

# Stroke in young women: An interpretative phenomenological analysis

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## Abstract

Stroke among adults of working age is increasing. We aimed to explore the experience of stroke among young women in Ireland. In total, 12 women (aged between 18 and 50 years) participated in semi-structured interviews. Data were analysed using interpretative phenomenological analysis. Four super-ordinate themes were identified: stroke as an illness of later life ('obviously it's for older people'), post-stroke selves, a desire for peer support and the impact of stroke on relationships. Findings indicate the importance of addressing the specific needs of younger stroke patients from admission to recovery through provision of inclusive all-age acute stroke services with tailored rehabilitation.

## Keywords

interpretative phenomenological analysis, meaning, patient satisfaction, qualitative methods, women's health

Stroke typically occurs in older adults, four out of five people admitted to hospital with stroke are over the age of 65 years, and therefore, stroke is normally associated with old age (Banks and Pearson, 2004). However, approximately one in five cases of stroke occur in adults of working age and 5 per cent of all strokes occur in adults under the age of 45 years (Johansson et al., 2000). Furthermore, research suggests that stroke among adults of working age is increasing (George et al., 2011). Although it is generally held that younger patients have better functional outcomes, data regarding such associations are sparse and conclusions inconsistent (Bagg et al., 2002; Black-Schaffer and Winston, 2004). A recent investigation of functional recovery after ischaemic stroke (Knoflach et al., 2012), which includes the largest sample

of young stroke patients to date, concluded that age was a significant inverse predictor of good functional outcome 3 months after stroke independent of clinical subtype or severity and that younger patients are more likely to be discharged home than older patients (Tooth et al., 2005). While many young stroke patients will make a good physical recovery, the psychological and social impacts can be significant.

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Younger stroke survivors are 'at a different stage of the life course' (Stone, 2005: 293), are often active in the workforce, have financial needs and family responsibilities such as childcare, and many will not have previous experience of health problems or functional limitations (Snögren and Sunnerhagen, 2009). Stroke in younger individuals may represent or be perceived as premature ageing; such identification can impact on self-concept as individuals feel *old before their time* and robbed of plans and aspirations for the future (Lindström et al., 2009; Röding et al., 2003; Stone, 2005).

The greater incidence of stroke in older adults is reflected in the research literature: samples typically comprise individuals aged 65 years and older. Studies exploring the personal experience of stroke among older adults highlight its transformative role in self-concept, themes of loss, uncertainty, social isolation and adaptation (see Salter et al. (2008) and Lamb et al. (2008) for reviews). Research specific to young stroke tends to focus on incidence, aetiologies, risk factors and rehabilitation outcomes (Lu et al., 2008; Putaala et al., 2009; Rasura et al., 2006). A review of the social consequences of stroke for working-age adults (Daniel et al., 2009) concluded that the majority of studies centred on return to work as a proxy for rehabilitation outcome. Much less is known about the subjective experience and meaning of stroke for these individuals, and there are few qualitative studies in which young stroke survivors provide their own accounts of the experience (Stone, 2005). Even though there might be considerable overlap in the experiences of younger and older stroke patients, the unique needs, challenges and experiences of younger patients warrant specific research attention (Kersten et al., 2002).

Developments in organised stroke care have reduced mortality and institutional care requirements (Collins et al., 2000). Nonetheless, research highlights gaps in stroke care for young adults and patient dissatisfaction (Banks and Pearson, 2004; Röding et al., 2003; Stone, 2005). In Ireland, access to rehabilitation and follow-up services for patients under the age of

65 years remains limited (Horgan et al., 2008). There is little evidence regarding the experience of young stroke patients in the Irish health-care system or in the longer term after stroke. Gaining insight into the subjective meaning and experience of illness is critical to furthering understanding of health and illness behaviour and can lead to more efficient and appropriate health services (Burton, 2000). This research aimed to capture the lived experience of stroke from the perspectives of young stroke patients. We employed interpretative phenomenological analysis (IPA), a meaning-focused qualitative method, as a suitable approach to achieving this aim.

