

The experience of mild stroke among young adults
and their spouses: an interpretative
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.

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Abstract

The aim of this research was to explore the experience and consequences of stroke amongst young adults and their spouses through semi-structured interviews and qualitative analysis. Individuals who were aged between 18 and 50 years, who had experienced a mild stroke and who were at least three months post-stroke, were eligible for inclusion. Individuals with persistent communication impairment, which would result in difficulties in taking part in an interview, were excluded. Patient participants acted as gatekeepers to the recruitment of their spouses. Fifteen individuals participated in the study, eleven patients and four spouses. Accounts of participants' experiences were transcribed and analysed using Interpretative Phenomenological Analysis. Four super-ordinate themes emerged from patient accounts: (1) sudden and unexplained: will it happen again?; (2) changes in daily life; (3) trying to get better; and (4) relationship changes. Accounts from the spousal participants are encapsulated in the super-ordinate theme: loss and change. Findings demonstrate the ongoing difficulties experienced and negative impact stroke has on young adults and their partners. Ongoing cognitive impairments were a major barrier to carrying out daily activities, suggesting a need for greater recognition of such impairments among rehabilitation staff. Greater support is also required for spouses of young adults with stroke. Despite persistent difficulties, positive consequences of stroke were reported both by those directly affected and their spouses. Relationships were changed both positively and negatively following stroke. Insights gained in the current research contribute to a richer and more balanced understanding of the implications of stroke for young couples.

Introduction

A stroke is a sudden and traumatic event that that can have long-lasting physical, emotional and social consequences. Stroke has been described as a ‘family dilemma’ as the condition can also result in alterations to the lives of those surrounding the survivor (Evans, Connis, Bishop, Hendricks, & Haselkorn, 1994). While stroke most commonly affects older individuals, estimates suggest that one-fifth of all strokes world-wide occur in individuals under 65 years of age (Teasell, McRae, & Finestone, 2000) and recent trends indicate that stroke among adults of working age is increasing (Pessah-Rasmussen, Engstrom, Jerntorp, & Janzon, 2003). There are substantial differences between younger and older stroke patients in terms of etiology, prognostic factors, the extent of functional recovery and comorbidities but also in terms of a variety of issues that are not as salient to older people, for example difficulty in returning to work, loss of employment and related financial difficulties, marital difficulties and responsibility for family activities such as raising young children and/or caring for older family members (Kersten, Low, Ashburn, George, & McLellan, 2002; Stone, 2005; Teasell et al., 2000; Vestling, Ramel, & Iwarsson, 2005). Yet while 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 et al., 2006; Putaala et al., 2009) much less is known about the subjective experience and meaning of stroke for these individual patients or for their spouse/partners (Stone, 2005; Buschenfeld, Morris, & Lockwood, 2009), and there is little evidence regarding the evolving impacts and consequences of stroke for the young adult, in either the short or longer terms (Leahy, 2010).

The literature review that follows will outline research relating to the physical, cognitive and psychosocial challenges associated with stroke. While younger stroke survivors are the central focus of the current research, studies examining older samples will also be reviewed, as some experiences of older and younger stroke patients overlap. However, important differences exist between the groups and areas that are of particular significance to younger stroke survivors will be highlighted. Literature relating to spouses of stroke survivors will be treated in a similar manner. It is important to note that the term 'young' is used to define a variety of age categories in the stroke literature. Throughout the literature review a young stroke patient will be considered to be someone aged between 18 to 65 years, reflecting the typical ages of adulthood and age of retirement, respectively. The review will begin by examining the different types of stroke and its physical impact, followed by consideration of the psychological consequences of stroke for younger people and their spouses. This section concludes with the rationale for the current study.

1.1 Stroke symptoms, types and risk factors

Stroke is characterised by a sudden deterioration of brain functioning leading to impairments which commonly include difficulty in language production and/or comprehension, problems with skilled movement, visuospatial problems and memory impairment (Lincoln, Kneebone, Macniven, & Morris, 2012). There are two main types of stroke; ischemic infarction and intracerebral haemorrhage (Lincoln et al., 2012). An ischaemic stroke occurs when there is a loss of blood supply to the brain. A haemorrhage occurs in the brain when a blood vessel or malformation ruptures causing bleeding (McDowell, 1998). Although hemorrhagic strokes occur more frequently in younger stroke patients than older adults (Rasura et al., 2006), the majority of strokes in

younger adults are ischaemic, accounting for 47% to 85% of diagnoses (Awada, 1994; Meyer, Orenea, & Biller, 1994; Groppo, De Gennaro, Granieri, Fazio, & Cesnik, 2012). The cause of stroke can be more difficult to establish in younger adults where usual risk factors are often absent. Young stroke patients therefore have a higher probability of receiving a diagnosis of *stroke with unknown causes* than older patients (Guercini, Acciarresi, & Paciaroni, 2008).

While more usual risk factors for stroke such as atrial fibrillation (an irregular heart rhythm), atherosclerosis (progressive occlusion of blood vessels due to accumulation of lipid plaques and endothelial damage) or ischaemic heart disease are usually age-related, a number of risk factors for stroke may be of particular relevance to younger adults including hypertension (high blood pressure) (Putala et al., 2009), smoking (Lu, Ye, Adami, & Weiderpass, 2008; Rasura, et al., 2006), alcohol and illicit drug use (Bruno, 2003), migraine (Malm, Kristensen, Carlberg, Fagerlund, & Olsson, 1999) and diabetes (Chen, Lee, & Li, 2009). Smoking is a greater risk factor for younger people when compared with older adults (Fromm, Waje-Andreassen, Thomassen, & Naess, 2011). A number of studies have found that risk of stroke was reduced in participants who consumed 1-2 alcoholic beverages per day, but risk increased with excessive drinking leading to increased blood pressure (Bruno, 2003; Lu et al., 2008). Oral contraception is suggested to be a risk factor for young women (Hillbom et al., 1995); however research in this area is conflicting (Petitti, Sidney, Quesenberry, & Bernstein, 1996; Rasura et al., 2006).

1.2 Incidence

Although stroke is most common in the elderly (>65 years), a significant number of young adults suffer from stroke (Ellis, 2010). Estimates suggest that one-fifth of all

strokes world-wide occur in individuals under 65 years of age (Teasell et al., 2000) and recent trends indicate that stroke among adults of working age is increasing (George, Tong, Kuklina, & Labarthe, 2011). Generally, stroke has a higher incidence rate in young men than in young women (Petrea et al., 2009; Vega et al., 2009; Putaala et al., 2009; Medin, Nordlund, & Ekberg, 2004; Naess, Thomassen, Aarseth, & Myhr, 2004). However, females under the age of thirty tend to outnumber males of the same age, with the pattern reversing following this age (Spengos & Vemmos, 2010; Rozenthul-Sorokin, Revital, Tamir, Geva, & Reuben, 1996). Younger stroke survivors tend to live longer than older people who have had a stroke and therefore prevalence rates have been estimated at 25% of stroke survivors who are living in the community under the age of 65 (Kersten et al., 2002).

1.3 Stroke Outcomes

Impairments following stroke are varied and depend on the type and location of the stroke event. Stroke severity is typically established by assessing the patient's basic functional ability and their capacity to perform personal activities of daily living (Nedeltchev et al., 2005; Leys et al., 2002). A mild stroke is generally defined as "no-or-slight motor impairment or a high level of independence in personal activities of daily living" (Carlsson, Möller, & Blomstrand, 2004, p.1373). Although patients with mild stroke usually achieve functional independence, they may still encounter difficulties with post-stroke fatigue, cognitive impairments and emotional regulation (Green & King, 2010). A patient with moderate stroke generally experiences mild paresis and is functionally dependent at discharge (Langhorne, Wagenaar, & Partridge, 1996). A patient with severe stroke is usually unconscious at stroke onset, unilateral or bilateral paresis is a common and unremitting functional outcome.

Post-stroke fatigue, a state characterised by tiredness that, unlike normal fatigue, is unrelated to previous exertion levels and is generally not improved by rest (De Groot, Phillips, & Eskes, 2003), is a persistent, long-term problem following stroke (White, Magin, Attia, Sturm, & Carter, 2012) and has been shown to increase over time (Schepers, Visser-Meily, Ketelaar, & Lindeman, 2006). Estimates of post-stroke fatigue range from 16% (Glader, Stegmayr, & Asplund, 2002) to 70% (Carlsson et al., 2004) depending on the methodology used (McGeough et al., 2009). Kikevold, Christensen, Andersen, Johansen and Harder (2012) reported 57% of a young stroke sample (n = 83, mean age = 53.8) were suffering from fatigue at a two year follow-up. Post-stroke fatigue has been associated with unfavourable functional outcomes and depression among young patients (Naess, Nyland, Thomassen, Aarseth, & Myhr, 2005). The impact of fatigue is further highlighted in a qualitative study by Rödning, Lindström, Malm and Öhman (2003) in which five young people (age range = 37-54) who had experienced a stroke were interviewed. Fatigue was identified as overwhelming and uncontrollable and had an impact on many aspects of their lives, including their family, social life, sexuality and ability to work full time.

Cognitive impairments commonly occurring after stroke include language difficulties (aphasia or expressive/receptive dysphasia), visuospatial inattention or agnosia, memory and attention difficulties and deficits in executive functioning, such as planning and problem solving abilities and decision making skills (Lincoln et al., 2012). Cognitive impairments may disrupt an individual's ability to carry out daily tasks and social activities (Cao, Ferrari, Patella, Marra, & Rasura, 2007). Findings from qualitative studies suggest that residual cognitive impairments are a source of deep frustration in young adult stroke survivors (Rödning et al., 2003). Stone (2005) termed

subtle persistent cognitive impairments as *invisible disabilities*, as although they may not reach the criteria for clinical diagnosis, they still have a profoundly negative impact on the lives of young stroke survivors.

Stroke can also affect emotional regulation, problems may include post-stroke depression (PSD), anxiety, emotional lability and anger or aggression (Lincoln et al., 2012). Post-stroke depression is the most widely studied emotional outcome, affecting approximately one-third of all stroke patients (Poynter et al., 2009). The incidence of PSD in young stroke patients ranges from 11% to 55% (Srivastava, Taly, Gupta, & Murali, 2010; Hindfelt & Nilsson, 1992; Kapelle et al., 1994; Neau et al., 1998; Cassidy, O'Connor, & O'Keane, 2004; Naess et al., 2005).

Rehabilitation of young stroke survivors traditionally adheres to the same process as older patients (Teasell et al., 2000), with a combination of physiotherapy, speech and language therapy, occupational therapy and pharmacological therapy (Stein, 2004; Teasell, Foley, Bhogal, & Speechley, 2003). O'Connor and colleagues (2005) suggested that the major difference between younger and older patients of stroke is that, on average, younger patients will have longer to live with residual impairments. Without appropriate rehabilitation, longstanding residual impairments can result in both personal, financial and emotional burden for the stroke survivor and higher dependency costs for health services (O'Connor, Beden, Pilling, & Chamberlain, 2011).

1.4 Return to Work

For young adults, successful return to work (RTW) is often considered a proxy indicator of rehabilitation outcome (Daniel, Wolfe, Busch, & McKevitt, 2009). RTW after stroke can enhance both functional recovery and personal life satisfaction by strengthening self-esteem, confidence and social identity (Wolfenden & Grace, 2009).

RTW is regarded as one of the most important outcome factors for working-age people, who have experienced a stroke, amongst healthcare professionals and patients alike (Hannerz, Pedersen, Poulsen, Humle, & Andersen, 2010; Treger, Shames, Giaquinto, & Ring, 2007; Vestling, Ramel, & Iwarsson, 2005).

Successful RTW rates are difficult to establish as studies have used different methodologies and diverse follow-up periods. However, recent analyses suggest that between 19% and 82% of stroke patients return to work following a stroke (Treger et al., 2007; Vestling et al., 2005; Lindstrom, Roding, & Sundelin, 2009). Most people who return to work do so in the first three to six months following stroke; however there is also evidence for a second peak at twelve to eighteen months (Daniel et al., 2009). Of those who do return to work, some have to alter their work practice in order to accommodate residual impairments (Varona, Guerra, Bermejo, Molina, & de la Gomez, 2007; Neau, et al., 1998).

Physical factors found to influence successful RTW include absence of language impairment (Black-Schaffer & Osberg, 1990), shorter rehabilitation stay (Saeki, 2000) and higher physical functioning on discharge (Gabriele & Renate, 2009; Vestling et al., 2005). Patients with higher levels of education are more likely to return to paid employment than those with lower educational status (Black-Schaffer & Lemieux, 1994). Numerous studies have found when a person returns to work following a stroke, they experience difficulties, even where there is no obvious disability (Alaszewski, Alaszewski, Potter, & Penhale, 2007; Glozier, Maree, Hackett, Parag, & Anderson, 2008; Teasdale & Engberg, 2005). Difficulties encountered include impaired organisational skills (O'Brein & Wolf, 2010), problems with maintaining concentration (Treger et al., 2007), memory problems (Vestling, Ramel, & Iwarsson, 2005), fatigue

(Choi-Kwon, Han, Kwon, & Kim, 2005) and inability to meet the physical requirements of the work (Hsieh & Lee, 1997).

Qualitative studies offer nuanced understanding of the complexities of RTW following stroke (e.g. Alaszewski et al., 2007; Medin, Barajas, & Ekberg, 2006; Koch, Egbert, Coeling, & Ayers, 2005). Lock, Jordan, Bryanc and Maxima (2005) held focus groups with 37 stroke survivors and 12 carers in order to explore the individual experience of supportive structures and barriers in RTW following stroke. Fifty two per cent of participants had returned to work (including voluntary work). Four themes emerged from the focus group discussions: (1) the rehabilitation process; (2) employer agency; (3) social and structural factors; and (4) personal factors. Stroke patients reported that the rehabilitation process was time limited and not orientated towards employment. Sick leave arrangements were looked upon as favourable by the group however employer inflexibility and ignorance about stroke and its effects were seen as barriers. Fatigue was a major personal factor in returning to work. Koch et al. (2005) identified similar themes in their analyses of the work related experiences of stroke survivors and their primary care givers. Participants attributed successful RTW to personal characteristics, resources located in families and social networks, healthcare services, and attributes of the employment itself. Using a grounded theory approach, Hartke, Trierweiler and Bode (2011) identified the 'critical factors' influencing successful return to work among twelve stroke survivors (mean age=51). Factors included financial pressure, physical impairments, interpersonal support, social welfare support and specific issues relating to work practice. Psychological issues including motivation, coping strategies and adjustment were also central to successful RTW.

1.5 Quality of Life

In the last ten years, numerous investigations of Quality of Life (QoL) in stroke patients have been published. For the most part, the published literature reflects the greater incidence of stroke in older adults; samples typically have an average age of at least 65 years (e.g. Algurén, Fridlund, Cieza, Sunnerhagen, & Christensson, 2011; Haley, Roth, Kissela, Perkins, & Howard, 2011; Hopman & Verner, 2003). Nonetheless, a relatively small number of studies have been published that specifically focus on younger adult samples. Previous research has shown that older adults with stroke tend to have lower QoL than younger adults (Kozielec, Rotter, & Karakiewicz, 2005; Madden, Hopman, Bagg, Verner & Callaghan, 2006). Using age and sex matched controls, Naess et al. (2006) studied QoL among people (n= 190; mean age = 47.8 years), who were on average of 6 years post-stroke. Patients had significantly lower scores on the Short Form Health Survey (SF-36; Ware & Shelbourne, 1992) in the domains of *physical functioning*, *role limitations due to physical health*, and *social functioning* compared to controls and compared to published norms. Using the Assessment of Life Satisfaction (LiSat-9; Fugl-Meyer, Bränholm, & Fugl-Meyer, 1991) with a sample of 1068 stroke patients (mean age = 49 years), Röding et al. (2010) found that the majority (53%) reported they were *not satisfied with life as a whole*. Rehabilitation has been shown to increase QoL after stroke. O'Connor et al. (2005) assessed the impact of late (mean time elapsed since stroke = 112 days) multidisciplinary rehabilitation in 50 consecutive patients under the age of 65. Participants completed the SF-36 during the second week of rehabilitation admission (baseline) and again during the week of discharge (median length of stay = 70 days). At baseline scores in all SF-36 domains with the exception of *role emotional* were significantly below age-match population norms; greatest decrements were evident in

the *role physical*, *physical function* and *social function* domains. At discharge, patient scores were within normative values for *bodily pain*, *general health*, and *mental health*; from baseline to discharge significant improvements were evidenced in *physical function*, *role physical* and *mental health* domains.

