Young adults' experience of stroke: a qualitative review of the literature

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Published in:
British Journal of Nursing

Publication date:
2010

Document Version
Author accepted manuscript

[Link to publication in ResearchOnline](#)

Citation for published version (Harvard):

Lawrence, M 2010, 'Young adults' experience of stroke: a qualitative review of the literature', *British Journal of Nursing*, vol. 19, no. 4, pp. 241-248.

<http://info.britishjournalofnursing.com/?infinity=gaw~Brand~BRAND%2BEXACT%2BBRGEN%2BBritish%20Journal%20of%20Nursing~22897498245~british%20journal%20of%20nursing~e&gclid=CNj_0uyPx70CFZDKtAodglYAmA>

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Abstract

The aim of this existential phenomenological study was to gain an understanding of the experience of stroke over an extended period of time, from the perspective of young adults. We recruited ten young adults from across central Scotland and interviewed them up to four times over a period of approximately two years. Data collection, analysis and reporting were informed by the existential phenomenology of Merleau-Ponty. The young adults' lived experience of stroke was explicated using the third order constructs Disoriented Body, which formed the ground of their experience, and Mortal Body, Situated Body and Embodied Perception of Difference, which stood out as the figural aspects of their experience. The sudden onset of stroke shocked the young adults out of their natural attitude and thrust them into a new, disoriented way of being-in-the-world. Over time, most participants were able to embrace the new set of possibilities represented by their post-stroke body.

Keywords: *embodiment/bodily experiences; existential approaches; families; interviews, unstructured; longitudinal studies; Merleau-Ponty; phenomenology; stroke; van Manen; young adults*

Stroke is a common, long-term condition, which is a principal cause of complex disability amongst those living in the community (Adamson et al., 2004). Stroke may affect physical, cognitive and emotional function and often causes major disruption to the life course (Kirkevold, 2002). It is often perceived to be a condition of older age, yet it is prevalent amongst younger adults i.e. adults aged less than 55 years (You, 1997). Traditionally, the design and delivery of stroke services, both acute care and long-term rehabilitation, have reflected the needs and priorities of older adults. Increasingly, however, there is recognition that young adults affected by stroke may have needs and priorities which differ from those of older people and which are unmet by stroke services (Low et al., 2003; Van de Port et al., 2007). To date, the majority of stroke research has been conducted from the clinicians' perspective; consequently, the focus tends to be on the first three to twelve months post-stroke, the period when clinicians perceive that they are able to intervene most effectively in stroke care and rehabilitation (Alaszewski et al., 2003). Only a few studies have been reported which reflect the patient perspective (e.g. Doolittle, 1992; Häggström et al., 1994; Green & King, 2007). Of this body of work, very few studies have considered the needs and priorities or experiences of young adults following stroke, and fewer have had a long-term perspective (Lawrence, 2010).

Stroke is also known to have a considerable impact on the health and well-being of family carers. However, there is only a limited body of stroke literature which reflects the priorities of carers and/or family members of adults who have had a stroke (Alaszewski et al., 2003; Visser-Meily et al., 2006). Yet it is acknowledged that, to deliver effective care following stroke, healthcare professionals need to understand the patient's perspective and acknowledge their perceived needs and priorities (Visser-Meily et al., 2006; Drew, 2008; Lawrence & Kinn, 2010).

To address some of these gaps in the stroke evidence base, we designed a programme of doctoral research which aimed to identify the needs and priorities of young adults who had had a stroke, and their family members. The programme of research included a systematic review of the patient-centred outcomes stroke literature (Lawrence & Kinn, 2010), a longitudinal qualitative study conducted with young adults who had had a stroke and members of their families, and a mapping of contemporary stroke services in Scotland (Lawrence, 2009). A research advisory group was established which comprised young adults who had had stroke, family members (carers) of young adults who had had a stroke, and stroke healthcare professionals who worked/had worked specifically with young adult who had had a stroke. The purpose of the programme of research was to provide evidence which could inform the design and delivery of appropriate patient-centred or family-centred services for young adults and their families following stroke. In this paper we report the findings from a phenomenological study which was part of a larger study looking at young adults and their families after stroke.

Philosophical Perspective

In his 1945 treatise, *The Phenomenology of Perception*, Merleau-Ponty expounded a phenomenology which was concerned with how individuals access and understand the world as embodied beings. Merleau-Ponty held that human consciousness is experienced, understood and expressed through the medium of the body (Wilde, 1999; Engelsrud, 2005). The individual understands the body, and the world in which it is situated, through its primordial and pre-reflexive perceptions of the body and its intersubjective relationships with others and with the world (Kvinge & Kirkevold, 2003). This is a dynamic process, therefore as the perceiving body changes, so does its intersubjective relationship with the world, and the dialectical relationship between the two begins over again (Sadala & Adorno, 2002).