## Method

### Participants

In total, 12 women who had experienced a stroke prior to the age of 50 years were recruited via an all-age stroke service in a hospital in an urbanised area of Dublin. Individuals between 18 and 50 years, who had experienced a mild to moderate stroke and were at least 6 months post stroke were eligible for inclusion. Studies vary in their definition of younger age. Here, 50 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 were excluded. An interval of at least 6 months between the stroke and research participation was considered appropriate to allow participants time to reflect upon the event and its place in their lives. A total of 16 potential participants (12 women and 4 men who met the inclusion criteria) were issued a preliminary information sheet, outlining the nature of the study, and an invitation to participate via their treating consultant; 12 women and 1 man agreed to participate. Although the man was interviewed, his data were excluded from the current analysis with a view to obtaining a more homogeneous sample. Smith et al. (2009) noted the importance of making participant

groups as uniform as possible in terms of obvious social factors or theoretical issues that are relevant to the phenomena under study, to determine psychological variability, or the pattern of convergence and divergence that may emerge within the group. Participants were between 20 and 48 years of age at the time of interview (18–47 at time of stroke); time since stroke ranged from 10 to 29 months.

### *Procedure and interview*

Ethical approval was obtained from both the clinical and academic institutions with which the authors are affiliated. Face-to-face interviews were conducted; eight participants were interviewed in a hospital office and four in their own homes. On initial meeting, a general preamble between the researcher and participant facilitated a relaxed atmosphere. Participants were reminded that the interview would be audio recorded. The average interview time was 1 hour. Participants were asked to tell the story of their stroke and the way it had affected their lives, beginning with the question, ‘Can you tell me about the onset of your stroke?’ The content of the interview followed the participants through their account of experiences in relation to stroke from life before stroke, to stroke onset and hospitalisation and life after stroke. Participants were asked to talk as widely as possible about the ways in which stroke affected or influenced their sense of self, emotional experiences and interactions with others. In keeping with the principles of IPA, the aim was to facilitate the participants in elaborating on aspects of their stroke experience that were of key importance to them; care was taken to avoid rigid application of the interview schedule and to allow participants to direct the content of the interviews. IPA, a meaning-focused qualitative method, is committed to understanding the first-person perspective from the third-person position through inter-subjective inquiry and analysis (Smith et al., 2009). Participants are seen as experiential experts; storytellers rather than respondents (Smith et al., 2009).

### *Data analysis*

Audio recordings were transcribed and transcripts analysed using IPA. IPA has a specific focus on how experiential phenomena have been understood from the ‘perspective of particular people, in a particular context’ (Smith et al., 2009: 29); its philosophical foundations are in phenomenology and ideography. The four-stage process of analysis was initially carried out on a case-by-case basis and was subsequently followed by a case comparison across transcripts. The analysis began with a detailed reading of the transcript to obtain a holistic perspective of the participant’s account. Initial themes were identified, clustered and checked against the data. Emergent themes were refined, condensed and examined for connections. These emergent themes served as the basis for development of a narrative account of the interplay between the interpretive activity of the researcher and the participant’s account of their experience. Presentation of this account is supported by excerpts from participant’s actual discourse to allow the reader to assess the reliability and validity of interpretations. Ellipses are used to represent words missing from quotations.

### **Results**

Four super-ordinate themes were generated from the transcripts.

#### *Stroke as an illness of later life: ‘obviously it’s for older people’*

Occurrence of stroke in young adults can be traumatic not only because of the seriousness of the event itself but also because of its stereotypical association with old age which can act as a barrier to diagnosis. In describing the early stages of their stroke, participants tended to minimise and normalise their unusual symptoms, interpreting them as minor ailments such as ‘a headache’ or a ‘trapped nerve’ and reassuring themselves that the symptoms would resolve: ‘I couldn’t lift my arm but I was kind of saying “no, I’ll be fine in a few minutes”’.