Additional factors that impact QoL include successful return to work, maintenance of family and social roles, participation in daily activities and the strength of relationship with ones partner (Röding et al., 2010; Gabriele & Renate, 2009; Kim et al. 2005; Vestling et al., 2005; Teasell et al., 2000).

1.6 Adjustment following Stroke

Adjustment is a “process of adaptation to disability” (Lincoln et al., 2012, p.296). Adjustment to stroke has been described as a four-stage process (Holbrook, 1982; Kirkevold, 2002). The initial stage is characterised by shock and suspense, and occurs when the patient has been hospitalised with a diagnosis of stroke. In this stage, the patient plays an almost passive role, and defers responsibility for their well-being to health care professionals and their family. Qualitative research supports this, showing that the patient often only has a partial memory of this stage, often relying on accounts of family members when describing the event (Eilersten, Kirkevold, & Bjørk, 2010). This is followed by an active rehabilitation phase, where the patient works to regain functional ability, usually under the guidance of health care professionals. During this stage, which lasts for approximately 8 weeks following the stroke event, expectations are typically high in terms of recovery outcome (Kirkevold, 2002). Emotional expression can be limited during this stage as the patient focuses on task-orientated, practical recovery (Buschenfeld et al., 2009). The third stage is marked by returning home from hospital. At this stage, rehabilitation is seen as the responsibility of the

patient and their family rather than the health care professionals. This stage can be characterised by negative emotional reactions including anger, frustration, depression and a sense of loss as the patient comes to realise that they may not fully recover (Green & King, 2009). The sense of loss has been shown to be related to a reduction in control (Becker, 1993), confidence (Burton, 2000) and independence (Rochette, Tribble, Desrosiers, Bravo, & Bourget, 2006). The final stage, adjustment, typically occurs 6 months following stroke when the patient may come to accept the reality of their situation in terms of recovery and their new self-concept. Adjustment to stroke has been likened to the bereavement model as both involve a loss and psychological adjustment to a new status and situation (Alaszewski, Alaszewski, & Potter, 2004).

Recently, a new model of emotional adjustment following stroke has been proposed. Unlike previous 'stage' model processes, the 'Social Cognitive Transition model for Stroke' (SCoTS) suggests a dynamic process that may result in a variety of outcomes for patients following a stroke (Taylor, Todman, & Broomfield, 2011). Adapted from a model developed for patients with cancer (Brennan, 2001), the SCoTS is stroke specific and describes a process by where a patient is challenged on their assumptive world (their beliefs, mental models, assumptions) following stroke. The model distinguishes between intra- and inter-personal responses. Intra-personal responses represent various cognitive and emotional reactions a patient may have in response to challenges their assumptive world following stroke. Inter-personal responses demonstrate the impact a stroke may have on a person's social self. Unlike the bereavement-based models, the SCoTS is dynamic and cyclical and acknowledges the unpredictable responses that occur in people who have experienced a stroke (Taylor, Todman, & Broomfield, 2011). Factors found to negatively influence adjustment in

young adults after stroke include the presence of depression (Hackett, Yapa, Parag, & Anderson, 2005), reduced life satisfaction (Röding et al., 2010) and disruption of self-identity (Teasell et al., 2000).

1.7 Self Identity

Adopting a phenomenological and hermeneutic view on self-identity, the self may be viewed as three interacting constructs; the mind, the body and the environment (Zahavi, 2005). A stroke can cause disruptions to all three of these domains; cognitive impairment and emotional distress and physical impairment may transform an individual's sense of self and how they interact with their own surroundings (Kitzmüller, Häggström, & Asplund, 2012). In a review of the qualitative literature (including samples of older adults and mixed age samples), Salter, Hellings, Foley and Teasell (2008) highlight the complex and dynamic process of reappraisal that many individuals undergo after stroke. They note that re-establishment of a coherent sense of self is hindered by discrepancies between pre- and post-stroke selves. These discrepancies are often characterised by loss; loss of physical and cognitive ability, loss of activities and participation, and loss of social contact.

Stroke may be viewed as a traumatic event (Carlsson, Möller, & Blomstrand, 2009). Because of its sudden onset and the potential threat to life it represents, stroke may disrupt and undermine an individual's life trajectory and future plans may become doubtful and unpredictable (Corbin & Strauss, 1987). Faircloth, Boylstein, Rittman and Young (2004) suggest a distinction between the perceived disruption a stroke has on younger and older adults. While older adults may view their stroke as "part of an ongoing life story", younger adults may perceive it as "an invader of everyday life" (Faircloth et al., p244). Age is therefore an important factor in considering the impact

stroke has on self-identity. Morris (2011, p.7) suggests that young adults who experience a stroke have “different psychological needs as the effects of stroke engender feelings of being ‘different’ and isolated from their young peers and ‘changed’ from their former selves”.

Qualitative studies suggest that younger patients view stroke as a sudden and overwhelming disaster (Lynch et al., 2008) causing deep disruption to their lives (Banks & Pearson, 2004) and those around them (Buschenfeld, Morris, & Lockwood, 2009). In a longitudinal, qualitative study, Erikson, Park and Tham (2010) found that young stroke survivors (n = 9, age range = 42 - 61 years) drew a clear distinction between their pre-stroke (able-bodied and independent) and post-stroke (cognitively impaired, burdensome) selves and experienced challenges in regaining their sense of self after stroke. Participants relied on interaction with others, through rehabilitation and social supports, in order to adjust to the reality of their “new world” (Erikson et al., 2010, p.835).

Although the vast majority of research focuses on the negative impact of stroke, recent studies have sought to investigate potential positive outcomes (e.g Bright, Kayes, McCann, & McPhearson, 2011; Gangstad, Norman, & Barton, 2009; Gillen, 2005). In a study of older adults (mean age = 72.9), Seale and colleagues (2010) found that positive emotion either increased (35.6%) or remained unchanged (35.2%) after a stroke. Gillen (2005) reported that 63% of respondents (mean age=61) were able to identify positive consequences attributable to surviving a stroke. Positive consequences identified included: closer bonds in intimate relationships; higher awareness of personal health and health behaviours; increased spirituality; personal growth; and altruism. Other qualitative studies have found similar results (Erikson et al., 2010; Röding et al., 2003).

1.8 Impact on Relationships

The traumatic nature of stroke and its potential for long lasting cognitive and emotional consequences may impact stroke survivors' relationship with their spouse or partner. Stroke survivors and their spouses/partners experience role changes, loss of social participation and an altered view of their self-identity (Mumma, 2000), which can influence relationship dynamics (Thompson & Ryan, 2009; Kitzmüller et al., 2012).

Relationship strain following stroke has been documented. For example, in a chart review of 83 consecutive patients under the age of 50 years at time of stroke, Teasell et al. (2000) found that of the 55 patients with spouses, 8 (14.5%) had separated within 3 months of discharge. Of these patients, notes made by health care professionals suggest that the marriages were problematic before the stroke, with the added stress of the stroke acting as a catalyst for the separation. Rochette et al. (2007) assessed adaptation processes and participation over a period of six months and found that perceived threat and stress decreased for both stroke survivors ($n = 88$, mean age = 71.8) and their spouses ($n = 47$, mean age = 69.2). However, they also found that positive appraisal of their situation decreased over time, which they suggested was due to a slower rate of recovery than both the stroke survivor and their spouse had expected.

Qualitative studies provide a deeper understanding of relationship dynamics following a stroke. Banks and Pearson (2004) interviewed young stroke survivors ($n = 38$, mean age = 44) and their spouse or long-term partner and found that most respondents reported negative changes in their relationships. Spouses/partners reported that the discharge period marked the beginning of heightened responsibility in terms of caring duties and associated increases in anxiety. The authors suggest that both the young stroke survivor and their spouse/partner go on similar but separate journeys or "careers" following a stroke. These "careers" begin in hospital during the initial crisis.

What follows is treatment and realisation, the patient receives rehabilitation and the spouse/partner copes with the crisis by managing hospital visits, work and family life. The final stage of the “career” for both is adjustment. The research concluded that although both members of the relationship were frequently worried about the same issues, lack of communication contributed to tension and confusion amongst them (Banks & Pearson, 2004).

1.9 The experience of spouses of stroke survivors

There has been growing interest in the role of caregivers of stroke survivors, however research has mainly focused on older carers (Morimoto, Schreiner, & Asano, 2003; Bakas & Burgener, 2002). Spousal caregivers of stroke survivors have unique characteristics, as unlike other carers, there is usually no period of transition. Young stroke survivors are more likely to have a living spouse who generally becomes their primary caregiver (Lincoln et al., 2012). Spousal caregivers enter their new role rapidly, usually without the opportunity to adjust to the change and learn the new skills required (Draper & Brocklehurst, 2007). This may lead to feelings of uncertainty and apprehension (Brereton & Nolan, 2000). Young stroke survivors generally return home following acute hospitalisation, only a small percentage of patients require long-term care (Teasell et al., 2000). In general, younger patients achieve greater functional recovery than older patients (Nedeltchev, et al., 2005) who are more likely to be discharged to nursing care home following stroke (Black-Schaffer & Winston, 2004). Spouses and long-term partners must often make significant adjustments to their lives in order to facilitate the needs and possible residual disabilities of young stroke survivors (Visser-Meily et al., 2005). Although younger stroke survivors tend to have better

functional outcomes, they also tend to have longer to live with a residual disability (O'Connor et al., 2005).

Age appears to impact on the experiences and well being of carers of stroke survivors. In a review of the literature Greenwood, Mackenzie, Cloud and Wilson, (2008) concluded that younger carers of stroke survivors experience lower psychological well-being, higher strain and higher risk of burnout than older caregivers. Spouses have been found to have lower life satisfaction than stroke survivors (Achten, Visser-Meily, Post, & Schepers, 2012). Low life satisfaction among spousal caregivers has been related to stroke survivor's activities of daily living (Visser-Meily et al., 2006), patient's cognitive, emotional and functional problems (Forsberg-Wärleby, Möller, & Blomstrand, 2004) and difficulties in the relationship (Ostwald, Godwin, & Cron, 2009).

Using interpretative phenomenological analysis (IPA) Buschenfeld et al (2009) studied the experience of seven spouses/partners of young stroke survivors. They found that the consequences of stroke were pervasive and impacted on many facets of the partner's life including home life, employment, social life and their new life as caregiver. The authors suggest that when stroke occurs within a relationship, the spouse/partner takes on a supporting role, the needs of the stroke survivor are viewed as the priority, with the psychological needs of the caregiver secondary. However, the findings also revealed that some partners reappraised their life situation, implemented positive coping mechanisms, and reached a stage of re-adjustment and acceptance of new life realities.

Although emphasis has predominantly focused on negative aspects of care giving following stroke, recent studies have highlighted important positive experiences that have been reported by caregivers. In a recent review, Mackenzie and Greenwood

(2012) found caregivers frequently reported improvements in the stroke survivor's condition as a positive and rewarding outcome (White et al., 2007), along with strengthening of relationships (Greenwood, Mackenzie, Wilson, & Cloud, 2009), and increased appreciation for life (Haley et al., 2009).

1.10 Rationale for current study

Stroke among young adults is relatively rare. There are significant differences between younger and older stroke survivors in terms of etiology, prognosis and the extent of functional recovery. Younger adults who experience strokes are also more likely than older adults to live longer with stroke-related impairments (Ellis, 2010). Although recovery after stroke is generally good for young adults, stroke in young adults is considered a “personal catastrophe” that can have far reaching consequences (Thompson & Ryan, 2009, p.1803). Difficulties include living with residual impairments, returning to employment, caring for dependent children and negative effects on interpersonal relationships. For these reasons research based on the stroke experiences of older adults may not be applicable to young stroke survivors.

Research highlights gaps in stroke care for young adults and patient dissatisfaction (Röding et al., 2003; Banks & Pearson, 2004; Stone, 2005). The first Irish National Audit of Stroke Care (INASC) highlighted substantial deficits in primary and secondary prevention, hospital treatment, rehabilitation and other services (Smith et al., 2012). The audit found that only five hospitals routinely admitted patients under the age of 65; day services and community stroke services for younger adults are underdeveloped and that limited entitlements to rehabilitation and home care can result in inappropriate long-term nursing home placement for severely affected young adults (Horgan, Hickey, McGee, & O'Neill, 2008).

Research concerning young adults and stroke has tended to focus on medical outcomes such as etiology, incidence rates and neurological and functional recovery. The available qualitative research highlights themes of loss, fear, changes in self-identity, adaptation and changes in relationship dynamics (Jones & Morris, 2012; Alaszewski et al., 2007; Bendz, 2003; Röding et al., 2003). Available research relating to spouses of young adult stroke survivors highlights similar themes, in addition to themes such as caregiver burden and relationship strain (Buschenfeld et al., 2009; Banks & Pearson, 2004; Hunt & Smith, 2004). By adopting a qualitative approach this research aims to provide a thick or rich interpretative account of the experience of young stroke patient and their spouses and to improve understanding of the different ways in which stroke can impact on the lives of both the person affected and their partner.

Method

2.1 Aims and Objectives

The aim of the current study was to explore the experience and psychosocial consequences of stroke amongst young adults and the impact it has on spouses of stroke survivors. Data was generated via semi-structured interviews and analysed using the qualitative method of Interpretative Qualitative Analysis (IPA, Smith, 2004).

The main objectives were to:

- Explore the subjective accounts of young adults' experiences of stroke, with particular regard to self-identity, emotional experience and the impact of stroke on spousal and partner relationships.
- Explore the subjective accounts of spouses of stroke survivors and the impact stroke had on their lives and relationship dynamics.

2.2 Design

Interpretative Phenomenological Analysis (IPA) is phenomenological and idiographic and its purpose is to examine, as far as possible, the feelings and experience of an individual, usually relating to a major life event (Smith, Flowers, & Larkin, 2009; Murray & Harrison, 2004; Hunt & Smith, 2004). Three philosophical principles underline the study of IPA: phenomenology, hermeneutics and idiography. These principles are theorised by the philosophers Husserl, Heidegger, Merleau-Ponty and Sartre.

Phenomenology is the study of experience. It can be seen to have two distinct phases. Transcendental phenomenology, as proposed by Husserl, suggests that we should reduce our understanding of experience to its core. Husserl recognised that

phenomenology involves the careful examination of human experience and argued that one must 'go back to the things themselves' (Zu den Sachen), the 'things' in this instance being the experiential content of consciousness (Smith et al., 2009). Husserl suggested that one must remove oneself from their natural attitude, their everyday experience, and instead adopt a 'phenomenological attitude'. To achieve this, Husserl developed a 'phenomenological method'. He suggested that one ought to 'bracket' off the objective world in order to concentrate on an individual's 'perception' of that world. For Husserl, this meant that human experience, in order to be examined, ought to be reduced down to individual psychological processes, such as perception, awareness and consciousness, a process he named 'transcendental reduction'.

In a move away from transcendental phenomenology, Heidegger, Husserl's student, suggested that it was impossible to bracket 'normal life' and questioned the possibility of any knowledge outside of an interpretative stance. Heidegger proposed that a human being is a "Dasein" which literally means "being there" but is more often referred to as "being-in-the-world" (Spinelli, 1989, p. 108). Heidegger suggested that a person is always a 'person-in-context' and to examine another person's experience, one would always have to consider their own context. The question remains, however, how does one go about studying a Dasein, a human existence, as it cannot be examined directly? If examined directly, attempts to reflect another person's experience, inevitably distorts the phenomenon (Moran, 2000). Acknowledging that one cannot study another person's direct experience, Heidegger suggested that we could access the 'factual existence', which means the experiences as they appear to another individual in his/her own way (Smith et al., 2009).