Merleau-Ponty believed that the reason for undertaking a phenomenological inquiry was to gain an understanding of lived experience, and this may be understood and explicated in terms of “figure” and “ground”. Thomas and Pollio (2002) used Rubin’s (1921) vase/faces drawing (Figure 1) to illustrate this concept. If an individual looks at the drawing and focuses on the white area, a vase is seen, i.e. it is figural against the black (back)ground. If the individual focuses on the black area, the profiles of two faces are seen, figural against the white ground. However, when the focus is on one aspect rather than the other, the other does not disappear. The two are essential to one another; they co-construct each other. If one aspect of the drawing were removed, the other would disappear. Similarly, figural aspects of an experience “stand out”, or have meaning for an individual, against a (back)ground (Thomas & Pollio, 2002).

[insert figure 1 about here]

Merleau-Ponty’s (1945/2002) phenomenological perspective assumes the taken-for-granted, “always ‘already there’” nature of the world i.e. a world that exists before reflection (p.vii). Within the context of this pregiven, pre-reflexive world phenomenology seeks to understand people as beings (Sadala & Adorno, 2002). Therefore, a phenomenological inquiry endeavors to gain prereflexive accounts from a number of individuals, sufficient to enable the researcher to identify the point of convergence and thus identify the essential structure of the phenomenon under investigation.

Sadala and Adorno (2002) have described data collection and data analysis methods congruent with Merleau-Ponty’s existential phenomenology, which we used in the study we report here (Norlyk & Harder, 2010).

Methods

Study Design

We conducted a longitudinal, phenomenological study to enable an understanding of young adults' experience of stroke, over an extended period of time.

Participants

To facilitate the gathering of pre-reflexive accounts from a variety of perspectives, we used purposive sampling to recruit a heterogeneous sample of young adults who had had a stroke. Therefore, we described broad inclusion criteria and recruited from four Scottish National Health Service (NHS) health boards, which incorporated urban, semi-rural, rural and remote populations within their catchments. Our inclusion criteria specified adults aged between 18 and 55 years of age, who had had a stroke between three months and two years prior to recruitment, and who were willing to talk about their experience; we made provisions for communication support for any participants with post-stroke aphasia.

We recruited ten young adults (five male, five female) to take part in a series of four interviews over the course of two years. All ten young adults participated at Time 1, nine participated at Time 2, seven at Time 3, and six participants took part at Time 4. Reasons for non-participation included terminal illness of a close family member, pressures of work and family life, and a lack of interest in continued participation. Participants were aged between 34 and 52, seven were in full-time or part-time employment at the time of their stroke, three were in receipt of long-term disability benefit. Four were married, five were divorced and one was single. All but one participant had children, ranging from very young families to adult children who lived away from home. To protect anonymity, we assigned pseudonyms to all of the participants.

Ethical Approval

We obtained ethical approval for the research from the Glasgow Caledonian University Ethics Committee and from the National Health Service Central Office for Research Committees, prior to recruitment and data collection.

Data Collection

The aim of this phenomenological research was to gain an insight into participants' spontaneous, unreflected experience of stroke. Therefore, the first author posed a single opening interview question, and did not ask follow up or additional, probing questions (Sadala & Adorno, 2002). We selected this single question method as it significantly counteracts researcher bias during data collection. The unstructured interview format enables the participants to talk about the topics that are of importance to them (Sadala & Adorno, 2002), and the researcher is able to listen to all that is being communicated, verbally and non-verbally, whilst holding their natural attitude in abeyance (Kvale, 1996, p.135).

However, using the single question method of interviewing proved challenging with regards individual participant's needs for communication support (Lawrence & Sadala, 2009). None of the participants had overt post-stroke communication impairments, yet some required communication support, in the form of a time spent in informal conversation on general topics, before they were ready/able to talk spontaneously about their experience. Kvinge and Kirkevold (2003) reported encountering similar challenges in their study with women who had had a stroke.

The first author conducted interviews at six-monthly intervals, over the course of two years. With one exception, all of the interviews were recorded digitally and then transcribed. Throughout the research process, the first author recorded the transitional stages of her awareness, understanding and knowledge in field notes and a reflective journal. To enhance

the transparency and the rigour of the research, these records were incorporated into the second and third stages of the analysis (Koch, 2004).

