorothy Leahy,  
Department of Psychology,  
NUI Maynooth

27 February 2009

RE: Application for Ethical Approval for a project entitled:  
***An investigation of the meaning and experience of stroke in young adults.***

Dear Dorothy,

The Ethics Committee evaluated the above project for ethical approval and we would like to inform you that ethical approval has been granted.

Kind Regards,

Dr Carol Barrett  
Secretary to NUI Maynooth Ethics Committee

cc. Dr Deirdre Desmond