Merleau-Ponty agreed with Heidegger that our knowledge of the world is both situated and interpretative. He emphasised the role for ‘contextual phenomenology’ and proposed that the body is constantly engaged with our sense of self, our surrounding environment and our interaction with others (Spinelli, 1989). Merleau-Ponty described a person’s relationship with the world as ‘body-subjects’ and suggested that a body is ‘no longer conceived as an object in the world, but as our means of communication with it’ (Merleau-Ponty, 1962, p. 106). He stresses that one’s perception of another person is always derived from their own embodied perspective. Therefore, while we can examine and experience empathy for another, ultimately we can never share the other’s experience (Smith et al., 2009). Sartre sought to extend the understanding of hermeneutic phenomenology, suggesting that we are always becoming ourselves and that the self is not a pre-existing entity to be discovered, but rather an ongoing project to be expanded upon. In developing Husserl’s work, Heidegger, Merleau-Ponty and Sartre develop the idea of a person being embedded and immersed in a world of objects and relationships, language and culture, projects and concerns. Phenomenology is both a philosophy and a research tool that enables the researcher to explore the nature and meaning of experiences that appear to other human beings (Finlay & Ballinger, 2006).

The second key theoretical foundation of IPA comes from hermeneutics. Hermeneutics, the theory of interpretation, was originally used in the analysis of biblical texts (Smith et al., 2009). Heidegger found a link between hermeneutics and phenomenology because interpretation was necessary to extract meaning from texts. The hermeneutic circle is concerned with the dynamic relationship between the part and the whole: “To understand any given part, one must look at the whole; to understand the whole, one must observe the parts” (Smith et al., 2009, p. 28). Thus, for IPA, the

process of analysis is iterative whereby a researcher can go back and forth through a range of different ways of thinking about the data, rather than completing each step, one after another. Heidegger realised that whenever interpretation occurs, one brings their fore-conception to the event, and therefore one cannot examine any new event without including their own prior experience in the analysis. IPA therefore recognises that the researcher will bring their own preconceptions when analysing a participant's experience of an event.

The third major influence upon IPA is idiography. Relating to the particular rather than the universal, idiography is important to the underpinnings of IPA on two levels. Firstly, there is a commitment to the detail in individual responses. This is borne out in the depth of analysis involved in IPA, which must be both "thorough and systematic" (Smith et al., 2009, p.29). Secondly, IPA is committed to the analysis of how particular events, processes or relationships have been understood from the perspective of particular people, in a particular context.

Since its development, IPA has become one of the most commonly used qualitative methods in psychology (Smith, 2011). To date, most research using IPA has been focused in health psychology, the majority focusing on patients' illness experience including cancer (Reynolds & Lim, 2007), chronic pain (Osborn & Smith, 1998), heart disease (Hogg, Garratt, Shaw, & Tagney, 2007) and stroke (Murray & Harrison, 2004). IPA attempts to move away from limitations of the medical model, where functional outcome and bodily processes are of key importance towards a deeper understanding of the subjective lived experience of illness (Brocki & Wearden, 2006). Healthcare professionals realise the importance of gaining an understanding into patient perspectives in the delivery of service and thus there is a greater focus of interest in health psychology research based on individual's subjective experience and

interpretations of bodily experiences (Brocki & Wearden, 2006). IPA enables researchers gain a deeper understanding of these experiences, through its interpretation of first person perspectives from a third person position (Smith et al., 2009).

In the current research the use of IPA allowed participants to talk freely about their experience of stroke, thus gaining a deeper understanding of the illness, from the perspective of the person with stroke and spouses of stroke survivors. Participants are viewed as the experts of their own life, and thus interviews are participant driven. The researcher's role during the interview is to help participants access their personal world, by providing open-ended questions and prompts in order to provide the opportunity for deeper reflection (Smith et al., 2009). The analytic account is formed by the joint reflections of both participant and researcher, referred to as a 'double hermeneutic' (Smith et al., 2009). The researcher is making sense of the participant, who is making sense of their lived experience, thus illustrating the dualistic role of the researcher being both similar and different to the participant. On the one hand, the researcher is similar in terms of being a human being and depending on everyday human resources in order to comprehend our surroundings. On the other hand, the researcher is not the participant, and only has access to their personal world through their reports of it and is also viewing this through the researcher's own life perspective. Therefore the "participant's meaning-making is first-order, while the researcher's sense making is second order" (Smith et al., 2009, p. 36).

Semi-structured interviews enable participants to talk about a particular aspect of their experience. Questions posed by the researcher can guide participants through this experience, enabling the retrieval of data which will help inform the research question. Maintaining a balance between guiding the direction of the interview and allowing the participant to contemplate and reorganise their thoughts during the interview is essential

(Willig, 2001). An interview schedule consisting of seven questions (along with prompting questions; see Appendix One) was designed with the goal of enabling participants to recount as fully as possible their experience of stroke. Interviews typically began with a descriptive question (e.g. Can you tell me a bit about yourself?, Can you tell me about the day you had the stroke?) which enabled the participants to become familiar with talking to the researcher. A conscious effort was made to avoid applying the interview schedule too rigidly, as this may suppress participants' ability to delve deeper in reflection or may prevent them from talking about aspects of their experience which are of key importance to them.

2.3 Sample

In keeping with IPA guidelines the current sample was selected purposively (as opposed to employing probability methods) which means that participants are selected on the basis “that they can grant...access to a particular perspective on the phenomenon under study” (Smith et al., 2009, p.49). 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. 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, English speaking, who had experienced a mild to moderate stroke and were at least three 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 difficulties taking part in an interview, were excluded.

Participants who met these criteria were considered gatekeepers to the potential recruitment of their spouse or partner. Participants were sent two invitations to participate, one for themselves, and the other for distribution to their spouse or partner if applicable. The term 'partner' was used on the recruitment letter to allow for inclusion of both spousal and non-spousal relationships. Of key importance was the stroke patient's self-identification of their relationship status; this provided the opportunity to include long-term or same-sex partners at the stroke survivors discretion.

Eleven stroke patients (9 female) and four partners of stroke patients (all male) participated in the research. Amongst the patient sample the average age was 41 years (range 30 to 49 years) and the average time since stroke was 17 months. Seven patients who were in paid employment prior to their stroke returned to their previous employment; three of them returned to work on reduced hours. The mean age of the four male spousal participants was 43 years.

2.4 Procedure

Participants were initially contacted by their treating Consultant to determine their interest in taking part in the study. From an initial list of 53 potential participants, 20 individuals did not meet the inclusion criteria. Therefore, 33 potential participants were contacted. Written information on the content and conduct of the study, consent forms and contact sheets were sent to all potential participants (see Appendix 2, 3 and 4). Fifteen individuals responded, including four patient and spouse couples and seven patients whose partner/spouse did not wish to participate. Following participants' initial indication of willingness to participate, interview terms and locations were arranged.

Face-to-face interviews were conducted at the convenience of the participants; 13 participants were interviewed in the Consultant's office in the stroke unit and 2 participants were interviewed in a private office at the University.

On initial meeting a general preamble between the researcher and participant facilitated a relaxed atmosphere and provided participants with an opportunity to ask any questions and express concerns they may have had at that point. Participants were reminded of the rationale behind the study and that the interview would be audio recorded. They were also informed that they were free to withdraw from the study if feeling uncomfortable or distressed. Following the conclusion of the interview, participants were debriefed and remaining questions or concerns were addressed.

Interviews ranged from 25 minutes to two and a half hours in duration, the average 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, both those who had experienced a stroke and those who were partners of people who had experienced a stroke, were asked to tell their story and describe the way stroke had affected their lives. The content of the interview followed the participants through their account of experiences in relation to stroke onset and hospitalisation and life following stroke. Participants were asked to talk as widely as possible about the different ways in which the stroke affected or influenced their sense of self, emotional experiences and the effect it had on their relationship with their significant other. These topic areas served as a guiding framework for the interview rather than a prescriptive line of questioning, an approach consistent with IPA.

2.5 Ethical Considerations

The “St. James’ Hospital/Adelaide and Meath Hospital incorporating the National Children’s Hospital Research Ethics Committee” and the National University of Ireland Maynooth (NUIM) Ethics Review Committee, approved the study protocol (see Appendix 6). Issues of key concern considered to minimise the stress and any possible negative effects of participation in the study included:

- (1) Confidentiality: Participants were informed that their identity would remain confidential and that pseudonyms would be used in any publications including the current report. Participants whose partners were involved in the study were informed that no information they provided in their interview would be discussed by the researcher during their partner’s interview and vice versa.
- (2) Information provision: Participants received an overview of the nature of the study and were told that the aim was to explore the meaning and experience of stroke in young adults and the affect it had on their relationships.
- (3) Consent: All participants read a consent form and had the opportunity to consider and discuss participation in the study before giving consent to participation.
- (4) Withdrawal: Participants were informed that if they felt uncomfortable at any stage, the interview could be terminated without implications for their future treatment.
- (5) Debriefing: At the end of the interview participants were thanked for their participation and were debriefed. Questions regarding the study were addressed by the researcher.

During the interviews some participants became visibly upset while talking about their experience of stroke and the repercussions it had on their lives. The interviewer was

mindful of their concerns and distress and empathic towards feelings expressed by participants. In these instances, participants were offered a break, their ongoing consent to participation was reviewed and the interview continued when they felt able to do so. None of the participants terminated the interview or withdrew from the study.

2.5.1 *Interviewing Couples Separately*

There are both positive and negative aspects to interviewing couples separately. Interviewing couples separately may cause distress and apprehension regarding what the other person may have said. However, it is also evident that responses to sensitive questions in interviews are influenced by the presence of a spouse (Taylor & de Vocht, 2011; Valentine, 1999). Therefore an advantage of separate interviews is that participants may be able to express their own individual views more freely than when interviewed together. Kitzmüller et al. (2012, p.6) interviewed spousal couples both together and separately as part of their research concerning the impact of stroke on the family unit, and noted that sensitive issues were not discussed during the couple interviews but “*they were disclosed in subsequent individual interviews afterwards, during which all participants showed more emotions.*” In acknowledgement of potential tensions arising from separate interviews care was taken to clearly outline the data collection procedures. All participants whose partner was also taking part in the study were informed that nothing they said would be brought up by the researcher in their partners’ interview and only those topics that they themselves brought up would be discussed. However, care was also taken to apprise participants of the potential for identification by their partner even with the removal of personal identifying information.

2.6 Data Analysis

All interviews were transcribed verbatim on a case-by-case basis. Participants were given pseudonyms and any names/locations mentioned in their interview were changed. Data analysis was carried out according to IPA guidelines (Smith et al., 2009). Analysis initially is conducted on a case-by-case basis and subsequently compared and contrasted across all transcripts. Data resulting from interviews with stroke survivors and partners of stroke survivors were analysed separately. Analysis is based on the close interaction between the participant's thoughts and experiences and the researcher's interpretations and comprises a four stage process, involving initial notes and comments, the development of emerging themes, the clustering of themes across transcripts and finally the formulation of super-ordinate themes.

Initial analysis is characterised by a thorough reading of each transcript on a case-by-case basis. This allows for a deeper understanding of the individual's experience and ensures that the participant remains the focus of analysis (Smith et al., 2009). Initial notes are recorded, highlighting descriptive and linguistic characteristics of the transcript. Descriptive comments include the noting of keywords, specific events and details relating to the participant's story. Examples of linguistic characteristics include the use of laughter, repetition, tone and degree of fluency. Descriptive and linguistic comments enable the researcher to take a more interpretative approach while still placing the participant's experience at the centre of analysis. Table 1 outlines examples of descriptive, linguistic and conceptual comments made during analysis.

Table 1: Exploratory Comments

Stage: Exploratory Comments		
Analysis	Findings	Example
Descriptive comments	Reflections on previous self	<i>everything takes so much concentration, whereas before it would be just run of the mill</i>
	Loss of Responsibility	<i>I would have been kind of in charge of a couple of people before, and now, that role is diminished</i>
Linguistic comments	Nervous repetitions and laughing	<i>Yeah I have just accepted it, yeah, yeah, yeah, yeah, yeah that's just me now (laughs)</i>
	Direct Speech	<i>it's like 'you can't be going out, because you've had a stroke'</i>
Conceptual comments	Frustration	<i>it is never just straight forward, like I can't just go about my daily business</i>
	Changed Role	<i>I am not a full mother, I am not a full wife</i>
	Metaphor for Fatigue	<i>it was like a wave of tiredness</i>

The next stage of the analysis involved the development of emergent themes. Once familiar with the content of the interview transcript, the researcher is able to establish key or super-ordinate themes from the data. Themes emerge by using the information from the exploratory comments in an interpretative manner, while still

being mindful of remaining close to the interview transcript. Table 2 provides an example of the development of emerging themes.

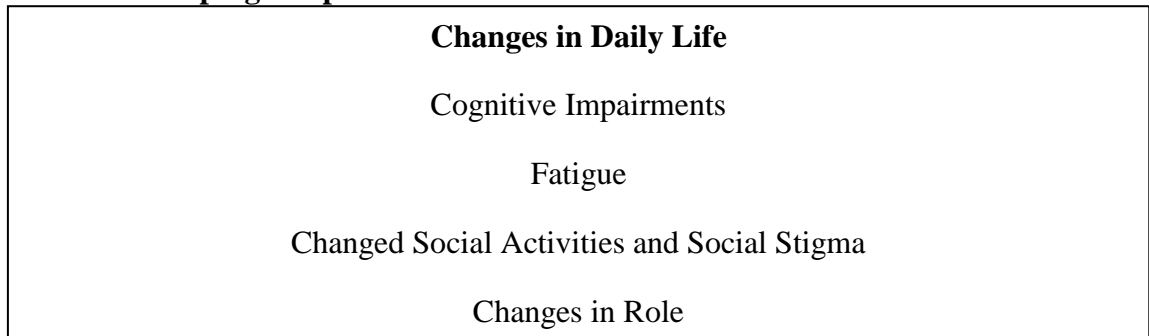
Table 2: Developing emergent themes

Exploratory Comments	Original Transcript	Emergent Themes
	Interviewer: So you said you have changed since your stroke, how do you feel about that?	
<i>Use of humour as coping mechanism</i>	I hate it, I do (laughs)...	Changes in Role
<i>Nostalgia towards previous social self. Lack of motivation towards returning to previous social life</i>	...you know, because I'd have a load of friends on my road, and you know, if there was a party it would be like 'Get Laura to the party, to get the crack going' whereas now, I wouldn't feel bothered to be going...	Change in Social Life
<i>Social withdrawal as a result of fear of stroke recurrence</i>	...I would just feel safe in my own house, you know that way?	Fear of Another Stroke

Developing super-ordinate themes requires the identification of patterns across emerging themes. This may involve the clustering of similar emergent themes together, or examining differences between themes in order to gain a deeper understanding of the participant's experience. Smith et al. (2009, p.99) suggested compiling files of transcript extracts relating to different emerging themes which helps examine "internal consistency, relative broadness, or specificity, of each emergent theme". Box 1

illustrates a sample of sub-themes contributing to the super-ordinate theme *Changes in Daily Life*.

Box 1: Developing a super-ordinate theme



The final stage of analysis involved searching for patterns across the interview transcripts. It is important when analysing subsequent transcripts to remain conscious of the individuality of each interview, which means “as far as is possible, bracketing the ideas emerging from the analysis of the first case while working on the second” (Smith et al., 2009, p.100). It was therefore necessary to keep the analysis of each transcript separate, which allowed for the development of new concepts and emerging themes in the subsequent transcripts. Finally, the merging of shared themes across cases was carried out, which resulted in super-ordinate and subordinate themes. Super-ordinate and subordinate themes encapsulate the participants’ shared experiences (see Table 3).