The persistence of symptoms coupled with recognition that they were ‘different’ or ‘unusual’ ultimately motivated help-seeking.

Stroke’s stereotypical association with older age acted as a diagnostic barrier. Some participants had difficulties in being taken seriously on presentation for medical assessment; for most, although the seriousness of symptoms was clear, neither the patients themselves nor it seemed the emergency room medical professionals interpreted the constellation of symptoms presented as stroke. Patients typically underwent a barrage of tests, and lengthy, anxious waiting periods prior to eventual diagnosis; misdiagnoses were common. One participant was initially sent home without diagnosis but with the observation that it was ‘not possible’ for her to have a stroke because of her age. Another participant, a health-care worker herself, described how she briefly contemplated stroke but dismissed the possibility in light of her age, ‘I’d even jokingly said “I think I’m having a stroke, this is ridiculous” but it was totally just a joke’. A third participant describes preoccupation with an initial diagnosis of multiple sclerosis (MS) and somewhat paradoxical relief on confirmation of stroke:

You’ll be glad to know it wasn’t a brain tumour ... I hadn’t even thought, I suppose in my naivety ... I hadn’t even considered ... it could be a brain tumour. I knew there was something serious but I was still clinging to the MS diagnosis that had been given by a doctor earlier ... So it was a sense of relief that yeah it wasn’t a brain tumour, wasn’t MS, it was just a stroke ... While I knew it was kind of serious enough territory it was kind of the preferred option I suppose.

Negative experiences of acute care had a lasting impact. For example, one participant commented,

I can’t go through that casualty effort again, I’d rather die I think than go through that again ... When it happened to me before, the way I was treated in casualty was unreal. They told me I was taking up a bed, I was wasting casualty time.

Older age was clearly a defining feature of stroke prototypes for acute care professionals as

illustrated in the following participant’s account of how her stroke diagnosis was queried by medical staff on a subsequent admission and she had to fight to be taken seriously as a stroke patient: ‘It was almost like as if I was being told “well you’re making it up you know, you’re too young you couldn’t have possibly had a stroke”’.

In general, reactions of shock, disbelief and distress followed eventual diagnosis of stroke. Participants struggled to reconcile the discrepancy between themselves and prototypical images of stroke patients. Again the association between stroke and older age featured strongly, ‘people think stroke is an old person ... in a wheelchair’. One participant commented, ‘I have to be completely abnormal cause like who on earth at the age of, I think I *was* 22 or 23 gets a stroke? It’s something you associate with your granny or your granddaddy’. Another participant observed, ‘No they got it wrong ... obviously it’s for older people ... still couldn’t kind of believe it’. The perceived ‘injustice’ of stroke at a young age was compounded by an inability to identify an underlying cause. Participants reflected on their pre-stroke lives and behaviours, noting the absence of primary stroke risk factors. For example, ‘I’m a vegetarian. I would be the active one, like I’d go to the gym. I’ve never smoked’.

### Post-stroke selves

Life after stroke was marked by feelings of anxiety and loss as pre-stroke selves, aspirations, plans and abilities were mourned. Feelings of being aged prematurely were common and were fundamentally linked to stroke diagnosis, as well as to lasting impairments and taking medication. For example, ‘I went from being a very active healthy busy engaged person to somebody who has a box with all my medication in it, you know everywhere I go I have to bring me box of tablets’. The problematic stereotype of stroke being a condition of old age resulted in some of the participants feeling ‘different’ and ‘old before their time’. One participant’s description of stroke being associated with a ‘granny’ implies that she felt separated from her

own age group. She suggested altering the current stroke adverts by replacing the person experiencing a stroke with a younger individual to raise people's awareness of stroke in the young, thus potentially decreasing the level of age-related stigma associated with stroke.

