Est. 1841 | YORK ST JOHN UNIVERSITY

Purton, Judith, Sim, Julius and Hunter, Susan M. (2020) The experience of upper-limb dysfunction after stroke: a phenomenological study. Disability and Rehabilitation. pp. 1-10.

Downloaded from: https://ray.yorksj.ac.uk/id/eprint/4539/

The version presented here may differ from the published version or version of record. If you intend to cite from the work you are advised to consult the publisher's version: http://dx.doi.org/10.1080/09638288.2020.1743775

Research at York St John (RaY) is an institutional repository. It supports the principles of open access by making the research outputs of the University available in digital form. Copyright of the items stored in RaY reside with the authors and/or other copyright owners. Users may access full text items free of charge, and may download a copy for private study or non-commercial research. For further reuse terms, see licence terms governing individual outputs. Institutional Repositories Policy Statement

RaY

Research at the University of York St John

For more information please contact RaY at ray@yorksj.ac.uk

The experience of upper-limb dysfunction after stroke: a phenomenological study

Abstract

Background: Stroke can bring about a profound disruption to people's lives, but what is less understood is the effect that specific dysfunctions can have. The aim of this study was to explore stroke survivors' experiences of upper-limb dysfunction over time.

Methods:13 adult stroke survivors engaged in a series of up to four semi-structured interviews over an 18-month period after stroke. Data were interpreted through a method based on framework analysis. An interpretive phenomenological approach guided the research.

Results: Upper-limb dysfunction brought substantial challenges for people, identified in a main theme of *an altered way of life*. Subordinate themes that contributed to this alteration were *challenges in personal care*, participating in *meaningful and valued activities,* and *managing life roles and relationships*. The second main theme was *the disrupted self,* with subordinate themes of *feeling devalued*, *disrupted self-image* and *changes in identity*.

Conclusion: The impact of upper-limb dysfunction on people's lives after stroke should be understood and acknowledged by rehabilitation professionals. Restoring some functional upper-limb activity could play an important role in enabling a person to regain a meaningful life and a coherent sense of self after stroke.

Keywords: stroke; personal care; activity; participation; roles; self-image; identity

Running Head: Experiences of upper-limb dysfunction

Introduction

Each year in the UK 100,000 people have a stroke, and the corresponding number worldwide is 15 million [1]. In 2013 there were thought to be 900,000 people living with the effects of stroke in the UK [2]. Approximately 70% of such people will have altered arm and hand function and 40% will be left with persistent lack of function in an upper limb [3]. This can lead to substantial disability, as the hands, and arms, play a central role in an individual's life, providing independence, competence and, thereby, a sense of autonomy. They enable individuals to manipulate objects and tools, express themselves through writing, music, arts and crafts, take part in sport and leisure activities, and participate in employment [4]. Typically, most tasks that people perform require the cooperation of both hands [5]. The hands are also vital in gesturing and to communicate affection and intimacy through touch, and the arms and hands play an important role in support and balance [6–8]. Thus, the hands are normally used in nearly all of the valued activities and life roles in which people engage; consequently, upper-limb dysfunction as a result of stroke can potentially have a marked effect on many aspects of a person's life.

Rehabilitation of the upper limb after stroke can be challenging because of the complex processes involved in controlling movement of the arm and hand [9]. Regaining good recovery in the upper limb can be more difficult than regaining lower-limb function, where walking can be achieved without such fine motor function [10]. Around 70% of stroke survivors achieve a reasonable level of mobility but are left with an impaired and dysfunctional arm and hand that are of little use to them [3,9,11].

People's experiences of stroke have been researched quite extensively and it is recognized that stroke can bring about a radical and profound disruption to people's lives [12–17], including effects on identity and the self [18–21].

The notion of the *self* plays an important part in our understanding of illness and the transformation that it may bring about in a person. As Charmaz notes: 'Chronically ill persons frequently experience a crumbling away of their former self-images without simultaneous development of equally valued new ones' [22, p.168]. The self has been defined as "an organized and interactive system of thoughts, feelings, identities, and motives that (1) is born of self-reflexivity and language, (2) people attribute to themselves, and (3) characterizes specific human beings" [23, p.226]. However, the self is not purely an internal psychological construct; it is essentially social in nature, constructed through social interaction and meanings that are shared or negotiated with others [24, 25]. Accordingly, the self is something that is 'presented' to the world and helps determine how the person is perceived and evaluated by others [26].