Table 3: Group analysis of super-ordinate theme “Changes in Daily Life”

Changes in Daily Life
<p>Cognitive impairments</p> <p>Barry: <i>I still cannot even read a paper. And I can read but I read a paper and obviously it's gone two minutes after I'm reading it. Do you understand? I'm after reading it and I say, 'what was I talking about?' I can't remember...</i></p> <p>Jean: <i>What I am finding difficult is I can't finish my sentences if someone interrupts and I go (exhales) 'where was I?' I know what I want to say but I can't start it, it takes me a few seconds longer...</i></p> <p>Katherine: <i>I just don't know, I don't know anything anymore, that's what it feels like.</i></p>
<p>Fatigue</p> <p>Maria: <i>I get very tired an awful lot. Now that is one of the problems when I first came home, being exhausted, and I remember coming back and saying to Dr X 'Jesus Christ, when is this tiredness going to leave?'</i></p> <p>Patricia: <i>But I still feel I get little dips in the energy levels, where I would be great, like today I am great, but I do get little sort of dips..</i></p> <p>Sally: <i>it was like a wave of tiredness, I can't explain, I never felt anything like that before...I never felt like I had a sleep, you know, you would wake up and you would still be tired and lethargic.</i></p>
<p>Changed social activities and social stigma</p> <p>Katherine: <i>I used to cry for the fact that I can't do normal things, like what is wrong with me, not being able to go shopping and then, go out for dinner, or go for a drink at night, or whatever.</i></p> <p>Frank: <i>We go out kind of later now, like...I just know I take my time...I know that if I drink to quickly, I'll want to go home...</i></p> <p>Laura: <i>I'd have a load of friends on my road...if there was a party it would be like 'Get Laura to the party, to get the craic going' whereas now, I wouldn't feel bothered to be going, I would just feel safe in my own house.</i></p>
<p>Changes in role</p> <p>Pauline: <i>if I can't function, it is going to break the family down, you know what I mean. So this is why I have to mind myself, and I am going to watch myself constantly, and if I feel things coming on me, I am going to investigate them.</i></p> <p>Katherine: <i>it's a catch 22, because in one way I want things to be the way they were, and in other ways I don't think I would be able for it, the way it was.</i></p>

Results

3.1 Introduction

In the sections that follow, a discussion of the super-ordinate and subordinate themes will be provided. Four super-ordinate themes were generated from the transcripts of stroke survivors, along with one super-ordinate theme for spouses of stroke survivors. Themes are outlined briefly in Table 4 (stroke survivors) and Table 5 (spouses of stroke survivors) below:

Table 4: Description of themes generated (young adults who experienced a stroke).

Super-ordinate and subordinate themes	Description
<p><i>Sudden and unexplained: will it happen again?</i></p> <p>Subordinate themes</p> <ul style="list-style-type: none"> • Minimising and normalising symptoms • Living with fear 	<p>Participants initially attempted to normalise and minimise stroke symptoms, which compounded their fear and shock upon diagnosis. Fear of stroke recurrence was ongoing source of distress that affected their daily lives</p>
<p><i>Changes in daily life</i></p> <p>Subordinate themes</p> <ul style="list-style-type: none"> • Cognitive impairments • Post-stroke fatigue • Changed social activities and social stigma • Changes in role 	<p>Participants experienced changes to their daily activities as a result of residual cognitive impairments and fatigue. Participants were more self-conscious in public spaces and worried about interaction with strangers. Participants were frustrated at no longer being able to fulfil certain roles.</p>
<p><i>Trying to get better</i></p> <p>Subordinate themes</p> <ul style="list-style-type: none"> • The role of formal services and supports • Benefit finding and social 	<p>Participants reported differences in how they engaged with formal services and supports during recovery. Some readily accepted help, while others viewed such help as a barrier to their recovery.</p>

comparisons	Positive consequences of stroke were reported by the majority of participants; use of social comparisons was also noted.
<i>Relationship changes</i> Subordinate themes <ul style="list-style-type: none"> • Strengthening bonds. • Relationship difficulties. 	The majority of participants reported the strengthening of relationship bonds after stroke, citing increased appreciation and valued emotional and practical support as reasons. For others, relationships became strained, with feelings of being over-protected were apparent.

Table 5: Description of themes generated (spouses of young adults who experienced a stroke).

Super-ordinate and subordinate themes	Description
<i>Loss and Change</i> Subordinate themes <ul style="list-style-type: none"> • She is not the same person • Supporting roles – changes in relationship dynamics 	Stroke also has a significant impact on the lives of spouses. Spousal participants found their wife to be different, with changes in cognitive ability affecting participation and mood. Loss of spontaneity and a heightened awareness of assuming the ‘caring’ role changed relationship dynamics.

3.2 Sudden and unexplained: will it happen again?

The occurrence of stroke was traumatic for participants, not only because of the sudden onset of symptoms but also because of the stereotypical view of stroke as a condition of the elderly. Initially, participants sought to minimise or normalise their symptoms of stroke which resulted in delays to seek medical attention. Shock and fear dominated participants’ reactions to stroke diagnosis. In addition they were compelled to come to terms with the diagnosis while being treated in a ward predominately

occupied by older people. Fear of stroke recurrence was reported as a persistent and debilitating feature of their lives. For some, fear of recurrence resulted in heightened attention to similar symptoms of stroke. For others, fear resulted in disengagement in leisure and social activities.

3.2.1 Normalising stroke symptoms

Participants described the day they experienced a stroke, however to varying degrees. What was common amongst participants was a sense of confusion and fear. Owing to the nature of stroke, recollection of the event can be hazy which led to some stroke survivors to rely on accounts from people who were present at the time of the acute event. For others, there was a sense of distance as though they were merely passive viewers of the event as cognitive functioning diminished. For example, Laura remembers the symptoms she was experiencing at the time of her stroke, but cannot remember other details such as her arrival at the hospital or being diagnosed with a stroke:

(Laura) *I just remember getting into the yard, and just literally collapsed, and my face just dropped, and just this weird feeling down my left side...kind of after that it is just a blank really...I remember then one of the teachers I think brought me up to the doctor's surgery in [home location] and they told me that they were more or less sure that I had had a stroke...they phoned for an ambulance and after that really, it's just a blank as well..*

Participants attempted to minimise or normalise their symptoms during the early stages of the acute event. For example, one participant related her face being numb to having “slept funny” the night before. Participants failed to fully appreciate the seriousness of the symptoms they were experiencing, and as a result, a lack of urgency to seek help was reported:

(Pauline) *He didn't call an ambulance or anything, and I said 'I don't want to get an ambulance' I didn't want the fuss, you know (laughs)*

(Frank) *I fell on the bed, I was sick about five times, and the wife was saying to me, you better go to hospital, and I was thinking, well the hospital is 130 quid, the doctor is only 60, I was going to wait a few hours and go to the doctor.*

Failure to recognise symptoms of stroke may be the result of incomplete or inaccurate illness representations. Stroke is a condition typically associated with older adults. This perception appears to have acted as a barrier for some participants to link their symptoms to the condition. Although Sally was able to link the symptoms she was experiencing to a publicised national stroke awareness campaign she still found it difficult to comprehend a diagnosis of stroke:

(Sally) *I kept saying “no it’s something else” in my head, but then when I went in to A&E and kind of when they were asking me the questions, I was kind of getting into a bit of a panic...I was still thinking ‘no I didn’t have a stroke, I didn’t have a stroke’. I suppose when I saw the really old sick people beside me and what they had gone through, and seeing people going straight from there to rehab and all, I had it in my head that ‘no I am different’.*

Participants had difficulties in identifying and comparing themselves with older patients on the ward. For Laura, comparing herself to other patients was distressing and anxiety provoking:

(Laura) *it was really hard actually [in hospital], because I suppose, I was probably the youngest on the ward, and I was looking at everybody else, much older, and there was a certain chap that would come in, and he was in his forties like and I remember looking at him, and I was like, am I going to be like that, how bad he was, you know?*

3.2.2 *Fear of stroke recurrence*

The length of time it took for diagnosis varied. Some received a diagnosis shortly after admission. For others, however, the process of receiving a diagnosis was lengthy, with participants having to undergo numerous tests. Diagnosis of stroke was met with shock by all participants. For Jean, the shock and sadness came not from the diagnosis of a stroke, but rather from realisation of the physical consequences of it:

(Jean) *But I got up one morning and I got out and my leg had gone and I was walking like that, and I got really upset then because I was like ‘oh I am after taking a stroke’ and it only hit me then.*

(Frank) *it was only kind of the other doctor that was with me, said to me ‘well, oh yeah, that’s a, you’ve had a stroke’. That was it, but he just left me then, and I remember that night, I was just lying in the bed, and I just started shaking.*

Participants also worried about why the stroke occurred in the first place. This is common as many strokes, particularly in younger adults, tend to have unclear diagnoses, and the etiology of the stroke remains unknown. For Frank, this was difficult to accept, as he was unsure whether his stroke was ‘self-inflicted’, through over-exertion, or was something that was destined to happen. For Michelle, lack of clarity on the reasons for her stroke resulted in frustrations with the medical profession:

(Frank) *I still never found out exactly how it happened. And if anything will ever happen to me again, or what happens me in the future...I am more wary about it, about it happening again.*

(Michelle) *they think they know everything, but they know nothing, like in this field, they know nothing.*

All of the participants described the ongoing and pervasive fear of stroke recurrence. This fear was manifested in a variety of ways, including restrictions in daily activities and greater awareness of risk, both personal risk and risk to others:

(Maria) *I’m scared at home, I have the granddaughters and I mind them. What happens if I’m behind the wheel of a car and this comes on, cause you don’t always get a warning, enough of a warning.*

(Katherine) *I used to swim with my head out of the water, so if you can imagine, that action on my neck is quite straining on my neck, so I am terrified of doing that again because of the tear in the carotid artery.*

Heightened attention to bodily symptoms, like headaches and dizziness which were integral to participants’ stroke experience, was evident in Pauline and Jean’s accounts.

For Jean, increased symptom surveillance and self-monitoring led to significant disruptions in her work life:

(Jean) *Yeah, like you could have another one, and it could be worse...like if I get the headaches, again, if I get it there [same area of head] I would say 'did I take my tablets? I did'....but I do worry.*

Pauline benefited from the contact with her support nurse by gaining information and reassurance in response to her symptoms:

(Pauline) *They said anytime I was feeling worried, I could come in, and I would ring her first and they would say 'well if you really are worried, come in' and I would say 'well no, I just want you to put me at ease a bit'.*

Both Laura and Katherine evidence a debilitating spiral of catastrophic thinking relating to stroke recurrence. The thought of stroke and fear of recurrence, in the absence of symptoms, are still sufficient to restrict their activities:

(Katherine) *I had this fear of I can't go out on my own with the baby, what if it happens again, what if somebody takes the baby, what if somebody thinks I am drunk and they don't help, you know you hear of these stories...*

(Laura) *'is this going to happen to me again?' and then it's just boom, straight on the bus...*

3.3 Changes in Daily Life

Cognitive impairments, such as difficulties with memory, concentration, organisational skills, decision making and to a lesser extent problems with speech production were common amongst participants. Participants struggled to cope with these impairments and became upset and irritated when their ability to carry out daily tasks was impinged. Residual impairments also affected participants' ability to perform previously held professional responsibilities and roles within the family. Fatigue was a major source of frustration, described as a "wave of tiredness" and a "train wreck" it had detrimental effects on personality and altered social activities. Altered mood and lack of motivation

also contributed to a changed social life. Social stigma was also reported and led to some participants avoiding certain social interactions due to the unwanted label of disability.

3.3.1 *Cognitive impairments*

Following discharge home from hospital, participants had to come to terms with residual impairments acquired from stroke. Working memory impairment is common after stroke (Lincoln et al., 2012). This was described by a number of patients including Barry and Laura. Barry, who is almost two years after stroke, still has problems reading a newspaper and retaining the information. Laura (> one year after stroke) is frequently burdened by forgetting simple daily tasks and is very frustrated as a result. They both describe everyday activities that have been affected by memory impairment:

(Barry) *I still cannot even read a paper. And I can read but I read a paper and obviously it's gone two minutes after I'm reading it. Do you understand? I'm after reading it and I say, 'what was I talking about?' I can't remember...*

(Laura) *..... it is gone out of my head. You know I would often go to the fridge, let's say if I am at the sink and I have to get something out of the fridge, I would go to the fridge, and I could be standing there for 10, 15 minutes, saying to myself 'Right, what were you doing, Laura, what were you thinking of, to make you go to the fridge?' and I could be standing there for 10, 15 minutes, before it actually registers with me...it is so annoying, so so annoying.*

Deficits in attention are also common after stroke and have been shown to have a negative effect on participants' ability to carry out activities of daily living (Hommel, Miguel, Naegele, Gonnet, & Jaillard, 2009). The inability to concentrate can also have knock on effects, as more energy is devoted to common tasks and exhaustion ensues:

(Sally) *... my concentration was so bad, really that was one major change...I'd read it over and over again, and I didn't kind of take it in, whereas before I would read it and I would take it in, I would have to read it a few times to actually make sense of it...And*

even reading a book, I love to read, I've always read, I didn't have the patience, a couple of paragraphs and I couldn't take any more.

(Katherine) *it is never just straight forward, like I can't just go about my daily business...the best way to describe it is, everything takes so much concentration, whereas before it would be just run of the mill. Like driving for instance, em, when you are learning to drive there is 100% concentration, but then you become, it comes easier when you don't have to concentrate so much, but everything for me takes concentration...that is why I am so tired because you are just concentrating on every little thing.*

(Jean) *What I am finding difficult is I can't finish my sentences if someone interrupts and I go (exhales) 'where was I?' I know what I want to say but I can't start it, it takes me a few seconds longer...*

Patricia remembers struggling to decide between items she wanted when shopping with her daughter. Finally, her daughter had to make the decision for her, as she was unable to do so. Patricia was unable to make what was essentially a non-consequential decision. Katherine also has to rely on others to guide her and depends on her husband to make decisions on her behalf. Katherine has lost her autonomy in respect to decision making which has left her doubting herself:

(Katherine) *I just don't know, I don't know anything anymore, that's what it feels like.*

3.3.2 Fatigue

Participants complained of severe lack of energy and overwhelming and debilitating tiredness. This tended to be most pronounced during the first few weeks following stroke, however fatigue was an ongoing issue for most participants and was pervasive in its impact:

(Maria) *I get very tired an awful lot. Now that is one of the problems when I first came home, being exhausted, and I remember coming back and saying to Dr X 'Jesus Christ, when is this tiredness going to leave?'*

(Patricia) *But I still feel I get little dips in the energy levels, where I would be great, like today I am great, but I do get little sort of dips...*

Frank and Niamh can manage during the day, but when it comes to night time, they are exhausted. Sally and Katherine describe how their sleep patterns have been affected and they wake up feeling fatigued:

(Frank) *I don't get mad tired during the day, I hit a wall (laughs) at night-time.*

(Niamh) *It's just at night time, like I am real tired, and my words will go blur, and then I have to go to bed.*

(Sally) *it was like a wave of tiredness, I can't explain, I never felt anything like that before...I never felt like I had a sleep, you know, you would wake up and you would still be tired and lethargic.*

(Katherine) *Like even waking up in the morning, it feels like there is lead in your bones, it feels like you have been run over by a train, your body just whacked, just absolutely, like you have just been run over, the only way I could describe it, like lead in your bones.*

Loss of energy and fatigue contributed to changes in other areas of participants' lives.