Data Analysis

Sadala and Adorno (2002) described a three-stage, iterative process of phenomenological analysis i.e. phenomenological description, phenomenological reduction, and phenomenological interpretation. In stage one (phenomenological description), the first author adopted a phenomenological stance during the interviews, which enables the researcher to hold his/her natural attitude in abeyance, and obtain the participants' pre-reflexive accounts. During the second stage of analysis (phenomenological reduction), the researcher's knowledge and experience are brought to bear on the data and in a process of critical reflection, the researcher endeavors to "see" the phenomenon from all perspectives, within the context of lived experience. This requires immersion in the data, which the first author achieved by listening repeatedly to the interview recordings, often whilst simultaneously reading the transcripts. The advisory group played an important role in this stage of the analysis, as their spontaneous responses to the anonymised interview excerpts provided yet another perspective on the data. By means of these processes, the first author identified meaning units and, in a further analytic iteration, identified themes from the convergence of meaning units. To support this process of phenomenological reduction, the first author used a conceptual framework congruent with the underpinning methodology and with her emergent understandings of the data (Campbell et al., 2003). The framework comprised four existential concepts, (Body, Time, World and Others) which are understood to be of particular relevance to nursing research as they enable a holistic perspective of individuals as embodied beings within a cultural and historical context (van Manen, 1990; Thomas & Pollio, 2002).

In stage 3 (phenomenological interpretation), the first author worked to develop the final theoretical framework that explicated the experience of stroke from the perspective of young adults. This involved an iterative process of alternating periods of reflection, writing and modeling (Edwards & Titchen, 2003). During this stage, the first author held a team analysis meeting. The purpose of the meeting was for us to try to understand how the previously identified themes related to one another, to identify overarching themes, and to develop third order constructs (Thomas & Pollio, 2000; Booth et al., 2010). By the end of the analysis meeting, we had agreed a thematic model which, in subsequent iterations of analysis, the first researcher developed further, using the modeling feature of NVIVO (a qualitative data analysis software package).

Results

As described above, lived experience may be understood in terms of what forms the ground of a particular experience or phenomenon, against which the figural aspects “stand out” (Thomas & Pollio, 2002). The data analysis process revealed that, for young adults, the existential concept which described the ground of their experience was the body, against which the existential concepts time, others and the world stood out as the figural aspects of the experience. The third order construct Disoriented Body, along with the third order constructs Mortal Body, Situated Body and Embodied Perception of Difference enabled an explication of the young adults' lived experience of stroke (figure 2). We present the findings from this phenomenological inquiry using these third order constructs as headings. However, it should be noted that although each theoretical construct is described separately, they are interrelated; such interrelation is inevitable as the underpinning existential concepts are themselves interrelated (van Manen, 1990; Thomas & Pollio, 2002). For example, it is difficult, if not impossible, to consider the perceiving body in isolation as this inevitably involves considering the body in its temporally situated context within the world, engaging in

reciprocal relationships with objects and with others (Secrest & Thomas, 1999; Wilde, 1999, 2003).

[Insert figure 2 about here]

Mortal Body

The suddenness of stroke and its devastating effects caused the young adults to become suddenly aware of and to reflect upon their own mortality. Prior to stroke, health and the ability to participate in everyday activities was taken for granted, forming part of the natural attitude. However, with the onset of stroke the individual was shocked out of their taken-for-granted way of being-in-the world; their body had let them down with sudden and devastating effect. Their embodied experience of mortality was conceptualized as suddenness and fear of recurrence.

Suddenness

Commonly, the onset of stroke was sudden; it came “out of the blue” (Donald, T1). Participants were shocked by the sudden onset and frightened as it took them by surprise, and had an immediate and devastating physical impact on their body. Adam described his fear of death and his awareness of the instant devastation that the stroke had wrecked on his life:

I found the worst thing is actually how it hit . . . and the devastation it caused just in seconds like that, you know . . . you think, “Is this it?” (Adam, T1)

Fear of Recurrence

The suddenness of this devastating and life-threatening event caused the young adults to become suddenly aware of, and to reflect upon, their mortality and they anticipated and feared the recurrence of stroke. Stroke had hit without warning and they were afraid it would happen again, at any time and without warning:

You're always waiting for another one (Audrey, T1)

Ambiguously, even though young adults felt they had no prior warning of the original stroke event, they feared that the bodily sensations they experienced subsequently were signs of immanent recurrence. Lorraine felt that since her stroke her tendency to worry about physical sensations had escalated:

Every time I don't feel a hundred percent I think, "Oh no! Is this me taking something major?" (Lorraine, T1)

And, as Cathy described, not only were young adults afraid of stroke happening again, they were afraid that if it did happen again, it would affect them more severely than their first stroke. The young adults experienced frustration, anxiety and depression in the face of their fears. Their questioning uncertainty caused them to ask if perhaps their future prospect was one of bodily disorientation, of disability and a limited ability to participate, of disruption to their understanding of themselves as being-in-the-world:

They put the Zimmer [a walking aid] at the bottom of the bed and said I'd probably not be able to walk again . . . you think, "Is this it?" (Adam, T1)

Some young adults reflected on aspects of their health and their lifestyle that were associated with risk of stroke. Lorraine voiced concerns about her unhealthy diet and lack of physical activity, and Cathy continued to smoke following her stroke, even though she was aware that she had a pre-stroke diagnosis of hypertension and that hypertension is a risk factor for stroke (Chalmers & Chapman, 2001). She had considered quitting smoking and had discussed this with her partner and her family doctor. However, she found that she lacked sufficient motivation to make the change, particularly since she knew that her blood pressure was now under control, even though she continued to smoke.

Situated Body

The embodied individual understands their being-in-the-world according to their orientation to the world horizon. Following the disruption caused by stroke, the individual's orientation to the world horizon altered in sudden and unlooked-for ways. The individual has to re-assess the ways in which they participate in the world and interact with others. The process of re-orientation and the re-gaining of an understanding of their situatedness in the world was conceptualized as attitude to life and reclaiming normality.

Attitude to Life

Often following a stroke, young adults seemed to review their lives, their priorities and their life-approach. For some this resulted in positive changes over time, for others negative attitudes were reinforced by the stroke event, as exemplified by Lorraine's description of her heightened tendency towards hypochondria. However, some young adults were able to draw on the strengths and strategies that previously had helped them to cope with major life events. Others found that their perspectives changed as their orientation to the world horizon shifted to accommodate recent events, insights and understandings. They developed new coping skills and implemented new coping strategies. For Donald, this involved choosing to adopt a positive mental attitude as a means of overcoming the depression that he experienced in the first days following his stroke:

I couldn't see a way out, you know, I couldn't see me coming home, I couldn't see me driving, I couldn't see my amateur dramatics going on . . . [but] then [you] get a grip of yourself and you think, "Right, come on! We've got to try something here. We've got to look for positives." (Donald, T1).

Adopting a positive mental attitude helped Donald to become proactive in the rehabilitation process as he began to see what might be possible if he made the necessary effort, psychologically and physically.

As time progressed some young adults adopted the pragmatic strategy of “just getting on with things” as away of moving themselves and their lives forward. Even Cathy, who at sixteen months post-stroke, was unable to picture a more positive future, felt that she was able to begin to move forward by simply getting on with life:

[The stroke] *happened* and that was it, you just get on with it . . . you just have to get on with it (Cathy, T2).

Reclaiming Normality

These young adults had survived a potentially fatal event. Once the immediate crisis had passed their prime objective was to regain pre-stroke “normality”. Part of that process required the young adult to re-claim normal life, as if the stroke event had been a temporary removal from normality. Now they were eager to declare that they were unaffected by their stroke and ready to re-engage with the world on their previous terms. Reclaiming normality is an ambiguous response to the experience of stroke. Declarations of normality, of regaining a familiar orientation to the world horizon, were interspersed with descriptions of change or difference, of altered participation. The claim “stroke has not affected me” was made by most participants and yet the claim was either preceded or succeeded by a description of the ways in which stroke *had* affected the individual's life, the ways in which it had prevented them from resuming life as it was before their stroke. As Audrey described:

It's not stopped me in anyway, you know, it's not made my life any different apart from . . . I don't like going to [town] or anything without a friend now, or one of my family (Audrey, T1)

Return to work was a key marker of the return to normality and of an individual's ability to participate in the world as they had done, prior to stroke:

I've carried on doing everything I've [always] done, you know, I helped in the charity shop and I still do that, I [look after] my grandchildren . . . and look after ma dad, I've really not stopped doing anything, which is quite good (Audrey, T1).