A number of other concepts are associated with the self. *Identity* is a "tool by which individuals categorize themselves and present themselves to the world" [27, p.206]; here, the appearance of the body can play an important part in how the self is presented to others in everyday interactions [26,28]. *Self-concept* can be described as how a person envisages and perceives his or her self [29]. *Self-esteem* is the evaluative part of self-concept [30], and includes: a) seeing oneself as competent and capable (efficacy-based self-esteem) [30], which is linked to role-based identities [31]; and b) feeling that one is accepted and valued (worth-based self-esteem) [29], which is linked to group-based identities [30]. In trying to manage ordinary life in the face of illness, individuals 'call into question and re-examine habitualized notions of self' [32 p. 32S]. At the same time, 'accumulated loss of formerly sustaining self-images without new ones results in a diminished self-concept' [22, p 168]. The individual's sense of *role identity*, and associated role behaviours, are learned through social interaction, with meaning acquired through the reactions of others [33]. Thus, one occupies a role and

incorporates the meanings and expectations of that role into one's identity and behaviours [34].

Bodily dysfunction and activity limitations experienced by stroke survivors can leave them feeling less capable, more dependent, helpless and, as a consequence, of less worth, thereby affecting their sense of self and identity [13,16,17,35–37]. However, what is not known about stroke, in as much detail, is the effect that specific impairments and dysfunction, such as upper-limb dysfunction, can have, how this is perceived by people with stroke, the effect on the self, their self-esteem and identity, and what this means for them in their everyday lives [38]. Therefore, the aim of this research was to explore stroke survivors' experiences of their upper-limb dysfunction, the meanings they ascribe to these experiences over time and the effect on their sense of self. Understanding these aspects of the experience of stroke could provide greater insight for health professionals as they support people in their rehabilitation and recovery.

Methods

The methodological approach taken in this study was phenomenology, which seeks to understand the social world as it is experienced by individuals, as distinct from an 'objective' perspective on the world [39], and without an attempt to apply notions of accuracy or truth to individuals' accounts [40]. The aim of phenomenology is to "capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place" [41, p.27]. In the specific context of illness, phenomenology "highlight[s] how when we are ill there is both an altered experience of one's whole body and an altered experience of the world – and that these are one and the same" [42, p.733]. As our intention was to gain an understanding of the meaning that participants ascribed to their experiences post-stroke, our study was centred in the interpretive rather than descriptive tradition in

phenomenology [43]. Here, the researcher does not try fully to set aside prior assumptions, knowledge and experiences – such as may occur in more descriptive models of phenomenological inquiry [44] – as this prior understanding may be essential to the process of sense-making when analysing participants' accounts of their experiences. Instead, the researcher adopts a reflexive, critical attitude to such prior understanding so that it does not distort or usurp participants' own perspectives [45]. The first author, who conducted the interviews, is a physiotherapist with a background in stroke rehabilitation and was therefore careful to be open to the participants' experiences, rather than drawing on her perspective on upper-limb dysfunction as a clinician.

Semi-structured interviews were used so that participants could engage with the researcher on a one-to-one basis to express their experiences and perceptions [41,46]. Participants were interviewed up to four times over an 18-month period to capture any changes in their experiences over time. No assessment of impairment or function of the upper limb was made as this could have made the relationship between participants and the researcher seem more clinical. Furthermore, we did not focus the interview specifically on function and impairment, recognizing that these might not have been the most meaningful facets of participants' post-stroke experience; instead, we conducted the interviews in such a way as to follow and respond to their own perceptions and experiences.

As the process of data collection and analysis progressed over the longitudinal course of the study, the interview guides at six, 12 and 18 months for individual participants evolved to reflect the data from the preceding interviews.

Sample

Participants were drawn from a population of adult stroke survivors with upper-limb impairment in a stroke rehabilitation unit, on the basis of purposeful sampling, whereby "the

sample derives its logic and power from the selection of information rich cases" [47, p.3]. It was important for the study that upper-limb impairment was clearly established in the participants by the time of the first interview, and that it was not transitory and likely, therefore, to resolve quickly with minimal impact in the longer term. Therefore, the inclusion criteria for participants were: having had a stroke within the previous two months; impairment of function in their upper limb causing limitation in spontaneous use in everyday tasks; 18 years old or over. Exclusion criteria were dysphasia or cognitive problems that would prevent engaging in interviews, and prior conditions that affected upper-limb function, such as arthritis. A local collaborator, who was a senior physiotherapist on the stroke rehabilitation unit, was able to identify potential participants who satisfied the inclusion and exclusion criteria, and then provided them with written information about the study. After a period of one week, to allow them to consider the information, the first author then met those people who had indicated an interest in participating to provide any further information and obtain their consent. The study was approved by an NHS Research Ethics Committee (Reference number 10/H1304/38).

