

Patient perceptions having suffered a stroke in Galway

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World wide, 15 million people experience a stroke every year, 5 million of which result in permanent disability (WHO, 2007). In Ireland the National Audit on Stroke (2008) identified that of the estimated 10 000 people annually who have a stroke about 2 500 will die, the remainder will continue to live with some residual disability. Most strokes occur in those above 65 years of age. People are living longer, so an increasing number of older people will be living with this disability in the future. It is of vital importance to understand their experiences so that health care structures and policies may be modified, devised and implemented which meet the needs of this vulnerable group.

Aim

The aim of this study was to explore Irish older people's perception of their health and level of independence following a stroke, as well as illuminate the factors that enhanced or diminished their ability to maintain quality-of-life after their stroke.

Literature review

Stroke has a negative influence on the quality-of-life for

sufferers (Widar, Ahlström and Ek, 2004; Robinson-Smith, Johnston and Allen, 2000). Some older people suffering from stroke reported a reduction in physical mobility and energy (Gosman-Hedström and Blomstrand, 2003). Whereas, Pound, Gompertz and Ebrahim (1999) reported that following the initial acute period, stroke patients find new ways of doing things and adapt to their disability and improve their quality-of-life.

Personal and environmental factors influence stroke survivor's ability to engage in social participation (Vincent et al, 2007). McKeivitt et al (2004) found in their systematic review which examined life after the acute event, that many studies reported sense of loss as a key theme. This included loss of identity, loss of activities, capabilities, independence, emotional and social loss. Clarke and Black (2005) found that patients reported that they could no longer engage in activities they previously enjoyed such as:

- ◆ Gardening
- ◆ Reading
- ◆ Travelling.

While others reported they could no longer drive or engage in their careers. Likewise, Hare et al (2006) found that most patients reported a lack of confidence and fear of leaving the house which prevented them from re-engaging in the social activities undertaken pre-stroke.

Levasseur et al (2004) examined the relationship between self perceived environment and subjective quality-of-life of a group of older adults with physical disability living in the community. The results suggest that the social environment was more important than the physical. Widar, Ahlström and Ek (2004) found that health-related quality-of-life outcomes could be improved by good relationships and support from others. Widar, Ahlström and Ek (2004) pointed to the need to consider relatives in the rehabilitation process so that they could provide emotional support and maintain good relationships with the patient. Pound, Gompertz and Ebrahim (1999) also found that families were the most important resource for stroke patients.

A supportive environment is key to maintaining stroke survivors, valued, life activities and reconstructing meaning in their lives (Clark and Black, 2005). The immediate physical environment, for example, negotiating access throughout the house has a major influence over the functioning of stroke survivors (Reid, 2004). Access to enough

ABSTRACT

Of the estimated 10 000 people annually who have a stroke in Ireland, about 7 500 will continue to live with some residual disability. This study explored older people's perceptions of health, level of independence as well as the factors that enhanced or diminished ability to maintain quality of life after stroke. A grounded theory approach was used and 20 stroke survivors were interviewed. Analysis of the data revealed three main themes: concepts of health and independence, sense of loss, and environmental factors. Despite their disability most participants continued to have a positive concept of health. Participants overall adopted a functional approach toward independence and those with severe disabilities felt less independent. Many reported a profound sense of loss in terms of identity and role function. Environmental factors including availability of transport and social connections had a significant impact on quality of life. Most participants appeared to be struggling to adapt to their disability and subsequent experiences in a rather unsupportive environment.

KEY WORDS

Stroke ◆ Disability ◆ Rehabilitation ◆ Qualitative research

Table 1. Participant's demographics (n = 20)