For example, Jean identified changes in her personality and self-imposed limitations in her social activities which she attributed to overwhelming fatigue:

(Jean) *I am wrecked, I am wrecked...it does my head in, it wrecks my head, you know? And that's probably why I am turning aggressive....I have no interest anymore...I am too tired, my brain is tired.*

There is a sense of hopelessness in Michelle's account as she describes the unrelenting nature of fatigue and the failure of her efforts to overcome it:

(Michelle) *If I was feeling the same as before, I could plan the things, I could do them, it was like, not me, that was acting now. 'Ok, don't sleep in the morning, try to shift a few things'. I tried, I tried some things, she was like 'try to walk some minutes, and then go back'. I tried to do this, but was feeling [more] tired than before (laughs)...it's like a vicious circle.*

3.3.3 *Changed social life and social stigma*

Participants described changes in the patterning of their social activities following stroke and clearly distinguished between pre and post stroke social selves. For some, impairments and fatigue necessitated a change in the nature and extent of socialising. For others, enjoyment in socialising was lost. Tiredness, lack of motivation, low mood and vulnerability were central reasons underlying these changes. The loss of everyday, simple pleasures is illustrated in Katherine's description. She just wishes to do normal things:

(Katherine) *I used to cry for the fact that I can't do normal things, like what is wrong with me, not being able to go shopping and then, go out for dinner, or go for a drink at night, or whatever.*

Frank articulates these changes in terms of their impact on him and his partner as a couple. By going later and pacing his alcohol consumption, Frank and his wife are able to maintain their social activities:

(Frank) *We go out kind of later now, like...I just know I take my time...I know that if I drink to quickly, I'll want to go home...*

Low mood and apathy towards socialising were problematic for others. For a long period after her stroke, Sally felt like she was 'going through the motions' when socialising and did not enjoy it. Laura admits that she effectively withdrew herself from her friends by ignoring their calls and staying at home. It appears that Laura feels vulnerable outside her home, suggesting a loss of confidence. Laura laments the loss of her previous social self:

(Laura) *I'd have a load of friends on my road...if there was a party it would be like 'Get Laura to the party, to get the craic going' whereas now, I wouldn't feel bothered to be going, I would just feel safe in my own house.*

Social anxiety and social stigma also negatively impacted social interactions. For Maria, Laura and Michelle concerns about physical appearance were central; Michelle was also fearful of not expressing herself clearly when talking to strangers. Heightened self-consciousness led to awkwardness, embarrassment and avoidance of certain social situations:

(Maria) *I do feel people look at me, because I do drag that leg. And I try so hard not to, but I know people look at it...I'd kind of avoid them, and go the other direction, I'm not talking to them...I know people talk.*

(Michelle) *I can't even utter a word, because I am afraid of not saying the right sentence or something. I can see them looking at me... I am embarrassed all the time.*

(Laura) *I was conscious of how I looked, even though I didn't really see any difference in myself if I looked in the mirror...but it was still this, I suppose this stigma attached to having a stroke so people are like 'I want to see her, to see if she looks different', so that's how I felt.*

Unwanted attention and emphasis on stroke was also a concern for Sally. She was nervous about returning to work and feared being treated differently:

(Sally) *Going back and having to talk about it...and feeling that everyone was pitying me...I don't know, it just, you do feel that people are going [whispers] "Oh god, yeah, Stroke" like "Mind her".*

The label of *different*, *less able*, or indeed *disabled*, whether externally imposed or internally generated, was unwanted and distressing. Michelle rejected her entitlement to disability benefit. Not only would it mean accepting a plateau in her recovery, it would also reinforce her disabled status:

(Michelle) *Even my [health care professional], she told me that I could apply for this disability benefit? I told her no...I can go to work in my state, you know. I can stay more hours on my feet, for longer, you know. But this would label me as a disabled person!*
(laughs)

3.3.4 *Changes in Role*

A major part of a person's identity can be linked to roles they assume as part of their life. The roles people adopt in work, family and other interests in life are formative in terms of personal identity. When a person's ability to carry out these roles is diminished or changed, it can destabilise their self-identity. The ability to fulfil previous roles may be affected by physical impairments.

For example, Michelle, a mother of young children, experienced sensory dysfunction following her stroke. This has made it difficult for her to bathe her children, as she is unable to determine the temperature of the water:

(Michelle) *I lost my feeling of cold and heat in this hand, like sometimes if I am washing my little girl's face, I am washing her, like we have two taps, and I don't realise it's hot, and she is like "Mommy that is burning me!"*

In addition, due to fatigue and concentration difficulties, Michelle is no longer able to help her children with their homework, in the way that she used to. She also feels incapable of what she sees as the 'duties' of a wife, in terms of household tasks, leading her to question her role within the family:

(Michelle) *I don't want to show him that I am not a woman that he loves. I am not a woman because he helps me with everything,*

For Michelle, it is the physical impairments caused by her stroke that restrict her from carrying out previous held roles. Although Laura too has residual impairments from stroke, such as concentration and memory difficulties, she attribute to her role in the family to those around her. She feels as if her husband and two older children are "constantly, constantly watching" her. The over-protectiveness and monitoring behaviour of the family is at issue. It serves to keep the stroke to the fore and may serve as a barrier in moving forward and adjusting to life after stroke. Laura's frustration is

clear. The carer has become the cared for, the dynamic in the family has shifted and the change is not welcome:

(Laura) *I wish they would lay off, especially [Husband] now, I find him, 'ugh, god, just leave me alone' like you know, every, it just seems that every, like no matter what I do, it's like 'don't do that, you've had a stroke' and I am like 'oh god'...*

It appears that the only person that still needs her in the same way as before her stroke is her daughter, her youngest child. As a result, Laura has been overprotective of the child in order to reassure her that she will always be there for her: *"I think I am just doing it to reassure [daughter] that if she wakes up to go to the bathroom during the night that mammy is still here"* However, Laura may also be overcompensating here in order to exaggerate her role as mother and carer to the youngest child, therefore regaining her role as mother in the house.:

(Laura) *since I got sick, I have got so protective of [daughter] to the extent that I will go to bed with [daughter] every night, I will sleep with [daughter] every night, I think it's to prove to her that nothing is going to happen to me, and that if she wakes up during the night, that I am there for her...*

For others, however, a stroke can reaffirm previously held roles. For Pauline, the stroke solidified her commitment to raising her children, and because of this, took greater care in her own health and lifestyle. Her increased self-monitoring behaviour is a result of Pauline's belief that without her, the family would fall apart. It is for this reason, that she now more self-aware about her own health issues:

(Pauline) *if I can't function, it is going to break the family down, you know what I mean. So this is why I have to mind myself, and I am going to watch myself constantly, and if I feel things coming on me, I am going to investigate them.*

Role changes can also be seen to affect people outside the home. Katherine returned to work on a part-time basis following her stroke. She described mixed emotions in returning to her previous employment on reduced hours. She found her employers to be

very supportive, but experienced difficulties in relation to the diminished responsibilities she now held:

(Katherine) *I would have been, kind of in charge of a couple of people before, and now, that role is diminished. And while nobody has said 'oh well you are not in charge of them anymore', I am not, because I am not there enough. And I just feel that I am just going in to do a couple of hours and I will go home, do you know what I mean, I don't feel like I have the responsibility that I used to have.*

Katherine found her new role within her employment difficult to assess. On the one hand, she recognises that she would not be able to resume her previous role which had greater responsibility due to the stroke. However, she wished she still held that responsibility:

(Katherine): *it's a catch 22, because in one way I want things to be the way they were, and in other ways I don't think I would be able for it, the way it was.*

The stroke has affected Katherine's ability to continue holding the same responsibilities in her employment and she says that the stroke '*has even taken that from me*'. She interprets loss as negative, although she accepts that she would not be physically able to carry out previous held responsibilities. Her value in her employment has lessened, but this is balanced by the added value she has gained in her new role as mother.

For others however, loss of responsibility at work is interpreted in a positive manner. Frank describes his working life prior to his stroke as being highly stressful, involving very long hours. Because of his stroke, he was forced to reappraise his work situation and came to the conclusion that it needed to change. Although he remains in the same employment as before his stroke, he now works part-time and as is less stressed. He looks back on his previous employment role and asserts that he would never return to it:

(Frank) *I wouldn't go back to it again, it's not worth the trouble.*

3.4 Trying to get better – coming to terms with stroke

Participants engaged in formal services and supports, viewing it as a mechanism to aid in their recovery. There were both physical and psychological benefits associated with contact with these services; participants received practical recommendations, but also had a point of contact to verbalise their worries and concerns. Others refused such supports, viewing them as a barrier on their road to recovery. Participants gained a new perspective after stroke, with many reporting positive consequences as a result of the event. Positive aspects included a sense of luckiness that the stroke was not more severe, greater appreciation of family and friends and an increased awareness of the importance of their own health. The use of social comparisons was central to participants' new perspective.

3.4.1 The use of formal services and supports

Participants used a variety of different strategies, services and supports to assist them in their recovery. Formal therapeutic services, such as occupational therapy, speech and language therapy and nutrition and dietetics were central. Katherine articulated the dual benefits of these services. While receiving treatment and learning prescribed exercise regimens to aid in her recovery, she also had opportunity to verbalise her problems and concerns. This outlet was of equal importance to her:

(Katherine) *Through the telling them what my problems are, where even on the outside world, they don't seem like anything, when you are telling them and you verbalise it, even it takes a weight off your shoulder just verbalising it.*

Refusals to accept and engage with services were also notable. While Barry attended speech and language therapy, he refused recommendations to attend counselling,

emphasising his need to move on and viewing counselling as a potential barrier to progress and an anchor to the past:

(Barry) *I just want to get on with my life, you know. You go to counselling and you'd be there for a year, counselling and this and that, you know, I just wanna get on, you know?*

Frank objected to the installation of support railings around his house. These physical aides would undoubtedly have been beneficial; however Frank viewed them as a psychological barrier to recovery. The perceived permanence of such aides is contrary to his determination to get better:

(Frank) *I actually phoned them up later on and said, 'There's no point, I am planning on getting better. I don't want frames outside the door'.*

Perceived progress in recovery was important in maintaining behavioural changes and engagement with rehabilitation:

(Sally) *I am doing the exercises they showed me in the hospital and all that sort of thing. So definitely it's getting better.*

Frustrated by the pace of her recovery and loss of autonomy, Michelle stopped attending rehabilitation services. As a fiercely independent person, this return to self-reliance, evidenced by her continued use of the personal pronoun 'my' in the quote below, paradoxically may be interpreted as positive:

(Michelle) *Yeah, so I am trying to get better, in my house, in my, trying to do my exercises even at home by myself, I am trying to go back to my studies, trying to read my articles, to memorise, to strengthen my memories, but normally I don't find the results, you know, eh, eh, the results are so slow, you know?*

Somewhat ironically for Jean, progress in her physical recovery led to failure to recognise and appreciate the significance of her ongoing problems:

(Jean) *I had to go to the stroke clinic for em, after three months, and everybody there was really bad, and she called out my name and went past me, because it didn't look as*

if there was anything wrong, but I went in and she said 'no, you are grand, no bother on ye' but I know there is and everyone around me knows there is.

3.4.2 *Benefit finding and social comparisons*

For many stroke may be considered a traumatic event; stroke is typically uncontrolled, unexpected and possibly life threatening. Consistent with the aftermath of other types of traumatic events, individuals may reappraise their life situation and can experience changes in self-identity. Participants were at different stages in their recovery and varied in terms of the extent they had dealt with and processed the experience. There was a sense that some people had integrated the stroke into their life narrative and had arrived at a sense of acceptance. For others there was an ongoing struggle to come to terms with stroke and its implications. The majority of participants were able to point to benefits arising from stroke, including greater appreciation of family and friends, increased health awareness, renewed feelings of personal self-worth and a reprioritisation of personal values:

(Pauline) *Family is the major thing, the major thing. Ok if it is time for me to go, I am gone, I'm gone. But my family are going to be there and they need me. And that is my main goal and my main drive, for them.*

(Frank) *I don't care anymore..... I used to wake up at three in the morning, and I would lie there, I would get up at half six, worrying about mortgages...but afterwards, once I got my few things sorted out, I just don't care anymore, what can they do to ya? You know that's it...There are more important things to life (laughs)...Like once we have a roof over our heads, I don't care.*

(Patricia) *I do look on it as being positive because it really made me think about me, and think about my health, it has made me realise people I have around me, and it has made me think about, you know, going forward and sort of really re-evaluating things, instead of just racing through life...*

Social comparisons were instrumental in gaining a sense of perspective on their current situation and in finding benefits. Both Frank and Sally came to the realisation of how

fortunate they were through downward social comparisons and used this as an impetus for a more positive outlook on life:

(Frank) *Jesus like you know, I was so lucky, you know, to get out of it cause there were people in there that...and they were just lying there not moving, and I was thinking 'it could have been me' no problem, you know? I was just blessed...I was just lucky.*

(Sally) *You hear terrible things happen to people all of the time, I know how lucky I am, I got over the feeling sorry for myself, I am just going out to enjoy my life now!*

3.5 Relationship Changes

When participants returned home from hospital, their primary source of instrumental and emotional support was derived from their spouse or long-term partner. The extent and nature of this support varied.

3.5.1 Strengthening Bonds

While stroke had a devastating acute impact, participants pointed to the invaluable support provided through their relationships and to ultimately positive impact of the experience. The shared aspects of recovery and adapting to life after stroke strengthened bonds and brought couples closer. Many of the participants described their partners as being shocked and scared during the initial phases of stroke onset and diagnosis, highlighting the traumatic nature of stroke for the couple. Sally's husband got the "fright of his life" when she was diagnosed with a stroke. Frank tried to protect his wife from his stroke diagnosis by delaying the news. It highlights the seriousness of the condition and the devastating effect such a diagnosis can bring upon a spousal relationship. Over a year after stroke, recounting the experience still evokes a strong emotional reaction:

(Frank) *I didn't phone home to the wife, because she would haven't fancied a night, you know? So that was it. The next morning, she phoned up, and she was on her way,*

and I said 'you better come in and sit down' but then I told her then on the phone and she lost it, you know? That was it, you know? I'm getting carried away with it now.

For Jean's husband, the sight of his wife limping from the hospital bed brought a strong emotional response. The physical manifestation of the condition (the limp in her leg) demonstrated her vulnerability, which brought about feelings of fear and grief for him:

(Jean) He was there, and I got out of bed, and he hadn't seen my leg gone. And when he seen me limping like that, he went 'Oh God. You better not let anything else happen to ya, leaving me with them two lads' and he started crying and he got really upset. And now he just minds me, do you know what I mean, we are closer.

Participants described how their spouse or partner played a supportive role in both the initial stages of their stroke and the subsequent rehabilitation and recovery phases. For some, this meant the spouse or partner taking an active role in their rehabilitation.

Katherine described how her husband helped her with her 'homework' from her speech and language therapist. For Sally, who suffered from depression following her stroke, her husband offered her encouragement to become more active which benefited her both physically and emotionally:

(Katherine) Sometimes it was interactive, like he would have to read something to me and I would have to say it back what he said. Or sometimes I would have to say something and he would have to guess what I was talking about, so it was interactive as well. So he helped to get through that rehabilitation.

(Sally) And he would go to me, 'come on, we'll go for a walk' and I would be like 'no way, I am too tired, I don't care, and don't want to go for a walk' you know and I did, I kind of struggled with my weight, since then, and I would say 'no' and he would say 'come on, it will do you good' and I would be like 'no I don't care' and you know eventually he would annoy me so much that I would go for that walk and I would feel the better for it then when I came back.

Many participants described how the stroke had brought them closer to their spouse or partner. For some this closeness was brought about by fear. In some ways, the stroke introduced the notion of mortality within the relationship, as demonstrated below when

Jean speaks directly to her husband. The use of humour as a coping mechanism is also demonstrated below:

(Jean) *[It brought us] closer because he got a fright, it brought us two a bit closer. Because he was afraid that something was going to happen, you know. And I said 'are you afraid because you thought I was going to be left in a wheelchair and you would have to mind me?! (laughs) you know, slagging, like you know. But when I seen him getting upset like, you know 'would ya miss me?!' Like it showed the both of us. It was kind of a wake up call.*

Although the majority of participants found their spouse or partner to be helpful, both members of the relationship had to make adjustments following the stroke. Frank, for example, spends a lot more time at home now, as he curtailed the number of hours he worked following his stroke. This affected his wife's routine in the home:

(Frank) *I wouldn't say she was happy having me around all the time, because I was probably getting in her way, she's used to the three kids going to school, she would have the house to herself.*

Good communication was highlighted as key tool in sustaining relationships throughout the recovery and rehabilitation phases. Participants described quite simple exchanges and interactions, like telling their significant other that they are tired or explaining why they did not want to socialise, as beneficial to their relationships. Through this communication, partners of stroke survivors learned more about the illness:

(Katherine) *..he knows when I am tired, he knows not to bother me, he knows literally from my responses how 'you've hit your wall, haven't ya' that's what he says 'you've hit your wall' and I just say 'yeah I am gone' like I literally can't hold a conversation, like a reasonable conversation like, so em. And then sometimes, we have weeks where it is brilliant like and he would say to me 'god I really feel that you are getting better, you are not half as tired' but literally he only says it and then the next day I am just wrecked, so yeah it's just swings and roundabouts definitely, like I can never see us leaving each other now like.*

3.5.2 Relationship Difficulties

While ups and downs are characteristic of all relationships, three participants described significant negative aspects of their relationships following stroke. It is not clear whether stroke and its consequences served to magnify existing relationship tensions, initiate new problems in previously harmonious relationships or a combination of both. Barry and his wife separated following his stroke and he directly attributes the breakdown of his marriage to the aftermath of stroke. While Barry's wife provided instrumental support in the early stages of his recovery, managing his medication and filling out forms on his behalf, it appears that a change in Barry's personality was partially responsible for the break up on the marriage:

(Barry) ...*she said I'm different. I haven't got a clue in regards to being different, but that's what she said... snappy she said. I think that's all it was, snappy. But after going through two years like that, you know, you will be snappy!*

Laura acknowledged that her husband was very supportive while she was in the hospital, but found his concern and attention over-bearing on her discharge home. She described feeling quite controlled by her husband and completely defined and limited by stroke in his eyes. Communication appeared to be difficult in the relationship:

(Laura)...*no matter what I do, [Husband] would say 'No you had a stroke, you can't do this'.*

Through impairments caused by the stroke, Michelle no longer believes that she can fulfill the roles of wife and mother as she once did: *I am not a full mother, I am not a full wife*. The changed dynamic and roles within the relationship are unwelcome and distressing, and have led her to question her husband's motivation for maintaining the relationship. In an effort to regain the role she once had in her family she feigns *normal ability*:

(Michelle)... *I say 'Ok, I am ok now, I can do it' but I am feeling exhausted and I ache, and when he goes out I [lie down exhausted]*

3.6 Loss and Change

Spouses reported a distinction between life before and after stroke, and described changes in their partner as difficult to adjust to. Changes included cognitive impairment, lack of motivation and alterations in mood. Spousal participants played supportive roles in their partner's recovery and rehabilitation; sometimes their new roles were emphasised at the expense of their own emotional needs.