Data collection

The first interviews took place at two months after the stroke had occurred to ensure that upper-limb impairment was established. Subsequent interviews were at six, 12 and 18 months post stroke. Five of the two-month post-stroke interviews were conducted on the stroke rehabilitation unit and the remainder of all the interviews were in participants' homes. An interview guide consisting of open-ended questions was developed after consultation with members of a stroke support group to ensure that the most appropriate and relevant topics would be covered. The interview guide was designed so as to keep participants' focus on their experiences and prompt and probe for more depth and clarification. The first author conducted all the interviews, each of which lasted between 35 and 60 minutes. They were

audio-recorded and then transcribed verbatim by a transcription service. Written field notes recorded notable changes in a participant's mood or body language during an interview. The initial impressions of the interview and the key issues to remember were noted immediately afterwards and used in the initial data analysis alongside the transcript.

We collected demographic information on the age and sex of participants and noted the affected arm and hand dominance. Stroke severity on admission to the stroke rehabilitation unit, in the form of the National Institutes of Health Stroke Scale (NIHSS) [48], was recorded, where available, to provide a context for each participant's experiences.

Data analysis

Data analysis was guided by a form of framework analysis, based on the work of Ritchie and Spencer [49], whereby themes were identified and then data charted, organized and interpreted both within and across all participants at the different data points. Table 1 shows the steps taken in the data analysis process.

[Insert table 1 near here]

Transcripts were read several times and interview recordings listened to again so that the full sense of the interview could be recalled before it was broken down into parts (steps 2 and 3). Field notes were also consulted. Each transcript was annotated to identify areas of interest and then coded, with the associated extracts of data from the transcript, using the computer package NVivo10 (steps 4 and 5). Recurring codes were then clustered into broader themes. A table of themes and sub-themes was thereby developed from each interview transcript, noting the themes and key words or phrases from the transcript that illustrated each theme (step 6). The next step in the analysis organized the tables of themes into charts of superordinate and subordinate themes, with illustrative extracts from transcripts, for each data

collection point of two, six, 12 and 18 months (step 7). This enabled data to be easily viewed across and within all participants, but still grounded in the transcripts, and notes of further interpretation were recorded within the chart. This allowed the researchers to move back and forth between and within participants' data until a coherent interpretive account was identified [50].

Several steps were taken to ensure the trustworthiness of the interpretation of the data. None of the participants were known to the researchers prior to the study. The interviewer engaged in a process of reflexivity in an attempt to adopt a phenomenological attitude before all interviews and data analysis (step 1). Thus, it was important that she acknowledged any prior knowledge, assumptions and understanding of stroke before each interview, but remained open to the possibility of new and unexpected data emerging. The first author analysed all transcripts and then independent analysis of a sample of interview transcripts from each interview point was undertaken by a second researcher, and tables of themes, charting and mapping were discussed within the research team (steps 8, 9 and 10). Decisions made at each stage of analysis were discussed within the team – with review of the transcripts, where necessary – to ensure that the analysis was faithful to the data. We sent a summary of the findings from the analysis of all the data to all participants to give them the opportunity to comment on the findings with regard to whether or not these resonated with their experiences. No such comments were received.

Results

Sixteen stroke survivors were recruited into the study; three withdrew before data collection began because of deteriorating health or personal reasons. In all, 13 people participated in the study. Table 2 shows details of the participants. All were 62 years old or over and all but two were retired. Participants' NIHSS scores ranged from 2 to 16. Each person is identified by a

pseudonym to maintain anonymity. Two participants unfortunately died during the study, at a point before completing all four interviews.

[Insert table 2 near here]

Two main themes were identified in the data: theme 1: *an altered way of life* and theme 2: *the disrupted self*. Both main themes had subordinate themes, shown in Table 3.

[Insert table 3 near here]

The sources of quotations can be identified by the pseudonym and a number that indicates the relevant data-collection point; e.g. '(Ada, 12)' indicates a quotation from an interview with Ada at 12 months post stroke.