Both Cathy and Juliet's employers had allowed them to phase their return to work. Both had been keen to return to work and Cathy had returned within twelve weeks of her stroke. In contrast, Lorraine had spent more than a year at home before returning to work as a nurse. At home in a familiar environment and with familiar routines, Lorraine had felt that she had recovered well. However, like Juliet, she found that returning to the workplace highlighted her limited energy reserves and revealed that her concentration and memory were more severely impaired than she had realised:

There are issues that I wasn't aware of, [because] being in my own environment, in the home, and doing things I've always done seemed easy, but the . . . memory issues, with working . . . I just felt like I . . . wasn't being quick enough, I was stressed out, because obviously I was trying to concentrate . . . and I find that when I get stressed or I get tired, that's when the memory problems are worse (Lorraine, T4)

Similarly, the ability to resume driving was used as a marker of recovery and a return to normal life. Both Donald and Lorraine worried initially that they would be unable to drive again and that consequently they would suffer a loss of independence. For Lorraine the inability to resume driving made her feel inadequate as she was unable to fulfill her role and participate in the family in the same way as previously. She was unable to share the task of

driving the children to a range of extra-curricular activities, and her own activities were curtailed because of her reliance on public transport:

There's a lot of dropping off and picking up [laughs] so [the inability to drive], that's really been my main problem and I think it leads to feelings of, you know, of inadequacy because I can't do what I did before and I can't help (Lorraine, T2)

Lorraine found it difficult to adjust to the loss of independence associated with her inability to drive, particularly as it entailed dependence on her husband, who had to assume sole responsibility for chauffeuring their children to their numerous activities. Twenty-two months after her stroke, Lorraine's driving license was revoked and she was forced to acknowledge that she was unable to participate as she had prior to her stroke. The burden of chauffeuring the children now fell entirely to her husband thus limiting his ability to participate in leisure activities:

Poor husband, he can't do anything! I say [to him], "You're not going out! . . . We've got the Brownies [a Guiding organisation for young girls] and the . . ." He's not allowed to go out! (Lorraine, T4)

However, for those who were able to resume driving, the practical and psychological benefits were significant. For example, David found that he was more independent, had more time, and that his commute to work was much reduced, and Donald felt that he had regained his independence.

Embodied Perception of Difference

For young adults, the perception of Embodied Difference following a stroke is experienced in terms of personal difference and social difference. Personal difference describes the ways in which an individual's perception of their own body has altered post-

stroke. Their body, the medium through which they perceive and understand the world and their place within it, has changed and consequently the ways in which the individual perceives and understands have changed, including their perception and understanding of themselves as a person with a role and a place in the world i.e. being-in-the-world. Social difference describes the ways in which the young adults' altered sense of self effects their perception of how they are perceived by others and their reciprocal relationships with others.

Personal Difference

During the course of the interviews participants described perceived differences in their bodies, in their emotions, in their activities and in their lives:

There's certainly a change in my attitude, a change in my personality, a change in everything really (Gordon, T3)

And for some, difference became more evident as time passed. Generally, when difference was spoken about, either directly or obliquely, it was in relation to feeling different, responding to stressors and to other people differently, or to not being as able physically as prior to the stroke. For example, Cathy found that the taken-for-granted physical ease with which she had customarily moved had been replaced with the slow and careful movements of an old woman fearful of doing herself harm. Physically, she felt that she would never fully be the person she had been before the stroke:

I would say 95% I'm back to what I was; I don't think the other 5% you ever get (Cathy, T1)

However for Donald, two years after his stroke, his sense of feeling different was related to the personal journey he had undertaken as a result of his recent lived experience.

He felt that he had a new understanding of himself; he perceived himself to be a better person:

I think you learn a lot about yourself . . . I am a completely different person
[emphasizes every word] . . . it's a completely different person, yes, I think it's a better person, yes, I think so, I think it's a more understanding person (Donald, T4)

However, most participants did not refer overtly to having an altered sense of self. In fact sometimes they clearly stated the opposite: "I don't feel any different" (Cathy, T1) and "My friends say I'm not the same person; I think I am" (Audrey, T2). Ambiguously, the follow-on from such statements was often a description of at least one aspect of life that was perceived as being different.