Codes	Age	gender	Length of time since stroke	Living arrangements	Urban/Rural	Residual disability	
SD05	71	M	1 year	Home - living with spouse	urban	Some paralysis in right hand and walks with a stick	walking
SD07	86	F	1 year	Home - lives alone	urban	Walking uses zimmer frame and wheelchair when outside	walking
SM01	80	F	1 year	Home - lives alone	rural	Walks with the aid of a crutch	walking
SM07	77	M	1.3 years	Home - living with brother	rural	Some slight paralysis of left hand	
SD01	82	F	1.7 years	Home - lives alone	urban	Nil	Nil
SM02	73	M	1.8 years	*LTC	LTC	Speech difficulties and uses a wheelchair	walking & talking
SM03	77	M	2 years	Home - living with partner	rural	Uses a wheelchair and some paralysis in left hand	walking
SD03	77	F	2.4 years	Home - lives alone	urban	Walks with the aid of a stick	walking
SD02	77	M	2.7 years	Home - living with spouse	urban	Some difficulty seeing and loses balance	Seeing
SD06	77	M	2.9 years	Home - living with spouse	urban	Nil	Nil
SM12	88	F	3 months	LTC	LTC	Speech difficulties and uses a wheel chair; some paralysis of right hand	walking & talking
SM10	70	F	3 years	LTC	LTC	Uses a wheelchair and some paralysis of left hand	walking
SM05	65	M	3.7 years	Home - living with spouse	rural	Some paralysis of right hand and walks with the aid of a stick	walking
SM11	70	F	4 years	LTC	LTC	Uses a wheelchair	Nil
SM04	75	M	4 years	LTC - wheelchair	LTC	Some paralysis of right hand and uses a wheelchair	walking
SM06	80	F	5 years	LTC	LTC	Some paralysis of left hand and uses a wheelchair	walking
SM08	78	F	5 years	LTC	LTC	Some paralysis of right hand and uses a wheelchair	walking
SD08	86	M	7 months	LTC	LTC	Uses a wheelchair	walking
SD04	80	M	8 months	Home - Living with spouse	urban	Some difficulty seeing and gets dizzy; loses balance	Seeing
SM09	87	F	9 years	LTC	LTC	Some paralysis of left hand and uses a wheelchair	walking

*LTC = Long term care

money to make appropriate modifications and retain some level of independence is not always an option. In some instance stroke survivors are forced to leave their homes and reside elsewhere due to environmental or personal barriers (Rowles, 1987).

Many researchers identified the importance of promoting independence as a goal of care for older people (Davies et al, 1997; Stabell et al, 2004). However, there is little consensus as to the meaning of these terms (Davies et al, 2000). Some researchers take a functional approach defining dependence or independence as what a person can or cannot do by themselves (Goodwin et al, 2003 and Covinsky et al, 2003). The shift from independence to dependence is a crucial point for older people, in particular, when an illness or disability makes them housebound. When this happens, autonomy, sense of identity and relationships with others should be

reviewed (McKevitt et al, 2005). Material circumstances and income have been identified as important to quality-of-life (Farquhar, 1995; Bowling et al, 2003; Browne et al (1994). Some stroke survivors maintain a sense of independence and control as they can afford hired home help (Reid, 2004). In summary, the literature reveals that stroke victims experience both physical and emotional problems. However, few studies have examined these issues in an Irish context.

Methods

Semi-structured interviews were used to collect the data and a grounded theory approach was used to guide sampling and analysis. Purposive sampling was employed to select 20 patients over the age of 65, who were living with a stroke and who were willing and able to participate. It was deemed that patients would probably have different experi-

ences related to the length of time spent living with their disability, whether they lived at home or in residential care, and whether they were living in a rural or urban environment. The sample was therefore stratified to ensure this was factored in (Table 1).

Access to the sample was obtained via advanced nurse practitioners (ANP) or clinical nurse specialists (CNS) working with stroke patients. These nurses supplied an anonymous list of patients who fulfilled the above criteria and the researcher, who was also a registered nurse with experience of working with older people, randomly selected patients from these lists. The ANP or CNS nurse then contacted the selected individuals to explain the study and to obtain informed consent. These interviews were carried out over a six-week period.

Ethics

Anonymity and confidentiality were guaranteed and ethical approval was obtained. As these patients were a vulnerable group, careful consideration was given to the nature of 'informed consent'. All patients were provided with verbal and written information about the study and the research team ensured that participants understood what the study was about and what participation meant prior to gaining consent. Patients were informed of their right to withdraw with no consequences. All were allocated a study number and all data was identifiable by this number only.

Credibility and trustworthiness

The criteria devised by Lincoln and Guba (1985) which includes credibility, dependability, conformability and transferability were used to maintain rigor. The interview guidelines were used consistently and two experienced nurse researchers independently coded the transcripts. Comparisons of coding frameworks revealed overall agreement. The richness of the data obtained allows judgments to be made as to the appropriateness of the findings to other similar groups of people and or contexts.