Cognitive deficits resulting from stroke that mirror those normally associated with the elderly encouraged reflection upon the aged self. Physical and cognitive impairments also had negative repercussions for body image and self-esteem and were associated with stigma and restrictions in participation. For example, one participant commented 'bringing my son to school ... I'd be trying to hide my walking stick'. Her comment suggests concern about the reactions of others, concerns regarding potential impacts on her child and a desire not to draw attention to her impairment. One participant associated her memory impairment with that of the elderly patients that she works with and feels that she needs to readjust her lifestyle now that she is getting older and has become more aware of her age.

For the most part, participants' physical impairments were not visible, but paradoxically the lack of obvious physical manifestations was problematic. The hidden physical, cognitive and emotional difficulties experienced in the aftermath of mild stroke went unnoticed and were not acknowledged or accommodated by others. One participant recalled unhelpful inferences among colleagues as she struggled to return to work despite the absence of physical symptoms:

there is a different ... sense in everyone's head of what exactly a stroke is ... some people are a little bit dismissive ... the fact that you are not going around with a lame leg, it can't have been that bad.

### *A desire for peer support*

Participants articulated the desire to talk to someone who had been through a similar experience and highlighted their need both for assurance and relevant, accurate information. Feelings of isolation were commonly reported in accounts of the acute hospitalisation period and the predominance of older patients on the

wards seemed to compound this sense of isolation: 'you don't see anybody your own age ... you don't feel you could talk to somebody in their 70s'. Another participant commented, 'if I had somebody to talk to ... that had been through what I had been through ... I would have known that what I felt was normal'. A lack of age-appropriate information/education booklets was also a source of frustration and dissatisfaction: 'a nurse came up ... with this booklet on stroke ... and I was going "please tell me what on this booklet actually applies to me," I'm not an old person'.

The lack of peer learning and support coupled with the lack of follow-up services after hospital discharge meant that participants felt isolated in dealing with the evolving problems and challenges resulting from the stroke. For example, concerns and difficulties in making decisions about having children after stroke were evident in the majority of participants' accounts and yet participants felt that there was no one with whom they could discuss their concerns. One participant commented,

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

The majority of participants commented on their desire to talk to younger patients with mild stroke. Being able to communicate with others who were similar in terms of age and experience might reduce feelings of isolation.

### *The impact of stroke on relationships*

Young stroke patients need a variety of supports (e.g. practical, emotional and financial) in adjusting to life after stroke. However, inappropriate or untimely support efforts can be

detrimental to the patients' attempts to *return to normal*. Participants described how some relationships after stroke were strengthened while others became problematic. Being *treated differently* or *wrapped in cotton wool* was disempowering and prolonged the patient role and led to feelings of frustration: 'my mother is a real fusspot. Anytime I'd come back for a check-up she was always with me ... in the room ... asking questions ... I hated that'. Some participants witnessed a gradual reduction in their support networks after stroke. One participant described being excluded from her social circle through her friends' failure to make allowances for her physical impairments: 'you expect them to understand that you cannot walk so fast and to slow down a little bit but they don't ... it's real life ... nobody needs you if you are sick and its very painful'.

Stroke not only affects the patient but also casts others in the role of caregivers. Participants were acutely aware of the pressure of such responsibilities and the distress felt by family members. For example, one participant commented, 'what I found difficult ... was for my parents to see me in that position ... I don't think there was any support for them ... to look after me'. Another participant's sense of uncertainty about her future led to anguish about being a burden on her partner. She felt that it would be an injustice to expect her partner to stay with her 'when I was up here at the start ... I turned to my boyfriend and told him to dump me because it wasn't fair'. Another participant described how she did not want her physical impairments to have an impact on her children's lives, fearing that her own resentment of her condition would be transferred onto her children, particularly when activities were restricted due to her limited physical ability: 'I want them to have a good childhood and not, "ah Mammy's stupid leg," we can't do this'.