Some young adults experienced mood disorders post-stroke, including clinically diagnosed depression and/or feelings of depression or low mood. For some, depression was experienced as something to be fought against, to be resisted. For other however, depression affected their ability to participate in the rehabilitation process and to reintegrate into family, social or work life:

[Depression] is a debilitating thing, it stops you from doing anything, really all I wanted to do was go in the corner, and sit and cry in the corner and not move [pauses] (Gordon, T1)

Tiredness and its impact on individual, family and work life was the most commonly experienced and frequently discussed short-term and long-term effect of stroke. Tiredness affected memory and concentration, and those who returned to work found that they were exhausted. Work left them with no energy, and they were unable to participate in other

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activities. Early bed times, clock watching and rationing their limited energy became features of daily life:

I come home [from work] and I lie in top of the bed for a minute, but I used to be able to go on to two in the morning, three in the morning (Audrey, T2)

And,

I clock watch all the time, all I think about is, "When can I go for a sleep?" (Cathy, T2)

Tiredness affected relationships as individuals were prone to feeling grumpy and argumentative. For example, Cathy felt that arguments between her and her partner were a result of her tiredness. Being "crabbit" or ill-tempered was a commonly described consequence of stroke. Young adults described themselves as argumentative, lacking in patience and more emotionally labile following stroke. They found themselves becoming uncharacteristically upset and angry and experienced major flare-ups and angry outbursts, often sparked by minor irritants.

I get tired a lot easier than I used to, my friends say . . . I'm crabbit [laughs] I've not got the patience I used to have (Audrey, T2)

And,

Silly little things that shouldn't annoy me, like a cup lying that they could've put in the dishwasher . . . I actually blow it all out of proportion . . . and I get so worked up . . . I just can't help it! (Cathy, T1)

Participants noticed many different cognitive effects of stroke, including memory problems, poor concentration, visual impairments, and impaired decision-making skills:

I find that I get tired quite easily, and I put off making decisions about things, because I can't be bothered [laughs] (David, T3)

Cathy mentioned that she was experiencing signs of ageing such as the worsening state of her eyesight, stiffness of movement and short-term memory problems. However, it was not always possible to be sure whether these were the result of stroke or, indeed the result of the normal ageing process. When she mentioned them to her sister or to friends, they said they experienced the same things. This was echoed by Lorraine, who also had short-term memory problems. However, she felt there as clear distinction between the memory problems she experienced and those experienced as part of normal ageing:

You think, "Why did that just go out of my head altogether?" I was talking to a friend last night and she said, "Oh! I'm the same! I do that as well." . . . I feel it's kind of different . . . it just disappears altogether and that can be [pauses] a bit annoying
(Lorraine, T3)

As described above, cognitive impairments and tiredness both had a negative impact on the young adults' ability to return to employment in their former roles. Although over time, some young adults did develop practical coping strategies such as those described by Juliet and Lorraine. For example, in order to manage the day-to-day problems associated with short-term memory loss, 16 months after her stroke, Lorraine realized she had to get organised:

Next year I'm going to buy a big thing for the wall, get the kids to write in their [leisure activities and appointments] . . . because there are so many things to remember
(Lorraine, T3)

Social Difference

Social difference describes the ways in which the young adults' altered sense of self effects their perception of how they are perceived by others. It includes aspects of body

image, self-image and self-esteem; complex issues about which several young adults found it difficult to articulate their feelings. This was due in part, perhaps, to a lack of understanding of their ambiguous responses to these issues. For example Donald was unclear whether his reluctance to be seen in public was a vanity issue, a self-image issue or if he was in need of psychological support. Gordon (T3) found the topic particularly difficult to discuss because he was “embarrassed by my condition [left-sided hemiplegia]”. His emotional response to his altered, physical, circumstances was complex and ambiguous. At Time 3, he described the dissonance between the way he thought about himself, i.e. as a physically able man, and the reality:

The problem is . . . I see my sons go out and play football [and] I want to go out and play with them – I can't! It's not even remotely possible for me to do it . . . but I still want to do it . . . the fact is I just can't do it any more at all, but you really don't think that way, your brain still says to you, “I can do that!” you know . . . I still dream that I'm running about and doing things . . . in my dreams everything still works fine, but, well, obviously it doesn't (Gordon, T4)

Some participants described an awareness of changes in their physical appearance and differences in physical and cognitive function which caused them to worry about the ways in which others, strangers, might respond to them. These worries and fears were such that the individual's being-in-the-world as a young adult who has had stroke was restricted, when compared with their sense of being-in-the-world prior to stroke. Donald acknowledged that this perceptual barrier had come to constitute a social barrier which had a significant negative impact on his ability to participate in the world. However, he did not know how to go about removing that barrier:

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The problem is me, it's me, it's how I think, it's how I perceive it in there [taps the side of his head] and I have tried to know how to change it, and I've tried and tried (Donald, T4)

Young adults' concerns regarding experiences of being seen to be different included the perception that others might feel sorry for them, might pity them or exhibit signs of sympathy towards them – this type of response was both feared and rejected. At Time 4, 27 months after his stroke, Donald described how, using his walking stick, he had enjoyed dancing at a wedding. However, the barrier raised by his perception of how strangers might respond to him remained:

Now, if these [wedding guests were strangers] down the sea front, and I wouldn't have got out of the car and walked, because there's too many people down there that would . . . turn round and say, "Oh! Poor soul!" (Donald, T4)

Often following stroke, young adults felt uncomfortable being in public. Crowded places were particularly difficult, as crowds were experienced as intimidating and hard to negotiate, particularly if the person's mobility was impaired. Both Audrey and Donald expressed a preference for going shopping with a companion rather than face crowds alone. Gordon's perception of his physical appearance post-stroke severely restricted his ability to participate in the world to the point that he had become reclusive.

At times the dislike or avoidance of crowds and crowded places, of being in public was associated with a disturbance of the young adult's sense of ease, possibly associated with altered self-esteem and self-image, resulting from changes in physical and cognitive function. For example, Cathy began to panic when she first realised that she could not function normally at a supermarket checkout:

I thought, "I don't have any money on me, I only have my [bank] card and I'll need to write my signature," and I started panicking. I think I panicked more than normal, I've lost all my confidence . . . I [was] quite a confident person (Cathy, T1)

Discussion

The young adults' experience of stroke has been presented here from the perspective of embodied difference, which has been conceptualized as the Disorientated Body. The body formed the "ground" of the young adults' experiences and figural against that ground were an awareness of the mortal nature of human being (Mortal Body; time), their dis-orientation and subsequent re-orientation as situated beings in the world (Situated Body; world) and their perception of being different, from both personal and social perspectives (Embodied perception of difference; others).

Following the initial shock of the stroke and its effects on their taken-for-granted way of being-in-the-world, young adults became aware of their mortality and the fragility of human existence. The possibility of death had been made manifest as a feature of the present; the taken-for-grantedness of the present and the immediate future had been disrupted, the future was perceived to be uncertain, and uncertainty gave rise to feelings of powerlessness and frustration (Burton, 2000; Stone, 2005). Even once the initial shock was over, the possibility of death or disability remained a powerful element of the post-stroke experience. Townend et al. (2006) reported fear of recurrence in 56% of patients, up to nine months post-stroke in their study of a general stroke population, and Immenschuh (2003) found that at 12 months post-stroke some participants were unable to "get on with their lives" because they "lived in fear" of recurrence (p.143). However, as Townend et al. (2006) found, fear of recurrence alone is not sufficient motivation to encourage people who have had a stroke to improve their lifestyle behaviors.

Once the immediate crisis had passed, the prime objective for young adults was to reclaim the normality of pre-stroke life. Participants in other stroke studies have described goals which were concerned with the resumption of normality and former activities, the latter commonly framed in terms of (motor) function (e.g. Folden, 1994; Pound et al., 1998), and Doolittle (1992) found that a return to normal and the resumption of pre-stroke activities was also associated with an individual's sense of identity.

In this study, the young adults who were in employment prior to stroke used the return to work as a milestone against which to measure recovery, reclamation of the individual's former role in life and confirmation that the individual remained the person they were prior to stroke. A successful return to work demonstrated the young adult's ability to meet their own expectations and those of others. However, negative consequences associated with a return to work were also described, including a limited ability to participate in family, social and leisure activities, due to fatigue. Although fatigue and other cognitive changes were impediments to the ability to return to work, often these consequences of stroke were not recognised by health professionals (Stone, 2005), and the young adults received little or no relevant information and were not offered treatment or any other form of assistance or support (Medin et al., 2006). The onus was on individuals and their families to develop strategies to help them to cope with problems such as memory impairment and concentration deficits.

For many, the ability to drive is a taken-for-granted aspect of daily life as it enables access to employment, facilitates social participation, supports individual independence and is a means of defining aspects of an individual's identity (Lister, 1999; Corr & Wilmer, 2003; MacKenzie & Paton, 2003). Corr (2003), in her study of young adults, found that the inability to drive post-stroke resulted in "an altered lifestyle, feelings of loss of control and loss of independence" (p.181). In this study, young adults used the resumption of driving as marker

of their recovery and a return to normality. The ability to drive was perceived as key to maintaining a sense of independence, as found by Lister (1999) in her study of older adults who had had their driving licenses revoked following stroke.