3.6.1 She is not the same person

Spouses described their partners as changed, changed with respect to their physical and cognitive abilities and changed in terms of their mood and/or temperament. For three of the four participants these changes were persistent at the time of interview while for one a return to *normality* occurred about a year after the acute stroke. Spousal participants described the impairments experienced by their wife following stroke. These included fatigue, concentration difficulties, and problems with memory and planning. These impairments lead to restrictions in activities and changes in lifestyle for the couples and were linked to feelings of loss and frustration for both stroke survivor and spouse. Spouses described negative changes in their partners' temperament, for example, they were quicker to anger; more volatile; colder. These negative changes in mood were ascribed to their partners' frustration arising from their impairments and to loss of confidence:

(Anthony) *Em, yeah, she probably would be giving out a little bit more now, like you know? (Laughs) Yeah, she is probably lacking a bit of confidence or something like that in herself like. But like, there is no physical reason why she should feel that way, because there is no change to her at all, but maybe she is just conscious of that.*

(Kevin) *She is not the same person in the sense, energy-wise she is not the same person, mood-wise, she is not the same person, she is more, much more cranky, she snaps a lot at the kids...she is snappy, very snappy, which is not like before.*

Spouses highlighted the differences between life before and after stroke and described themselves as more restricted in terms of lifestyle and increased responsibilities. There were numerous losses in their accounts, loss of normality, loss of spontaneity, loss of companionship, loss of intimacy, loss of balance. For example, Derek feels that he can no longer be spontaneous in his relationship and laments not being able to do what a young couple *should* be able to do:

(Derek) *...in the past, you could spring a weekend on her, you can forget about it, you better give her a week's notice. The effect that will have on her, only having two or three days to decide what clothes to bring, would well outweigh the benefits of taking her away.*

For spouses of stroke patients, stroke served as an alarm bell, an event that confronted them with the fragility of life and underlined what was important to them. While they focused on describing changes in their spouse, it was evident that they too were different; more health conscious, more fearful about the future and more aware of vulnerability. The stress and trauma of the acute period and the continued effort to cope with both the acute event itself and its lasting implications are illustrated in Derek and Kevin's accounts and are suggestive of a potential need for greater support for partners:

(Derek) *Like [wife] would be saying 'it wasn't that bad, it could have been worse' but I would be thinking to myself 'yeah, you weren't watching' because a lot of it, in a way, with the stroke, the person themselves won't see a lot of it, and god they have enough to be worrying about, so you don't expect them to, but it is easier from them to think, 'god this was a walk in the park'...it wasn't, you weren't looking at it..*

(Kevin) *I understood, why people go to drink alcohol...I understood that people have to turn to something, to relieve, or at least forget about it for a couple of hours.*

In addition to these changes and losses, stroke served as a catalyst for positive reappraisal of relationships and personal priorities. Derek, Gerry and Kevin experienced strengthening of their relationships and a deeper appreciation for their partners:

(Gerry) *I suppose at times I took her for granted...Whereas now, you appreciate every moment with her...you appreciate every moment you get with her now, because you just never know.*

(Kevin) *It brought us a bit closer and it brought a bit of humbleness into the situation...You know, work, work, work, do all the overtime and buy this, and run, run, run...*

[motions that 'what's the point?' by shrugging shoulders]

(Derek) *My perspective has changed, like in the sense that, the things that would have bothered me before, like forget about it, what is the big deal. I would be a bit of a detail kind of freak, em, but those little things wouldn't be as important as before.*

Participants also expressed feelings of luckiness that their partners' stroke wasn't more severe in comparison to others. Luck was qualified however; both Anthony and Gerry felt that the stroke did not serve as a sufficient catalyst for significant and permanent lifestyle changes:

(Gerry) *when we were in the hospital, there was people there as young as her, and they couldn't feed themselves and stuff like, you know? We were very, very lucky, you know? I think that would scare 'me', to almost making sure you are 100%, I would kind of keep fit and just do everything you can, like you know?*

(Anthony) *But as I say, but probably because it wasn't a very severe stroke, which we were lucky enough, that it didn't have as big an impact, that you would like it to have, and the life changing things that she would say 'right that's it, I am not going back there'.*

3.6.2 Supporting roles – changes in relationship dynamics after stroke

All participants described the ways in which they assisted and supported their wives after stroke; however the extent and type of support varied and participants differed in

terms of their motivation and their interpretation of their supportive role. Participants readily described the various instrumental supports they provided taking on new roles and responsibilities such as looking after children and carrying out daily household chores. They also provided encouragement and support, taking an active role in rehabilitation, recovery and maintenance of positive health behaviours. Emotional support centred on communication and was influenced by the patients' and partners' reaction to stroke and pre-existing relationship dynamics. Derek explicitly identified himself as a 'carer'; drawing on his experience of stroke in an elderly relative, his anxiety about the future and his ability to cope were illustrated during his recollection of the acute phase:

(Derek) *I was worried about her, how I would look after her, and then in selfish ways, how I would look after [another dependent] and is it going to be like permanently that you are going to be, you won't have, not necessarily two children to mind, that sounds a bit selfish, but again, you are saying 'how do you do it?'*

For Derek, assuming the role of 'caregiver' was difficult and isolating. His role as a husband was redefined; he lost important aspects of his relationship including the sense of an equal partnership and the emotional support it afforded:

(Derek) *But as regards being able to, be like a couple, and I am not even talking about the physical contact, but just the emotionally, I hadn't got my partner to talk to. I had someone that I had to look after and if I had anything on my mind, I had to keep it to myself because I knew it wasn't fair to burden her.*

In contrast, Gerry viewed his wife's stroke as part of their evolving history as a couple. He adopted a supportive caring role, viewing recovery as a collaborative process. Their emotional connectedness prior to the stroke was central to this process. Gerry's empathy is illustrated in mirroring his wife's distress: *I cried with her*. Anthony's experience was different; despite efforts to open lines of communication, he felt that his wife was withdrawn and unwilling to reciprocate. While this seemed to be an established pattern

of their relationship, his feelings of isolation and frustration were exacerbated after stroke:

(Anthony) *[Wife] would be a very closed person, like she wouldn't really talk about her emotions, like she would be better off to talk to a stranger than to talk to me about it. You would often say it to [Wife] about certain things, and she would close up, and not want to talk, and she would say 'Stop, there is nothing wrong', do you know what I mean?*

Anthony adopted a much exaggerated and directive role in reaction to his wife's perceived disregard for the risk of another stroke. He feels he is shouldering the burden of responsibility for his wife's health and is frustrated with her as a result. He is aware that his increased monitoring behaviour is almost dictatorial, that it is not normal for a young couple and that is motivated by his fear:

(Anthony) *Like I would be ringing her constantly during the day you know, to make sure like....Just small talk...because in the back of your mind you are saying like if I can't get through to her, I am saying 'is she in the house, has something happened to her?'...which is strange for someone, 39 that you are kind of, like my own mother, bloody 80s and I wouldn't be worried like that. Do you know what I mean like, it is just strange in that way, you know?*

Kevin described how he and his wife held clearly defined roles within their relationship prior to the stroke. He had difficulty in adjusting to the changes in these roles and relied heavily on his religious beliefs for comfort and guidance. Similar to Anthony, fear of stroke recurrence was a motivating factor. Kevin provided instrumental support by taking on more responsibility within the household and became more attentive to limiting stress in the relationship:

(Kevin) *we used to argue and stay two or three days without talking, but now it is quicker, because there is no point, because I worry in case, I don't know, she gets upset, it might snap another vein in her brain, so we try to be more calm in the house...*

Discussion

The current study adds to the literature concerning the subjective experience and meaning of stroke for young patients and their spouses through application of the meaning focused and idiographic method of IPA. This study is novel in its inclusion of both partner and patient perspectives as research to date, in Ireland and internationally, has generally focused on patient experience in isolation. Furthermore, insights gained through the current research address notable gaps in the literature on male spouses of young stroke survivors. The key findings in the research relate to: the persistent and pervasive nature of cognitive impairments; the ongoing fear of stroke recurrence; the impact stroke has on relationships; changed lives after stroke; and the positive consequences for both stroke survivor and their spouse. This chapter will discuss the findings in light of existing research in the area. Limitations of the study and directions for further research will also be discussed.

4.1 Sudden and unexplained: will it happen again?

Minimising and normalising symptoms: Previous research has found young adults struggle with self-identity after stroke. They find it difficult to come to terms with the fact they have experienced a condition typically associated with older adults. Low, Kersten, Ashburn, George and McLellan (2003, p.1056) described younger adults with stroke as an “invisible group” because of the strong association between stroke and old age. Findings from the current study support the connections between stroke and old age, evidenced by participants’ attempts to normalise their initial stroke symptoms, disregarding the possibility of stroke, and also in their shocked reactions on diagnosis. However, in contrast to previous findings which point to young adults prematurely

feeling old or aged as a consequence of stroke (e.g. Röding et al., 2003; Stone, 2007), the ageing effect of stroke in terms of self-identity was not apparent. The reasons for this are unclear. It may be that a recent national stroke awareness campaign has effectively highlighted the signs and symptoms of stroke adults (Hickey, Holly, McGee, Conroy, & Shelley, 2012). It may point to greater sensitivity amongst rehabilitation staff regarding the specific needs of younger adults with stroke. In an earlier study conducted at the same site participants reported feeling alienated by rehabilitation staff and suggested a need for greater awareness of the psychological impact of stroke in young adults (Leahy, 2010). Developments and improvements in standard care practices at the research site may partially account for this finding.

Although participants reported frustration about not being able to do ‘normal’ activities that a young person should be able to do, the distinction between pre- and post-stroke lives did not seem pronounced or as discrete as described in previous research (e.g. Leahy, 2010; Röding et al., 2003). When people acquire a chronic illness, like stroke, life stories are interrupted, the sense of coherence is damaged, and thoughts about the future become uncertain and erratic (Corbin & Strauss, 1987). This is known as a ‘biographical disruption’ (Bury, 1982). In the current study, the majority of participants appeared to have adapted to life after stroke and incorporated the consequences of it into their identity. Although frustrated with persistent cognitive impairments, there was a sense that many participants had reached a level of acceptance about their stroke and its impact on their lives, thus preserving a sense of continuity in their life narrative (Secrest & Thomas, 1999). Previous research has shown that non-acceptance of disability, characterised by feelings of resignation, inadequacy and hopelessness, was strongly associated with depression in a sample of stroke survivors,

heterogeneous in terms of age (mean age = 70.13, age range = 32 to 90 years; Townend, Tinson, Kwan, & Sharpe, 2010). Further research is needed that specifically examines the processes by which acceptance of disability occurs following stroke. Such understanding could lead to the development of appropriate strategies for intervention to support those who experience difficulty in reaching acceptance.

Fear of stroke recurrence: Fear of another stroke was reported by all participants, for some it was a constant worry in their lives. Stroke with unknown etiology is particularly common among young adults (Rasura, et al., 2006). Lack of clear casual factors may contribute to heightened fear of recurrence, feelings of powerlessness and loss of control. Ruminations concerning the reason for the stroke and apprehension of stroke recurrence, evidenced in the current study, are also reflected in the literature (Banks & Pearson, 2004; Bendz, 2003; Röding et al., 2003). In the only study to date to specifically examine the phenomenon in a general stroke sample, Townend, Tinson, Kwan and Sharpe (2006) found fear of stroke recurrence to be highly prevalent. In contrast to cancer patients who characteristically worry about recurrence leading to death, stroke patients tend to be more fearful that a recurrent stroke will lead to severe physical or communicative disability (Hanger, Fogarty, Wilkinson, & Sainsbury, 2000; Thewes et al., 2012). In the current research, fear of stroke recurrence led some participants to disengage from activities perceived to be stressful, such as driving, work, and travelling abroad, and physical activities such as swimming. These perceived risk factors and withdrawals from activity may be considered the result of idiosyncratic beliefs about the causes of stroke and may highlight a lack of knowledge concerning stroke risk factors (Townend et al., 2006). Alternatively, such restrictions in activity may signal increasing distress and spiraling anxiety. Education relating to the

causes, symptoms and treatment of stroke may be beneficial in reducing fear of stroke recurrence (Hoffman, McKenna, Worrall, & Read, 2004) and may have positive spillover effects in terms of improved quality of life and greater participation. For those with clinically significant levels of anxiety, formal counseling may be required.

4.2 Changes in daily life

Cognitive Impairments: Cognitive impairments, including limited ability to concentrate, memory problems and difficulties with speech, affected participants' lives in many ways, curtailing their activities and participation and reshaping their view of themselves and perceptions of how others viewed them. Few participants reported residual physical disability, reflecting the typically favourable functional outcomes for young adults with mild stroke reported elsewhere (e.g. Naess et al., 2004; Nedeltchev et al., 2005). Nonetheless, all of the participants reported ongoing residual cognitive impairments. These impairments had a significant impact on their daily lives and were a source of frustration, fatigue and distress. Difficulty in carrying out previously taken-for-granted, basic, tasks like reading, driving and shopping were common. Participants no longer trusted their own judgement; some had difficulty making inconsequential decisions leading to a loss of independence and diminished self-efficacy as they relied on others to guide their decision making. The ongoing decrements in cognitive abilities and the associated burden of these impairments are cause for concern. Participants were acutely aware of the impairments in their cognitive abilities. While problematic in their own right, cognitive impairments also engendered feelings of being different, different than they were before stroke, different from their peers, different on a social level.

Post-stroke fatigue: In their grounded theory study on young stroke Rödning et al. (2003) pointed to the overwhelming and uncontrollable nature of fatigue which

rendered engagement in everyday life extremely difficult and had negative implications for family and social lives. Findings from the current study parallel these results; fatigue was described as a “train wreck” suggesting its devastating and pervasive debilitating effects. Reduction in social activity, reduced working hours and disruption in sleep patterns were frequently reported. In addition to the associated restriction of activity and participation, some participants noted that their personalities had been altered by the effects of fatigue, reporting increased irritability and negative changes in mood. A recent study (Parks et al., 2012) suggested that post-stroke fatigue is more prevalent among young stroke survivors compared to older patients and that it has greater impact on cognitive and psychosocial functioning for younger patients.

Difficulties in diagnosing, addressing and treating post-stroke fatigue are evident. Bendz (2003) examined stroke in young adults (<65 years) from two perspectives; from the perspective of the patients and from the perspective of their clinician. Although patient participants recognised post-stroke fatigue as having significant and negative consequences, it was not referred to or routinely assessed by the medical professionals. None of the participants in the current research mentioned a formal diagnosis of post-stroke fatigue; this may point to difficulty in diagnosis, subclinical levels of fatigue among participants or to lack of routine assessment of fatigue in the post acute period. Others have also documented the significant and disabling nature of post-stroke fatigue for young stroke survivors, noting that the prevalence and consequences of the condition seem to be underestimated in clinical practice (Thompson & Ryan, 2009). There is a need for greater awareness and recognition amongst rehabilitation staff of the presence and psychosocial consequences of fatigue in young adults. Patients also require more information and support in order

to cope with the consequences of fatigue (Lawrence & Kinn, 2012). Rigorous trials of effective strategies to control and manage fatigue are lacking. A recent Cochrane review of interventions to treat post-stroke fatigue identified just three studies that met the reviews' inclusion criteria (McGeough et al., 2009). Neither the pharmacological nor psychological interventions reviewed demonstrated efficacy in reducing fatigue (Choi-Kwon, Choi, Kang, & Kim, 2007; Ogden, Mee, & Utley, 1998; Lorig et al., 2001).