## Discussion

This research adds to the literature on younger stroke through its novel focus on the meaning and experience of stroke for young women

through the application of IPA. Key issues emerging from the study include the following: age-related stigma and associated repercussions of such stigma in terms of experiences within the Irish health-care services, differences between the pre- and post-stroke selves, the importance of peer support post stroke and changes in interpersonal relationships.

Stroke is not a word normally associated with young and healthy adults. Low et al. (2003) described younger individuals with stroke as an 'invisible group' because of stroke's epidemiological association with ageing. While cardiovascular decline is associated with ageing, it is not entirely age-determined (Stewart et al., 2014); among young and older adults alike, stroke risk factors include modifiable lifestyle variables. Assumptions regarding the role of ageing in stroke can be problematic; causal attributions linking acute cardiovascular episodes and old age have been negatively associated with lifestyle behaviour changes among older patients (Stewart et al., 2014). Current findings reiterate the strong perception of stroke as an illness of later life, solely for older people; this link was evident from participants' efforts to normalise stroke symptoms, dismissing the possibility of stroke, and in their reactions on diagnosis. Stroke is not unique in this regard; age-related stigma associated with specific diseases has been documented. For example, Bury (2006) noted the distress felt by young arthritis patients because of the cultural belief that arthritis is a disease of old age and that arthritis at a young age is suggestive of premature ageing. Minimising and normalising acute stroke symptom onset has been documented elsewhere. Faircloth et al. (2005), in their analysis of the narrative construction of stroke onset, point to the use of relatively innocuous and common language to minimise symptoms and ground them within ordinary experience. Banks and Pearson (2004) also noted the normalisation of initial stroke symptoms in a younger sample of stroke survivors (aged 18–49 years) and suggested that the 'reluctance to bother GPs or call out emergency services can be misinterpreted by health professionals who may not

appreciate how difficult these decisions are for people who have no previous experience of ill health' (p. 419). Increasing general public awareness about the possibility of stroke in the young might reduce delay in seeking medical assistance and improve outcomes.

Age-related stigma associated with stroke extended beyond participants' initial reactions and hospitalisation experiences to their lives after stroke. For some participants, stroke had an ageing effect in terms of self-concept and identity. The lack of younger role models with stroke, the requirement to take stroke medication and experiences of stroke-related impairments such as memory loss (itself normally associated with old age) contributed to perceptions of an aged self. Similar findings were noted in previous studies with young female stroke survivors (Stone, 2005). Together, these findings highlight current attitudes to stroke in young people in terms of associated stigma and perceptions of an aged self.

In a systematic review of qualitative studies of stroke survivor's rehabilitation experiences, Peoples et al. (2011) highlight the importance of peer learning and comparisons in facilitating empowerment in rehabilitation. Participants in this study articulated a sense of isolation during inpatient care; opportunities to engage with and relate to similar others in terms of age and experience were lacking. This is consistent with the theme titled 'outside and invisible' derived in Rödning et al.'s (2003) study of young stroke patients' rehabilitation experience. Participants were frustrated with the lack of age-sensitive rehabilitation, insufficient rehabilitation, lack of information and lack of participation. Stone (2005) aptly described the problematic nature of experiencing a stroke at a young age stating that 'in popular consciousness, the virtually exclusive focus on the elderly regarding the potential for suffering stroke means that young survivors are largely invisible' (p. 302). Opportunities to communicate with similar others do not routinely occur; facilitation of social support groups specific to younger individuals with stroke might be beneficial. Some of the participants experienced a phase of self-doubt

after stroke and questioned their emotional responses to the event. Opportunities to share such concerns would combat feelings of isolation and feeling 'abnormal'. However, given the low numbers of young adults with stroke 'in-person' stroke support groups specifically for younger patients may not be feasible, an online forum might be a practical alternative to assist younger stroke survivors in communicating and sharing information. Stroke survivors with more severe and debilitating impairments might struggle to utilise online support programmes; however, with appropriate modifications, facilitating such interactions is possible. For example, the 'Think and Link email system' was designed for individuals with severe cognitive impairments due to brain injury. The system features include the following: picture icons to eliminate lengthy email addresses, a simplified interface and on-screen prompts tailored to the user's needs (Todis et al., 2005).