Theme 1: An Altered Way of Life

Life for participants after stroke was very different from that before stroke, and this was often directly attributed to the acquired upper-limb dysfunction, which caused a radical alteration in many important aspects of their lives:

> Everything stops, everything you used to do you can't do… you've even someone to wash yourself… It changes everything, changes your whole way of life, and it's very difficult, very difficult. (Colin, 2)

The implications of loss of hand function after stroke were unanticipated and profound:

> Well it's my right hand, and I'm right handed so I feel shattered really… I've got to have this [pointing at affected dominant hand] back quick to carry on with my life. I never thought it would be so difficult being without your hand. (Jenny, 2)

Thinking back to life before her stroke, Eve (12) described her current life as: "non-existent... All I do is sit in a chair and watch [the television] all day and all night."

The subordinate themes of *challenges in personal care*, *meaningful and valued activities*, and *managing life roles and relationships* indicate how wide-reaching the changes were in altering how participants lived their lives after stroke. Furthermore, the points in time for each of the quotations within the themes indicate that, for many, these changes were not resolving over time.

Sub-theme 1.1: Challenges in personal care

Having a dysfunctional upper limb affected individuals' ability to be independent in basic activities of self-care, and this dependency could leave them feeling vulnerable and at the mercy of others:

> I feel like these people who collect butterflies, I feel like one of them pinned to a board… only if the master comes in and takes the pin out and moves you can you do anything. (Harry, 2)

Loss of strength, manipulation and dexterity in an arm and hand left several participants unable to manage vital aspects of their self-care, such as using the toilet, bathing and feeding. Participants reported being able to walk into a toilet independently, but because of lower-limb weakness and/or reduced balance, some had to use their unaffected hand on a stick or grab rail for support. Therefore, they no longer had a useful hand to adjust their clothing and attend to their hygiene, and so needed assistance:

> Wiping my bum, 'cause I need to hold on, and I can't hold on with that [pointing to her affected hand], and I need that hand to do it [pointing to her unaffected hand]. (Ada, 2)

Eve also mentioned this it at all four interviews, suggesting that this was an important issue for her, and one that had not improved over time. She not only was very embarrassed, but also explained the effect of feeling 'useless' on her mood. She was angry with herself, but also angry at what she perceived to be a lack of understanding on the part of others.

Even where it was possible to adjust clothing in the toilet with just one hand, the impact of being one-handed clearly affected the speed with which this activity could be achieved, even at six months after stroke:

> I went to the supermarket and went in the toilet and a woman came in after me, and I'd been in there a bit and I was getting my clothes down to get on the loo and next I heard her washing her hands… and I hadn't even got my clothes down… I was always a very quick person. (Lily, 6)

The intrusion of other people into this normally private sphere of self-care was hard to accept and left individuals feeling exposed and embarrassed, and this often did not change over time, as can be seen by Alan's comments at 12 months post-stroke:

> I can't do what I used to do like have a bath on my own, you get embarrassed when they strip you and things like that, and you've got other people coming in and stripping you. (Alan, 12)

Several participants described how having just one functioning hand meant they needed someone else to cut up their food for them, and for Meg this had not improved by 18 months post stroke:

> He [husband] brought chops in the other night and he'd forgotten to cut it up and I say "oh! but it's so… I'm so messy." Oh, I'm quite upset about it. I'm embarrassed. (Meg, 18)

Sub-theme 1.2: Meaningful and valued activities

All participants reported that their upper-limb dysfunction had affected their capability and skill in activities that were valued and meaningful to them and an important part of their lives prior to their stroke, such as general household activities and hobbies. Normal activities such as cooking, which "gave me something to live for" (Ada, 12), could no longer be achieved because of the loss of bimanual ability needed to manipulate equipment in the kitchen.

Ballroom dancing was no longer possible for Eve because "you can't really jive with just one hand – it's two hands" (Eve, 2).