Changed social activities and social stigma: Current findings point to changed social activities as a result on ongoing cognitive impairment. Others have also pointed to major activity and participation restrictions as a result of cognitive impairment after mild stroke (Carlsson et al., 2009; Hommel et al, 2009). Such restrictions have direct implications for general quality of life and life satisfaction (Naess et al., 2006). When coupled with restrictions in social interactions their effect is compounded as people may become isolated and withdrawn. Public spaces and interactions with strangers became difficult and intimidating for participants in the current research, many attempted to avoid such interactions as they were more conscious of their impairments while interacting with people they did not know. Similar findings were reported by Röding et al. (2010) who found that participants were conscious about how they were viewed in public and attempted to hide impairments in order to be accepted socially. The current findings, together with previous research, demonstrate the stigma associated with young stroke. Perceptions of stigma amongst younger adults are also documented in other illnesses that are typically associated with old age (Schrag, Hovris, Morley, Quinn, & Jahanshani, 2003). There is a need for greater awareness on a societal level regarding the prevalence of such conditions and for greater understanding regarding their implications for individuals affected.

Stone (2005) suggested that being young with hidden impairments poses further difficulty as others do not expect young, apparently healthy individuals to have cognitive difficulties. Indeed it is suggested that having a *visible* rather than *invisible* disability may lead to more understanding reactions from others (Leahy, 2010; Murray & Harrison, 2004). While participants worried about receiving unwanted attention from strangers, paradoxically, their impairments remained unnoticed by medical staff. Patients diagnosed with mild stroke are expected to achieve full recovery with minimal intervention (Wolfenden & Grace, 2009). With an emphasis on physical rehabilitation outcomes, hidden cognitive impairments may go unnoticed and untreated in routine clinical follow-ups. For patients experiencing such impairments failures to acknowledge and address these problems may lead to dissatisfaction with the medical profession. The long-term and persistent nature of these problems suggests the need for greater focus on identifying strategies and supports to ameliorate their impacts.

Changes in roles: Stryker (1968, as cited in Terry, Hogg and White, 1999) suggested people construct their identity around the roles they occupy. When roles are disrupted, personal identity may be altered (Thompson & Ryan, 2009). In the current study, participants experienced changes in roles and responsibilities in multiple domains of family, work and social life. Loss of cognitive ability was often reported as a primary reason for negative changes. Female participants reported loss of gendered roles within the family (Röding et al., 2003); the ability to be a '*full*' mother and wife was restricted due to impairments, while some were able to adopt compensatory strategies to regain/maintain their roles others struggled to adapt to enforced changes. Reports of feigning recovery in front of family, demonstrates a strong desire to regain lost roles. Kitzmuller et al. (2012) reported similar findings suggesting that stroke survivors

experience guilt and shame about their inability to fulfil former family roles and expectations and attempt to limit burden placed on others, such as family and friends, by reducing their own activities. In the current study role reversals were also apparent, children became carers for parents. This particular transition was problematic; participants typically struggled to accept their young children taking on a caring role. It is interesting to note for older adults, it may be more common for their adult children to assume a caring role as health deteriorates. However, role reversal as evidenced in the current research, where young children worried about their parent's health brought about feelings of anxiety and guilt in the stroke survivor. Change and loss of roles has been cited in previous research as a source of frustration and anxiety for young stroke survivors and can have a harmful impact on a person's sense of self (Thompson & Ryan, 2009). The current research also provides evidence that the resumption of roles, particularly roles within the family unit, can be beneficial to the stroke survivor in their recovery. The reaffirmation of important and valued roles held within the family contributed to a greater emphasis on the importance of their own health.

Although not a standalone theme in the current research, the issue of work was salient for participants. All of those who were in employment at the time of their stroke subsequently returned to work. For some participants, return to employment contributed to the formation or reformation of their 'post-stroke' selves. This is understandable as for young adults work may be an essential part of life in terms of financial and social capital (Lindstrom et al., 2009). Some viewed returning to work as an important milestone in their recovery from stroke. This suggests that they used it as a mechanism to regain a sense of control over their lives.

Lock et al. (2010) identified a number of barriers and enablers of return to work following stroke: (1) rehabilitation process factors, including information provision and attitudes of rehabilitation staff towards RTW; (2) employer agency factors, including adjustment to work practices, employer attitudes towards stroke ; (3) social structural factors, including social welfare system and health care funding; and (4) personal factors, including individual characteristics and current financial situation. The current findings support both barriers and enablers in returning to work after stroke, particularly in relation to employer agency factors and personal factors. Although all of the participants who were working before their stroke returned to their previous employment, some had to make adjustments to their work practices, moving from manual to more sedentary positions, or relinquishing positions of responsibility. These changes were sometimes unwanted, but seen as necessary because of diminished cognitive ability or fatigue. Participants relied on and were grateful for the support of their employer in facilitating changes in work practices. For others, stroke presented an opportunity to re-evaluate life priorities; some participants made personal decisions to reduce working hours and instead spend more time with family. In these cases, participants reduced the value placed on the importance of their employment in shaping their identity and placed more emphasis on other aspects of their lives such as increased time with their spouse or children. Such reappraisal of life priorities and situations following significant health events has been documented in previous research (Thompson & Ryan, 2009).

4.3 Trying to get better

The role of formal services and supports: Outpatient rehabilitation services were beneficial to patient goals in terms of recovery. Not only did participants receive

exercise regimes and nutritional advice, they also received informal psychological support. Participants used their time with professional staff as an opportunity to discuss ongoing problems and concerns. Rehabilitation staff may be in a better position to respond to such concerns than informal supports, such as family and friends, they typically have experience in dealing with difficulties encountered by young adults with stroke and because they are acting in a professional capacity may be less burdened by disclosures. International clinical guidelines for stroke care propose that all members of the multidisciplinary team should be able to identify and manage psychological issues, even if their role is to simply recognise problems and refer on to the appropriate services (Gillham & Clark, 2011). The current findings highlight the practical and psychological support provided by formal services to young adults in their recovery from stroke. In 3 notable cases, offers of support from formal services were refused. Such refusals highlight the personal and individual nature of responses to stroke and the idiosyncratic models of recovery that individuals may adopt.

Benefit finding and social comparisons: Of note in the current study is the emphasis on positive consequences arising from stroke. Owing to its sudden and unexpected nature, stroke may be considered a traumatic event (Field, Norman, & Barton, 2008) and current findings suggest the presence of post-traumatic growth, or benefit finding. Participants reported increased time with family members, strengthening of spousal relationships and reappraisal of life priorities amongst positive outcomes. Participants felt a sense of good fortune to have survived the stroke and that it was not more severe. This sense of luck provided participants with the impetus to reappraise their lives after stroke and to make positive changes in terms of their health, family and life goals. These findings are supported by studies in stroke and in other

illnesses. For example, Gillen (2005) found that the majority of stroke survivors interviewed were able to identify positive consequences of their stroke, including increased health awareness and personal growth. Similarly, Thambyrajah, Herold, Altman, and Llewellyn (2010) reported improved personal resources, an enhanced sense of purpose, closer relations with others, and changes in life priorities in a study exploring the experiences of cancer patients in remission. Post-traumatic growth, also known as benefit finding (Affleck & Tennen, 1996), has been positively associated with improved mood (McGrath & Linley, 2006) and higher quality of life (Tomich & Helgeson, 2012) in patients with ongoing illness. From a study examining positive consequences of people who experienced a traumatic injury, Turner and Cox (2004) proposed a number of ways in which post-traumatic growth may be facilitated by rehabilitation staff, including recognising the worth of each individual, facilitating conversation about goals and potential, actively involving each person in their own recovery and recognising changes to individual's sense of self.

The use of downward social comparison was common during the recovery phase particularly while participants were hospitalised. Social comparisons influence both emotional regulation and coping (Taylor, Buunk, & Aspinwall, 1990). For some participants, comparisons highlighted areas of their functional and cognitive ability that had not yet improved or gave a glimpse into what their 'new' life would be like if they were unable to recover fully. Whether a person views downward social comparisons as positive or negative has been linked to individual factors such as self-esteem and perceived control (Buunk & Mussweiler, 2001). The majority of participants compared themselves favourably to other patients on the ward, and felt that they were 'lucky' to have made more progress in terms of recovery than others. Reed, Harrington, Duggan,

and Wood (2010) found similar results examining the needs of stroke survivors within the community. They found that participants often compared themselves to others with stroke who they perceived as ‘more’ disabled, which resulted in increased self-esteem. The impact of peer comparisons within the community was not documented in the current research, the majority of social comparison instances reported related to participants’ experience of being on a hospital ward during the acute stage of recovery. The lack of contact with people in a similar situation as their own restricts participants’ perception of their own recovery, as they have no one to compare themselves to. The recent development of a voluntary community stroke support group attached to the hospital, where the research was carried out, is encouraging, although greater awareness of the group is needed for patients already discharged into the community. A recent audit of stroke care in Ireland (Horgan et al., 2008) reported that half of respondents would have liked information in relation to voluntary support groups in their area but did not receive any.

4.4 Relationship Changes

Strengthening bonds and relationship difficulties: Stroke has been described as a family illness as life changes that occur after stroke may have long-lasting consequences for all family members, particularly the spouse or partner (Visser-Meily et al., 2006). Foster et al. (2012, p.2) suggest “family can be considered the most important members of the rehabilitation team (in addition to the client themselves)”. Yet at the same time family members rarely receive training and support in their roles as central rehabilitation workers (Visser-Meily et al., 2006). Interestingly, despite the difficulties and stresses associated with stroke, the majority of stroke survivor participants in the current study reported little or no negative changes in their relationship with their

spouse or partner following their stroke. In fact, many reported feeling closer to their spouse or partner than before. This may reflect positive communication among many of the stroke survivors and spouse/partners. Participants commented on how they were able to speak openly about problems they were experiencing and their feelings towards their stroke and towards each other. In contrast, communication appeared to be difficult for those who did find negative changes in their relationship with their spouse/partner. Communication may be viewed as a central process within a relationship and when it is reduced or removed completely, it can result in problem-solving and coping difficulties for the dyad (Day, 2010). Banks and Pearson (2004) reported a lack of communication among participants and spouses/partners after stroke, even though both were usually worried about similar issues, suggesting a need for greater education for spouses/partners on the consequences of stroke and, in some instances, the provision of support services such as couples counselling (Thompson & Ryan, 2009).

Some participants provided examples of how their spouse/partner helped them in their recovery by taking an active role in their rehabilitation. This was achieved through encouragement and an effort on the part of the spouse/partner to understand the condition. It appeared that many participants viewed their spouse/partner as being on the same team as them in terms of recovery. Similarly, Kitzmüller, Asplund and Häggström (2012, p. E8) reported that the ability to solve problems relating to stroke as a couple was viewed in terms of a “shared victory”. However, sometimes support from spouses/partners was perceived as over-bearing and inappropriate. Persistent expressions of concern resulted in feelings of distress and suffocation, findings that have been highlighted elsewhere (e.g. Leahy, 2010). Increased health monitoring behaviour and persistent ‘checking up’ by the spouse/partner, although well intentioned,

may have resulted in a loss of independence and self-efficacy from the participants' point of view. Carlsson et al. (2004, p.1378) also noted that stroke survivors felt that too much support from their spouses "hindered" them, resulting in imbalanced relationship dynamics.

Owing to the trauma and the life-threatening nature of a stroke event, thoughts about one's own mortality may be brought into consciousness and thus the issue may be raised within the relationship. Issues surrounding mortality and chronic illness are not typically to the fore amongst younger adults. The current research has shown that these thoughts within the relationship brought about feelings of closeness and a deeper appreciation for their spouse/partner. Previous research has studied self-perceived burden of older stroke survivors in relation to spouses, reporting a high prevalence rate (McPherson, Wilson, Chyurlia, & Leclerc, 2010). In their study of young stroke patients, Banks and Pearson (2004) noted that some participants expressed worry about being a burden on their spouse/partner, an issue reflected by one participant in the current study. Lack of independence and a perceived lack of control in recovery contributed to feelings of self-perceived burden. However, most participants acknowledged the difficulties their partners experienced but felt that they dealt with problems as an equal team.

A stroke is a sudden and shocking event; previous research has shown that it can be a time for the stroke survivor to reappraise their life situation, including their relationship with their significant other (Bendz, 2003; Röding et al., 2003). The current research findings suggest that for the most part, relationships remained strong after stroke, perhaps reflecting a continuation of previous relationship status. This may also reflect the small number of stroke survivors reporting negative changes in their relationship with their spouse/partner. Perhaps for some, the new sense of perspective

arising from stroke served to consolidate and escalate previously held thoughts concerning their relationship with their spouse/partner. The predominantly positive relationship impacts identified by participants in the current study contrast with findings reported by Banks and Pearson (2004) who reported that negative changes in spousal relationships were prevalent. Differences in patterns of communication and premorbid relationship characteristics may offer some explanation for these contrasting results.

4.5 Loss and Change

The current study adds to the understanding of experiences of spouses of young stroke survivors. Overall, it appears that spousal participants adjusted well to life after stroke. Nonetheless, changed relationship dynamics and feelings of loss in relation to their life before stroke were evident. Uncertainty and apprehension characterised spouses' initial reactions to stroke, these feelings still present at time of interview. Although spousal participants focused on changes in their partner, it is clear they themselves also changed as a result of the stroke.

She is not the same person: Spousal participants experienced change, loss and growth in their relationships after stroke. They related stroke as a condition of the elderly, which added to their shock and apprehension, an issue highlighted in previous research (Hunt & Smith, 2004). Application of illness representations based on stroke in older adults led to catastrophic thinking, heightened distress and anxiety, suggesting a need for greater information provision for spouses of stroke survivors during the acute stage of stroke. Fear about the possibility of their wife's stroke leading to death or severe disability subsided after the acute stage, and was replaced by feelings of loss and change. The transition from hospital to home marked a realisation of the extent of impairment and disability. The rate of gain in functional and cognitive recovery

typically slowed and the substantial improvements evident in the early post stroke period gave way to a plateau in recovery. Realisation that 'full' recovery would be a very long term prospect, if achievable, was met with distress and uncertainty about the future. Discharge home from hospital may also mark a transition of responsibility (Banks & Pearson, 2004); while in hospital, the locus of responsibility for the care of the stroke survivor was with medical professionals, it now lay with the spousal participants.

The current findings reiterate the sense of loss experienced by spousal participants documented elsewhere: loss of leisure and social participation, loss of spontaneity, but above all, spouses felt they lost certain parts of their marital partner. Alterations in personality and mood contributed to feelings that their wife was not the same person as before. Loss of spontaneity and a sense of being a 'normal' young couple were also evident. The theme of loss is common throughout the qualitative stroke caregiver literature and has been described as a "multi-dimensional experience" (Coombs, 2007, p. 116). Loss of independence (Greenwood, MacKenzie, Cloud, & Wilson, 2010), loss of leisure activities (Forsberg-Wärleby et al., 2004) and loss of spouses' previous everyday life (Saban & Horgan, 2012) has been documented.

Supporting roles – changes in relationship dynamics: Change was experienced in relationship dynamics. Prior to the stroke, caring may have been viewed as a mutually balanced and reciprocal process, with both individual's needs being met and supported. After stroke spousal participants were compelled to take on a more defined role as a 'carer'; one participant likened his wife's needs in the early acute period to that of a child. Spousal participants had to adjust to new relationship dynamics, their partners' emotional and practical support needs were regarded as more important than

their own. In a sense, stroke survivors took centre stage in the relationship, with spousal participants playing a supporting role. Spousal participants felt it necessary to avoid expressing their thoughts and feelings to their partner, fearing that it would cause them further stress and anxiety. Although emotional and instrumental support provided by spouses can improve functional and psychological outcomes for the survivor (Carod-Artal & Egido, 2009; Morris & Morris, 2012), the suppression of emotion and feelings by spousal participants may lead to difficulties in terms of the adjustment and recovery of the relationship (Robinson et al., 2005). While spousal participants were mindful of not causing untoward stress to their partner, such avoidance of emotional expression may result in feelings of isolation and burden (Green & King, 2010; Visser-Meily et al., 2009). Partners of stroke patients may benefit from greater information provision and formal support services in coping with evolving challenges following stroke. The national audit of stroke care concluded that ‘dramatic improvements’ were necessary in provision of information concerning the consequences stroke may have on both the person affected and their family (Horgan et al., p. 58). Findings from the current research further highlight potential for improved information and support provision

Spouses reported a strong desire to care for and protect their partner following discharge from hospital. This can disrupt the equilibrium within the relationship (Buschenfeld et al., 2009). Although only one spousal participant explicitly identified himself as assuming a caring role for his wife, others described themselves as being over-protective. Buschenfeld et al. (2009, p.1648) suggested that spouses exhibit over-protective behaviour towards their stroke survivor partner as the result of a “fear orientation” about further strokes. A fear orientation was apparent in the current findings, with spousal participants fearful of the future and the possibility of stroke

recurrence. The current findings suggest that as a result of a “fear orientation” male spouses assume a gendered role of ‘protector’. This is in contrast to recent findings. Kitzmüller et al. (2012) reported that while male spouses encouraged their partners to engage in demanding activities, female spouses were often overprotective and restricted their husband’s participation in activities.