Analysis

After each data collection period, data were transcribed verbatim and the accuracy of the transcriptions checked by listening to the tapes. Data analysis was guided by the grounded theory approach using the constant comparative technique which meant that data collection and analysis occurred simultaneously (Glaser and Strauss, 1967).

Findings

The analysis of the data revealed three main categories, namely:

- ♦ Concepts of health and independence
- ♦ Sense of loss
- ♦ Environmental factors.

Concepts of health and independence

This category describes the onset and impact of stroke patients' concepts of health and their perceptions of inde-

pendence and dependence.

Having a stroke was clearly a turning point in the patients' lives and most participants described their life in terms of 'pre-stroke' and 'post-stroke.' Patients described the onset of a stroke as sudden and traumatic, which occurred either while they were undertaking an activity, for example shopping, or just relaxing quietly at home:

'I just got up one morning went into the bathroom and I couldn't see what was in front of me... I just got out of bed and that was the way it happened'. (SD02)

The stroke resulted in key lifestyle changes for all patients and the majority were left with some residual deficits including weakness or paralysis on one side of the body, speech difficulties and vision loss. The majority of patients reported that mobility and walking had become difficult. Most patients despite having had a stroke held a positive concept of their health, perceiving themselves to be healthy. Those patients with severe disabilities felt that as they retained the ability to do some self caring activities unassisted that they, too, were healthy. Likewise most patients defined independence in terms of the extent to which they were able to do things for themselves unassisted and dependence as the absence of independence. Understandably those with more severe disabilities felt less independent as they were reliant on their spouse/ partner or nursing staff to undertake the activities of daily living.

'She (partner) brings me to bed each night, and she has to undress me, and put on my night clothes, and put me into bed, and cover me over and all the rest of it' (SM03)

This increased dependence on others for assistance led to feelings of helplessness and depression for some. Others commented on the fact that they now felt like a prisoner within their own body or within their own home:

'Some days I feel very downhearted... I think what I was able to (do) and what I'm not able to do now... you are looking at four walls... it's like prison actually.' (SD02)

A few patients reported that once the immediate stroke rehabilitation period was over they received little support to help them regain independence in physical functions such as walking. They described services as fragmented, unstructured and unavailable.

Some had adjusted to the changes brought on by the stroke emphasizing that they now made the best of their current situation. They described the importance of having a positive outlook as paramount in maintaining independence. Others described how they motivated themselves to persevere and maintain as much independence for as long as possible. For other patients, becoming more dependent on

Levels of function differ in stroke survivors

others engendered a fear of becoming a burden on family and relatives, or having to move into long-term residential care. In addition, the negative impact their disability had on their loved ones was a concern for those whose spouse or partner was their main carer:

'For my wife this is sort of restricting, its restricting her life as well as mine. I feel sort of a bit guilty about that'
(SD05)

Sense of loss

This theme describes the sense of loss experienced and the mechanisms used to retain some control over their lives. Some mourned the changes in their sense of identity and sense of self, the loss of control over managing their personal affairs, and the loss of personal pastimes and pursuits.

Some reported that the stroke meant that they had to retire and they therefore lost their occupational role and their sense of identity. Others reported that they felt differently about themselves. Having a stroke therefore fundamentally altered their sense of identity and reduced their sense of self-worth:

'You can do some jobs but you can't do all the jobs. I wouldn't have a hope of being a farmer like I used to be' (SM04)

Many male patients expressed a sense of loss that they could no longer undertake DIY activities around the house, while women mourned their inability to maintain the house in terms of shopping, cleaning and cooking. They therefore were no longer able to retain their managerial and caring role within the household which had a negative effect on their quality-of-life. Not being able to drive and go where they wished unassisted or tend the garden was a particularly poignant loss for most:

'I miss messing around the house and doing jobs... I am a DIY enthusiast... I miss that'
(SD08)

Others commented on the loss of autonomy and control in managing their personal finances and how they were now dependent and reliant on their spouse/ partner to undertake these activities. Patients reported how they could no longer do things when they wished but rather had to sometimes wait patiently for others to provide help. Some described how they managed to reduce their sense of loss and maintain some level of control by being able to leave residential care on a regular basis and visit their home; decide on when their friends should visit and having some involvement in planning their own daily activities. For others having the financial resources to purchase home help or to purchase equipment reduced

their sense of loss and promoted self-reliance:

'I know they [her nieces] were trying to get someone to come in and give me meals, but anyway, I don't know whether, they're paying for it. So she comes in and gives me my meals... My nieces pay them actually, now I have it, my nieces pay them'. (SD07)

Following their stroke, patients reported a profound sense of loss in terms of identity, role function and self confidence which had a negative effect on quality-of-life.