Similarly, confidence in participating in leisure activities, such as swimming, was affected by only having function in one upper limb:

> Well I can't move this arm, so I'd be going round in circles. It's getting in and out of the pool… I could jump in but getting out up the steps with just one hand? (Eve, 12)

Loss of bimanual function also affected participation in creative activity such as crafts and in do-it-yourself:

> Like the craft things, I sit and watch a lot, where I would like to join in. I feel in my brain my hand wants to do it, but it can't. I don't like it. (Jenny, 18)

> My mate had to have a look at that clock on the wall. I couldn't because I haven't got the use of my left arm… I just sat in the kitchen out of the way… felt terrible. I feel guilty – we've got to rely on other people. (Alan, 18)

Losing function, particularly in the dominant hand, was also a key factor in not being able to return to work. Gordon seemed to view his redundancy with a degree of acceptance:

> Interviewer: So, what does it mean for you then not being able to work anymore?
> Gordon (18): Well, it means nowt really, it means I've got to try and keep myself busy at home.

Upper-limb dysfunction can lead to loss of the ability to engage in activities that were once integral to, and added meaning to, the lives of stroke survivors before their stroke, robbing them of some purpose and pleasure in life. As can be seen by the data collection points in the quotations above, for these participants there had been little improvement over time in their ability to participate in meaningful activities.

Sub-theme 1.3: Managing life roles and relationships

The roles and relationships that participants had enjoyed pre-stroke were an aspect of normal life that was altered by upper-limb dysfunction, and often associated with the valued activities of which they were no longer capable. For example, lack of movement and control in the arm and hand contributed to their being unable to drive. For some male participants, this loss of what they considered a traditional responsibility of a husband or male partner, coupled with the acquired inability to complete heavier domestic tasks around the home and the additional need to have their spouse help them with self-care, was disrupting the balance and roles within their relationships:

> Well [wife] has to cut the grass you know and its hard work, I'm thinking I'm sure I could do that, you know… doesn't feel right. No. Well it's my job. Well it's tiring her out. (Colin, 18)

Alan said his partner looked after him "like a nurse", and felt guilty about the restrictions that his stroke had on their life together:

> I feel guilty that I can't do this, and I can't do that... And she says "I would like to go here" and I say "no we can't". It's changed the way we sort of get on. Well I was number one, now I'm number two. (Alan, 6)

As a grandfather, Alan feared he would no longer be able to dress up as Father Christmas to entertain his grandchildren. Similarly, Eve expressed concern about not being able to fulfil her role as a grandmother. Involuntary spasms in her hand, and the resulting lack of control, raised concerns about the potential to cause harm when caring for her small grandchildren: "If she puts her little hand in mine and mine grips hold of it, well I could really hurt her" (Eve, 6).

This powerful image of how the role of a caring grandmother had been altered by the loss of manual dexterity and fine control of grip, the perceived inability to provide safety and

protection, and the resultant immobility caused by hemiplegia, illustrates the significant and personal sense of loss experienced:

> I wouldn't feel safe holding the baby. I can't hold her [granddaughter's] hand or anything 'cause with the stick being in this one [unaffected hand], I can't hold on to her, so we can't go out for little walks. We don't play games like we used to… I can't get down and sit on floor with her because I can't get up with just one hand. (Eve, 12)

Theme 2: The disrupted self

The findings from this study indicated that upper-limb dysfunction had not only altered people's lives but had also disrupted their sense of self. The subordinate themes of *feeling devalued*, *disrupted self-image*, and *changes in identity* indicated that there were alterations in how participants thought about and evaluated themselves and their sense of how others perceived them. This disruption in the sense of self seemed to persist at 12 months post-stroke, and for some even further.

Ordinarily, many activities, whilst carried out in full sight of others, are 'invisible', as they are taken-for-granted aspects of functioning that do not command others' attention. However, functional limitations – for example, when help was needed to get food on a plate at a buffet during a social gathering – made participants feel conspicuous:

> I had to go up to the table, I could hold my plate, but my partner had to put food on the plate… Just feels like everyone in there's watching you. (Alan,12)

This conspicuity often led to stroke survivors making choices about the type of food they would choose to eat in a social setting, based on avoiding the need for someone else to cut it up for them:

> Well I mean, I've been out a couple of times to eat but I've managed to get food that was easy to manage with a fork. (Lily, 12)

> We went to the local pub with our friends, they ordered steak and I thought "Oh, I'll have scampi, that'll be easier." (Meg, 18)

For Cath, at two months, such difficulties led to her no longer wishing to eat in public.