The young adults' embodied experience of stroke was centred on their perceptions of bodily difference and on the impact of that difference on the nature and quality of their interactions with others (Toombs, 2001, pp. 255-258). The experience was complex and ambiguous; an experience that the young adults found difficult to give clear expression to in words, which reflected the difficulty they experienced in trying to understand or assimilate their own ambiguous perceptions into a newly oriented way of being-in-the-world. They experienced a constant tension between sameness and difference; a sense of difference was ambiguously inherent in their sense of sameness, a finding echoed by Murray and Harrison (2004).

The "stroke" body was ambiguously experienced partly as a consequence of the young adults' intersubjective stance. The presupposition of the thoughts and reactions of others, caused the young adults to feel shame or embarrassment in front of others, which Toombs (2001) described as an integral element of the experience of physical disability (p.257). Contemporary western culture celebrates youth, productivity, physical health and well-being, and individuals who are physically different or physically dependent feel shame or embarrassment in anticipation of negative responses from others (Toombs, 2001, p.256). The young adults in Immenschuh's (2003) study described feelings of "stigma and shame" as a consequence of not conforming to their own and others perceptions of "normality" (p.164). Merleau-Ponty (2002) used the example of the ageing body or the physically disabled body to illustrate how an individual's situatedness (context) limits their way of being-in-the-world. Embodiment is a (contextually) limited representation of the self that the individual feels capable of being, outwith their situatedness. In this study, the feelings of shame and

embarrassment described by the young adults were accompanied by a sense of being diminished as a person as a result of perceived bodily difference (Finkelstein & French, 2001; Toombs, 2001). The shame that was associated with alteration in physical appearance and loss of bodily mastery also caused alteration and disruption to the quality of the young adults' relationships with others.

Recovery and rehabilitation were hindered in young adults whose orientation remained fixed on a future that appeared suddenly uncertain. The ability to recover, to progress and to resume participation in the world is dependent upon the individual's ability to accept their "body at this moment". As Merleau-Ponty (1945/2002) described: "It is by being unrestrictedly and unreservedly what I am at present that I have a chance of moving forward . . . by plunging into the present and the world, by taking on deliberately what I am fortuitously . . . that I can go further" (p.529). Merleau-Ponty held that individuals can attain freedom by living fully in the present and by accepting the "set of possibilities" that constitutes their present body (Sadala & Adorno, 2002). As time progressed, the focus of the young adults in this study was more likely to have shifted from the uncertain future to the (disoriented) present. One notable exception was Gordon, who battled with depression possibly as a consequence of his inability to focus on the present, a present in which he could accept and maximise the set of possibilities that his present body constituted (Merleau-Ponty, 1945/2002). Ultimately, acceptance of the present self represents a vital step in the process of rehabilitation, one which enables participation and facilitates meaningful engagement and interaction with others.

Limitations

Attrition is known to be a problematic aspect of longitudinal research, as there is an increased potential for participants to "drop out", and for the drop out rate to increase over time (Murray & Sheik, 2006). Attrition was a feature of this study, often due to life events

such as the terminal illness of a close family member. However, many of the participants took part in three or four interviews enabling insight into perspectives of the experience over time.

The lack of representation of young adults with aphasia in this study highlights one of the challenges associated with the use of intermediaries or gatekeepers in research recruitment (Thomas & Pollio, 2002, p.31). Although we assured the recruiting clinicians that we would provide communication support, they did not attempt to recruit patients with aphasia. If clinicians consider stroke-related communication impairments constitute a barrier to participation in healthcare planning, as described by Nordehn et al. (2006), they may also consider such impairments to be an impediment to meaningful participation in qualitative research. Therefore qualitative researchers need to ensure that they openly and fully address this issue with recruiting clinicians.

Conclusion

When an individual becomes suddenly disabled the body is experienced ambiguously; it is revealed to the individual as a body comprised of two distinct aspects: the “habit body” i.e. the body of which the individual has an instinctive, intimate and familiar knowledge and the “body at this moment” i.e. the strange, unfamiliar body with its unfamiliar potential and its new way of being-in-the-world (Merleau-Ponty 1945/2002, p.95). In this study, the sudden onset of stroke shocked the young adults out of their natural attitude and thrust them into a new and disoriented way of being-in-the-world, with an uncertain future. Over time, most participants were able to shift their focus to the present, and embrace the new set of possibilities represented by their post-stroke body, and to incorporate their embodied understanding into their new way of being-in-the-world.

Funding

The first author received a postgraduate studentship from the Chief Scientist Office, Scotland and was supported by the Nursing, Midwifery and Allied Health Professions Research Unit at Glasgow Caledonian University, Glasgow, Scotland.

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