Environmental factors

Environmental factors have the potential to enhance or diminish patients' ability to live well after their stroke and maintain quality-of-life either in their own homes or in residential care. This theme describes the impact of environmental factors on quality-of-life related to issues within the home environment.

Disability for those living in their own homes meant that they were no longer able to go upstairs, use the bath or walk unaided. Many reported that they therefore had to make changes within the home environment to adapt their homes so they could continue to live there. However, the experience of obtaining modifications to the home environment varied. Some were able to get grants to assist in these modifications others, however, found great difficulty. Patients living in residential care, commented on a lack of personal space, insufficient call bells, showers and inaccessible toilets.

'It's very hard to get showers here because there's only one shower you see and there's a lot of people wanting the showers you know... there's not enough toilets as well' (SM11)

Patients also described how broader environmental issues including access to transport facilities, feeling connected to community and recreational activities influenced their ability to maintain quality-of-life. This was particularly highlighted by those who lived in their own homes. Access to local services and amenities was governed by where they lived, their degree of physical disability, availability of transport and financial income. Most patients depended on family, friends or neighbours to drive them so they could access services. In a few rural areas patients reported that there was local transport available which would collect people at their homes and take them to day-centres or church, but this service was rare.

Some reported that feeling connected to the local community was vital in maintaining quality-of-life. Relationships with friends and family facilitated companionship, and were a means of maintaining contact with the outside environment:

'I have one very good friend... well she would be a distant relation... and she brings me books and

she brings me goodies of all kinds... she comes nearly every week' (SM09)

Maintaining connections with family and friends was difficult either because family/ friends had moved away and/ or their work commitments were such that it meant they saw little of them. Some patients living in urban areas reported that their local communities had changed radically and they no longer knew or felt known by people within the community. They found themselves surrounded by strangers, office buildings or neighbours who were out working most of the time.

In contrast, others described how they still had good social connections and networks. They described how the families in their neighbourhood had grown up together and had known each other for years, these long term relationships enhanced quality-of-life and enabled them to support one another:

'The neighbours come in... some of them come every day, a neighbour there she's on her own as well, her husband died and she'd be a lot lonelier than me and she comes in to me'. (SD03)

However, patients living in isolated rural communities mourned the fact that neighbours no longer routinely visited each other—a common feature of their childhood. Some described how they felt lonely and missed these neighbourly interactions. They blamed the pace of modern life and the fact that people had little time for others.

Within day care or long-term care environments social interactions tended to revolve around recreational activities. Many commented that these activities were limited to bingo, card playing and sometimes art and so had become repetitive and uninteresting. This had a negative impact on their quality-of-life as they reported that the days were long and dull. They did acknowledge that staff were busy and had little time to organize activities. Others commented that they only continued to attend the day care facilities to give some respite to their families:

'I don't like coming in here at all... no, listening to the same thing over and over every day you know that sort of way, if it weren't for the wife I wouldn't come at all' (SM05)

Environmental factors in the immediate home environment which had a negative impact on quality-of-life included, lack of personal space, hygiene facilities, call bells and being unable to access upstairs rooms and toilets. Other factors that compounded the problems of living with a disability were the difficulties related to accessing local services, a key problem being the absence of suitable and regular transport. Relationships with family and friends were paramount to quality-of-life, as they enabled them to feel connected and in contact with society.

Discussion

This study reflects the findings of other studies with regard to the profound physical and emotional impact of suffering a stroke (Pound et al, 1998; Mayo et al, 1999; Dowswell et al, 2000; Clarke and Black, 2005). Despite the restrictions to living and resultant disability most patients continued to have a positive concept of their health. Some redefined health in terms of their overall abilities. These findings are also supported by the literature (Lawton, 1983; O'Boyle, 1997; Bowling and Gabriel, 2004). Many factors moderate perceptions of health including the extent to which a physical function is retained in relation to self-caring activities. Health professionals, therefore, have a key role in encouraging stroke survivors and focusing on the individual's ability rather than disability.