Even though spousal participants experienced loss in some aspects of life, through the experience of stroke they also gained new perspectives. Reappraisal of life priorities was apparent among spousal participants. Some acknowledged a strengthening of their relationship with their wife, brought about by a greater appreciation for what they as a couple had been through, supporting previous findings (Haley et al., 2009). In addition to positive outcomes in relationship status, personal reappraisals, such as a changes in how participants viewed employment and worrying about the ‘little things’ in life were also apparent. A recent review of positive experiences of caregiving in stroke suggested the need for a more balanced view of caregiving in stroke, incorporating both positive and negative experiences (Mackenzie & Greenwood, 2012).

4.6 Limitations

The current study offers novel insight into the lives of young adults and their partners after stroke; however, some caution is warranted with respect to interpretation of these results. The current research was cross-sectional and offered a snapshot of participants’ lives after stroke. As it was apparent that participants were at different stages in their rehabilitation and perception of recovery, further research is necessary to explore adjustment to stroke longitudinally. Questions were posed that covered an extended period of time (i.e. from time of stroke, to time of interview) and selective

recall may have been present in individual responses. Furthermore, as stroke affects the entire family, further research is needed on the effect on other family members, such as children and parents.

4.7 Conclusion

The current research has contributed to understanding the meaning and experience of mild stroke, through its novel exploration of stroke amongst young adults and their spouses. Persistent cognitive impairments experienced by the stroke survivor affected both members of the relationship. For participants with stroke, impairments resulted in the inability to carry out daily tasks, loss of previously held roles and perceived stigma. For spousal participants cognitive impairments led to perceptions of difference. Greater recognition of cognitive impairments by medical staff, through routine follow-up and information provision, may make it easier for young adults with stroke and their partners to accept and integrate impairments into their lives. Although participants with stroke reported receiving good support from formal services and their partners, spousal participants appeared to lack such support. Spouses of young adults with stroke require emotional and practical support, through information provision and in some instances support groups and formal counseling. Even though both participants with stroke and spousal participants were still experiencing ongoing difficulties as a result of stroke, positive consequences were reported frequently. Insights gained here contribute to a richer and more balanced understanding of the implications of stroke for young couples.

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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.

Appendix 1 – Interview Schedules

Interview Schedule: People who have experienced a stroke.

1. Can you tell me a bit about yourself?
2. Can you tell me about the day you had your stroke.
 - a. Who was with you?
 - b. Can you remember what thoughts were going through your head on that day? Were you able to make sense of what was happening with you?
 - c. Did anything stick out in your memory about your time in hospital?
 - d. How do you think it was for your partner/family when you were in hospital?
3. What was it like returning home after your stay in hospital?
 - a. How do you think your partner felt about you returning home?
 - b. What was the reaction like from your friends after your stroke?
 - c. Was everyday life different for you and your partner when you returned home?
4. How have things changed for you since you had your stroke.
 - a. How do you think things have changed for your partner since your stroke?
 - b. How do you think things have changed for your relationship since your stroke?
 - c. Perhaps financially, emotionally or physically.
 - d. What are your thoughts about the future? Have your goals/plans changed? What about your partner's goals/plans?
5. How has your social life been since your stroke?
 - a. Do you still get to do the same activities/hobbies/sports/socialising as before? How does this make you feel?
6. Did the stroke introduce any situations in your life that you could look upon as being positive/negative?
 - a. Do you think your partner has seen anything positive/negative coming from your stroke.

7. Is there anything that you feel is important that I have missed? Is there anything else you would like to talk about?

Interview Schedule: Partners of those who have experienced a stroke.

1. Can you tell me a bit about yourself?
2. Can you describe what you were feeling on the day of your partner's stroke?
 - a. What was it like for you when your partner was in hospital.
3. How did you feel when your partner returned home from hospital following the stroke.
 - a. What did you have to do differently, if anything?
 - b. What areas of life most concerned you about your partner returning home?
 - c. Were there any things that you had to do differently? Do you feel you had new roles within the household?
4. Has your relationship with your partner changed at all since his/her stroke.
 - a. How do you think things have changed for your partner since your stroke.
 - b. Perhaps financially, emotionally or physically.
 - c. What are your thoughts about the future? Have your goals/plans changed? What about your partner's goals/plans?
5. How has your social life been since your partner's stroke?
 - a. Do you still get to do the same activities/hobbies/sports/socialising as before? How does this make you feel?
6. Did the stroke introduce any situations in your life that you could look upon as being positive/negative?
 - a. Do you think your partner has seen anything positive coming from his/her stroke?
7. Is there anything that you feel is important that I have missed? Is there anything else you would like to talk about?

Appendix 2 – Information Sheets

Information sheet for Potential Participants*

(People who have experienced a stroke)

* Please note that research design was originally planned as a longitudinal mixed-methods approach, which was subsequently changed.

Researchers: Mr James Hanney, Dr Deirdre Desmond, Dr Rónán Collins, Professor Desmond O’Neill, Dr Tara Coughlan.

Introduction

You are being invited to take part in a research study entitled “Stroke in young adults”. Before you decide to take part or not, it is important that you understand why the study is being conducted and what it will involve. Please take time to read the following information carefully and feel free to discuss it with others. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The aim of this study is to explore the meaning and experience of stroke in young adults and their partners. Very little is known about the experience of a young person with stroke in Ireland, even though about one in five people who experience a stroke are under the age of 65 years. Even less is known about the experience of partners of stroke survivors. The study is being supervised by Dr. Rónán Collins, Director of Stroke Service and Consultant Physician in Older Adult and Stroke Medicine at the Adelaide and Meath Hospital incorporating the National Children’s Hospital and Dr. Deirdre Desmond, Department of Psychology at the National University of Ireland Maynooth.

Why have I been invited?

You have been chosen to take part in this study as you have experienced a stroke.

Do I have to take part?

No, it is completely up to you whether you take part or not. If you decide to take part, you will be given this information sheet, and asked to sign a consent form to show you have agreed to take part. You are free to withdraw at any time without giving a reason.

What will happen to me if I take part?

You are being asked to take part in three research sessions over the course of a year. Each session will involve taking part in a one-to-one interview and completing a questionnaire. The interview will involve talking about your thoughts and feelings about your stroke and your experiences during and after your stay in hospital. Each interview will last about an hour and will be audio-recorded and transcribed so that the data may be analysed. No one will listen to the audio recording of the interview, apart from the members of the research team. Information will remain confidential. Please note that participation in the interview does not constitute any kind of counselling or medical treatment. The questionnaire asks questions about your quality of life, mood and how you are coping and will take approximately 15 minutes to complete. If you are interested in taking part, please fill out the *Willingness to Participate* form below and return it in the stamped addressed envelope provided.

What are the possible risks of taking part?

There are no physical risks in this study. There is a risk that when discussing your experience of your stroke, you may experience emotional discomfort. If you feel

uncomfortable or distressed at any stage, you can withdraw without any consequences. In addition, the research team will support you in accessing suitable support systems if required.

What are the possible benefits of taking part?

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

What information will be held about me?

If you agree to take part, information that you provide during the interview will remain confidential within the research team (as listed above). This means that your partner, if he/she wishes to participate, will not be provided with any information concerning your responses during the interview process. You are free to discuss your responses with each other outside of the research setting if you so wish.

Information that you give will be securely stored in the Department of Psychology at NUI Maynooth. The researcher, Mr. James Hanney, will be responsible for safety and security of the data. The procedures for handling, processing, storage and destruction of your data will be compliant with the Data Protection Act 1998.

What will happen to the results of the study?

The results of the study will be used to contribute to the small but growing amount of research concerning the experience and impact of stroke in young adults. Information provided by each participant will be combined and analysed and reported in a postgraduate thesis. Direct quotations will not include any names or any other personal information. Future publications may include the use of direct quotations from your interview. Please note that may be possible, even with the removal of personal identifying information, that your partner may be able to identify you.

What will happen if I don't want to carry on with the study?

Your participation in the study is entirely voluntary. Your partner's participation is also entirely voluntary. If your partner does not wish to participate, it does not affect your participation. You are free to decline to enter or to withdraw from the study any time without having to give a reason. If you choose not to participate in the study, or to withdraw once entered, you will not be penalised. Any participation you had in the study previous to your departure from the study will be stricken from the record and destroyed if you so wish. Participation in this study will in no way affect your legal rights.

Who is organising and funding the research?

This research is being organised by a research team from the Adelaide and Meath Hospital, Dublin Incorporating the National Children's Hospital and the Department of Psychology, National University of Ireland Maynooth, County Kildare. The research is funded by the Irish Heart Foundation Noel Hickey Bursary and the Meath Foundation.

Will you be paid if you join this study?

You will not be paid for your participation in this study.

Complaints

If you have any concerns about this study, please contact a member of the research team who will do their best to answer your questions:

Mr. James Hanney (postgraduate student researcher): e-mail james.hanney@nuim.ie

Dr. Rónán Collins (External Research Supervisor): e-mail Ronan.Collins2@amnch.ie

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 research.ethics@nuim.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

You will be given a copy of the Information sheet and a signed consent form to keep.

Thank you for taking time to read this sheet.

If you have any queries regarding this study, please contact me at the following:

Name: James Hanney

Address: Department of Psychology,
National University of Ireland Maynooth,
Maynooth, Co. Kildare.

Email: james.hanney@nuim.ie

INFORMATION SHEET FOR POTENTIAL PARTICIPANTS (PARTNERS OF PEOPLE WHO HAVE EXPERIENCED A STROKE)

Researchers: Mr James Hanney, Dr Deirdre Desmond, Dr Rónán Collins, Professor Desmond O'Neill, Dr Tara Coughlan.

Introduction

You are being invited to take part in a research study entitled “Stroke in young adults”. Before you decide to take part or not, it is important that you understand why the study is being conducted and what it will involve. Please take time to read the following information carefully and feel free to discuss it with others. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The aim of this study is to explore the meaning and experience of stroke in young adults and their partners. Very little is known about the experience of a young person with stroke in Ireland, even though about one in five people who experience a stroke are under the age of 65. Even less is known about the experience of partners of stroke survivors. The study is being supervised by Dr. Rónán Collins, Director of Stroke Service and Consultant Physician in Older Adult and Stroke Medicine at the Adelaide and Meath Hospital incorporating the National Children’s Hospital and Dr. Deirdre Desmond, Department of Psychology at the National University of Ireland Maynooth.

Why have I been invited?

You have been chosen to take part in this study as you a partner of someone who has experienced a stroke.

Do I have to take part?

No, it is completely up to you whether you take part or not. If you decide to take part, you will be given this information sheet, and asked to sign a consent form to show you have agreed to take part. You are free to withdraw at any time without giving a reason.

What will happen to me if I take part?

You are being asked to take part in three research sessions over the course of a year. Each session will involve taking part in a one-to-one interview and completing a questionnaire. The interview will involve talking about your thoughts and feelings about your partner's stroke and your experiences while your partner was in hospital. Each interview will last about an hour and will be audio-recorded and transcribed so that the data may be analysed. No one will listen to the audio recording of the interview, apart from the members of the research team. Information will remain confidential. Please note that participation in the interview does not constitute any kind of counselling or medical treatment. The questionnaire asks questions about your quality of life, mood and how you are coping and will take approximately 15 minutes to complete. If you are interested in taking part, please fill out the *Willingness to Participate* form below and return it in the stamped addressed envelope provided.

What are the possible risks of taking part?

There are no physical risks in this study. There is a risk that when discussing your partner's stroke and your own experiences of that, you may experience emotional discomfort. If you feel uncomfortable or distressed at any stage, you can withdraw without any consequences. In addition, the research team will support you in accessing suitable support systems if required.

What are the possible benefits of taking part?

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

What information will be held about me?

If you agree to take part, information that you provide during the interview will remain confidential within the research team (as listed above). This means that your partner, if he/she wishes to participate, will not be provided with any information concerning your responses during the interview process. You are free to discuss your responses with each other outside of the research setting if you so wish. Information that you give will be securely stored in the Department of Psychology at NUI Maynooth. The researcher, Mr. James Hanney, will be responsible for safety and security of the data. The procedures for handling, processing, storage and destruction of your data will be compliant with the Data Protection Act 1998.

What will happen to the results of the study?

The results of the study will be used to contribute to the small but growing amount of research concerning the experience and impact of stroke in young adults. Information provided by each participant will be combined and analysed and reported in a postgraduate thesis. Direct quotations will not include any names or any other personal information. Future publications may include the use of direct quotations from your interview. Please note that may be possible, even with the removal of personal identifying information, that your partner may be able to identify you.

What will happen if I don't want to carry on with the study?

Your participation in the study is entirely voluntary. Your partner's participation is also entirely voluntary. If your partner does not wish to participate, it does not affect your participation. You are free to decline to enter or to withdraw from the study any time

without having to give a reason. If you choose not to participate in the study, or to withdraw once entered, you will not be penalised. Any participation you had in the study previous to your departure from the study will be stricken from the record and destroyed if you so wish. Participation in this study will in no way affect your legal rights.

Who is organising and funding the research?

This research is being organised by a research team from the Adelaide and Meath Hospital, Dublin Incorporating the National Children's Hospital and the Department of Psychology, National University of Ireland Maynooth, County Kildare. The research is funded by the Irish Heart Foundation Noel Hickey Bursary and the Meath Foundation.

Will you be paid if you join this study?

You will not be paid for your participation in this study.

Complaints

If you have any concerns about this study, please contact a member of the research team who will do their best to answer your questions:

Mr. James Hanney (postgraduate student researcher): e-mail james.hanney@nuim.ie

Dr. Rónán Collins (External Research Supervisor): e-mail Ronan.Collins2@amnch.ie

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 research.ethics@nuim.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

You will be given a copy of the Information sheet and a signed consent form to keep.

Thank you for taking time to read this sheet.

If you have any queries regarding this study, please contact me at the following:

Name: James Hanney

Address: Department of Psychology,
National University of Ireland Maynooth,
Maynooth, Co. Kildare.

Email: james.hanney@nuim.ie

Appendix 3 – Consent Form

Title of project: Stroke in young adults.

Researchers: Researchers: Mr James Hanney, Dr Deirdre Desmond, Dr Rónán Collins, Professor Desmond O’Neill, Dr Tara Coughlan.

Please read the following statements and **tick** the boxes provided:

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions and have had these answered satisfactorily.	
2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study.	
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
4. I understand that participation in the study does not constitute any kind of counselling or medical treatment.	
5. I agree to take part in the above study.	
6. I understand that I will be contacted by the researcher over the course of the following year in order to schedule research sessions.	

Name of participant Date Signature

Name of person taking consent Date Signature

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

Mr. James Hanney,
Postgraduate research student,
Department of Psychology,
National University of Ireland, Maynooth,
Maynooth, Co. Kildare.
Telephone: (087) 126 08 15.

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
(National University of Ireland Maynooth)

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



NUI MAYNOOTH
Óliscoll na hÉireann Má Nuad

Dr Carol Barrett
Secretary to NUI Maynooth Ethics Committee

28 June 2011

James Hanney
Psychology
NUI Maynooth

RE: *Application for Ethical Approval for a project entitled:*
"Stroke in young adults: a longitudinal, mixed-methods investigation of coping, continuity and transformation in post-stroke couples"

Dear James,

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

Kind Regards,

Dr Carol Barrett
Secretary, NUI Maynooth Ethics Committee

CC Deirdre Desmond