Peoples et al. (2011) also highlight the expressed need for sufficient and individualised information. Lewinter and Mikkelsen (1995) suggest that in stroke, the process of adjustment to disablement is more closely tied to rehabilitation experiences than is the case in more progressive illnesses and conditions. Similar to previous findings from qualitative studies on the unmet needs of younger stroke patients (Lindström et al., 2009), the lack of age-attuned and personalised information was a key concern for the participants. Efforts to adapt to life after stroke became more difficult in the absence of relevant information. The need for relevant, age-attuned information seems to be even more significant for younger stroke survivors because of the uncommon occurrence of stroke in the young. Participants perceived age-attuned information as an essential stepping stone that could assist them in adjusting to life after stroke.

In addition to increasing awareness regarding the possibility of stroke in young adults, our research suggests that the complex nature of mild stroke needs to be addressed. Previous authors have noted difficulties in clinical evaluation and detection of hidden dysfunctions (particularly in the domains of cognition related to

social dysfunction) associated with mild stroke because of the ceiling effects that occur with commonly used scales in stroke care, for example, the Barthel Index (BI) and Mini Mental State Examination (MMSE). (Röding et al., 2010). For example, Kapelle et al. (1994) found that 92 per cent of their study sample of younger stroke survivors had nearly perfect BI scores (>95), but half of the participants reported a deteriorated quality of life and only 42 per cent returned to work. The development of appropriately sensitive assessments is needed. Furthermore, rehabilitative strategies designed to address the specific needs of patients with mild impairments could assist their transition back into the community.

This study offers a novel insight into the meaning and experience of stroke in a sample of young Irish women; however, some caution is warranted with respect to interpretation of these results. The study focused on the psychological impact of stroke from the perspectives of young women. Consistent with IPA guidelines, the purposive sample in this study was chosen for its homogeneity. However, the gender-specific differences noted by Röding et al. (2010) with regard to decreased quality of life after stroke warrants further investigation in regard to the psychological impact of stroke from the perspective of young men who have experienced a stroke. Additionally, individuals with aphasia and other impairments that would result in difficulty in participating in interviews were excluded from this study. It would be informative to explore the experiences of younger stroke patients with post-stroke aphasia via provision of communication support.

Improved understanding of the lived experience of stroke and the biopsychosocial consequences of stroke in young adults can inform efforts to enhance rehabilitative outcomes and promote a fuller return to health and participation in society after a stroke. There are five key issues emerging from this research; these may be understood in terms of a trajectory of stroke experience from symptom onset to diagnosis, hospitalisation and rehabilitation and reintegration to community life after discharge. Many of

these key issues are located at the interface between the health service and the individual patient. They can be addressed via (a) increasing awareness of the incidence of stroke in younger patients among medical staff and the wider community to prevent the dismissal of initial symptoms and delayed medical intervention. (b) Facilitating patients with opportunities to communicate with similar others (e.g. informing patients about relevant social networking websites) may combat feelings of isolation and anxiety both during and after hospitalisation. (c) Younger patients with stroke may feel less isolated in their rehabilitative setting if facilities and services were age-adapted, for example, information booklets and rehabilitative programmes designed to cater for younger patients' needs. (d) Younger stroke patients reported feeling cut off from medical support because of the lack of follow-up services. While it may not be possible to restore follow-up services for those with mild impairments, efforts to assist patients in terms of their transition back into the community may reduce their level of dependency on medical services. (e) Finally, medical staff need to address the mild impairments that might hinder or impede return to the workplace and negatively impact on quality of life.

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