There are no commonly accepted definitions of the terms dependence or independence (Davies et al, 1997). In this study, patients tended to adopt a functional approach, whereby dependence was viewed in terms of the extent to which they were reliant on others for care and independence as the ability to self care (Goodwin et al, 2003 and Covinsky et al, 2003). The need to stay positive and to retain control over some of the activities of daily living was emphasized in the current study as in other literature (Cox et al, 1988). This study showed that access to financial resources was a means of retaining some independence allowing patients control in purchasing help or equipment, this echoes Reid (2004). Ultimately the loss of control and independence had far reaching implications for stroke survivors. It led to feelings of depression and helplessness, fear of becoming a burden on their carers or of being forced to move into care. Health professionals need to work with stroke sufferers and their families in promoting continued independence.

In this study patients grieved for the loss of their pre stroke lives. This life had suddenly vanished and they expressed a profound sense of loss for its demise. This sense of loss is a common theme in the literature (Dowswell et al, 2000; Clarke and Black, 2005; Pound and Gompertz, 1998; Hilton, 2002; O'Connell, 2001; Ellis-Hill et al, 2000; Hare et al, 2006). The overall disheartening consequences of stroke therefore led to reduced self-confidence, which prevented patients from re-engaging in social activities all of which led to further isolation (Dowswell et al, 2000; Hare et al, 2006; Clarke and Black, 2005; Vincent et al, 2007). Participating in leisure activities is related to health status and life satisfaction (Sjoren, 1982; Drummond, 1990), and this participation is also recognized as a contributory factor in preventing health decline and isolation (Hartman-Maeir et al, 2007). It is therefore important that health professionals work closely with stroke survivors to encourage patients to engage, where possible, in some pre-stroke activities or else provide assistance or foster interest in other meaningful activities. Health professionals should also target more resources on enhancing the social environment for older adults with a disability (O'Connell et al, 2001; Levasseur et al, 2004; Hartman-Maeire et al, 2007).

Many environmental factors both inside and outside the

home had a significant impact on quality-of-life. Within the home, access to resources and assistance from service providers to facilitate modifications was key. For those living in residential care the lack of personal space, meaningful activities and hygiene facilities negatively impacted on quality-of-life. These findings are in broad agreement with that found by another Irish study undertaken by Murphy et al (2006).

Some patients perceived that their rehabilitation needs in terms of physical therapy were no longer a priority for health professionals and therefore were not being met. While there might be uncertainty as to how much more improvement might be attained, it would be important that stroke survivors do not perceive their needs as less important. Education and counselling for self assessment is therefore recommended as it might help stroke survivors become more aware of the limited impact some therapies have once a specific time period has elapsed.

Other environmental factors in the current study that impacted on quality-of-life included the availability of transport and social connections. The absence of regular bus services available locally was a real problem for some. This finding is echoed in work by: Pound et al, 1998. This problem warrants an urgent re-evaluation of transport service provision for older people with a disability who continue to reside in the community.

Conclusion

Charmaz (1995) states that people with chronic illness pass through three stages when adapting to their disability. First assessing the fact that they have the impairment, second realizing that their future is going to be affected and finally accepting their illness. It was evident from patients' accounts that few had come to terms with their loss. Most seemed to still be struggling, attempting to adapt to their disability and subsequent experiences in a climate far from supportive. The need for health professionals to counsel stroke survivors and support them as they advance through their stroke journey is vital.

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KEY POINTS

- ◆ Older people's perceptions of health, level of independence as well as the factors that enhance or diminish ability to maintain quality of life following stroke were explored.
- ◆ Many participants reported a profound sense of loss in terms of identity, and role function but despite their disability most continued to have a positive concept of health and adopted a functional approach, toward independence.
- ◆ The availability of transport and social connections had a significant impact on quality of life.
- ◆ Most participants were still struggling to adapt to their disability and subsequent experiences in a rather unsupportive environment.
- ◆ The need for health professionals to counsel stroke survivors and support them as they advance through stroke trajectory is therefore of vital importance.