For some participants, needing assistance with self-care changed their perception of themselves from being a competent adult to feeling "treated like a child" (Doris, 2) and "feeling like a baby" (Barbara 2) when having help with bathing and using the toilet. Needing help with using cutlery and feeding was particularly difficult, and similarly was evocative of childhood:

> Well [wife] will cut it up for me, and I drop a lot, I feel a bit of an idiot, you know you have to cut your own food up, and a bit like a baby, you're dropping food all over the place. (Harry, 12)

> Makes you feel like a baby! (Barbara, 12)

Other everyday taken-for-granted manual skills that were considered to be at the level of a young child included writing, particularly where the dominant hand had been most affected, and the stroke survivor was having to relearn this skill with the non-dominant hand:

> The four-year-old [grandchild] writes better than I do. (Harry, 6)

This emphasizes just how essential the bimanual function of the hands is as people develop through childhood to become competent, independent adults.

Sub-theme 2.1: Feeling devalued

It was apparent that the embarrassment and vulnerability that people experienced when needing help with personal care and other activities had an effect on their self-esteem,

causing some to feel that they were of less worth than before their stroke. The lack of mastery over personal care because of upper-limb dysfunction, sometimes such that individuals felt like a child again, and an inability to carry out valued activities and fulfil roles, often had a great impact on participants, some of whom described "feeling degraded" while being helped with personal care (Cath, 2; Eve, 2).

Many participants spoke about themselves in a variety of ways that suggested a perceived loss of worth. Ada, Doris, Barbara and Colin described themselves as useless at two months post-stroke, and Colin added that he felt inadequate. These feelings persisted for Barbara to six months and for Ada until her final interview at 12 months. Similarly, Eve considered herself useless at the 12- and 18-month interviews. This sense of being devalued was particularly marked when participants described their inability to manage personal care or to feed themselves, indicating that they viewed themselves as of less worth than prior to their stroke:

> Your self-esteem plummets a bit. (Doris, 2)

> You feel useless; you ought to do it for yourself. (Barbara, 6)

> …feel like a bit of an idiot… like a baby… dropping food all over the place. (Harry, 12)

Alan's description of the effect of upper-limb dysfunction on his self-esteem suggests a perceived loss of value at a broader social level:

> Before, I used to look as though I was a first-class person; now I'm sort of like a second-class citizen. It downgrades you. (Alan, 6)

There was also a clear sense in Alan's account that, through losing the ability to be independent and competent in the activities of daily living that depend on the use of both arms and hands, he no longer felt complete:

> [I'm] not a whole person. I feel half a person because I can only do half the things I used to do. I can't do what I used to do. (Alan, 12)

Sub-theme 2.2: Disrupted self-image

The presentation and appearance of the body are strongly related to self-image and the way in which the self is presented to others [24]. The findings indicated two issues that affected self-image. Firstly, because of their upper-limb dysfunction, participants were unable to present or adorn their body in their preferred way. Manipulating fastenings, such as buttons, zips and laces, and pulling on closer-fitting garments, such as socks and tights, require bimanual dexterity. Consequently, a number of participants had made changes to the type of clothing they wore to make it easier to dress independently or for carers to assist, often wearing looser-fitting garments with fewer fastenings. Although this was very practical, it often meant that their preferred style of dressing was no longer an option, and this persisted for many throughout the 18-month period of the study.

> Sometimes I feel scruffy when I go out… seeing everybody else smartly dressed and I'm sort of there in a pair of tracksuit bottoms… not wearing proper trousers… I feel out of place a bit. (Alan, 12)

> I don't like it because I've always been what you call a smart person and I like the clothes to fit, you know, properly. (Meg, 18)

Altered posture and lack of control in the arm affected the fit of clothes, particularly around the shoulder and upper arm where clothing can slip off the contours of the shoulder. Sometimes the affected limb was covered up to try to conceal this:

> I'm so fed up with my clothes. They're always dragging down, that's why I put a scarf on. (Meg, 18)

The contribution of a preferred way of dressing to one's self-image and identity was highlighted in many ways. Some of the women stated that they no longer had the fine control and dexterity in their upper limbs required to put on make-up, or to style their hair, which often requires both hands to work together. Being unable to use both hands to style her hair with a hairdryer and brush left one female participant feeling she looked *"*a mess*"* (Ada, 12), and another could no longer "tidy" herself up by doing her make-up and hair and wear more fitted, smarter clothes. This affected the younger image she liked to present to the outside world:

> I'm not impressed… I used to like to dress up… and I never looked my age. (Meg, 12)

The second source of dissatisfaction with self-image for some was the appearance of the affected arm, which caused them to hide it away.

> Yes, I keep it under the covers. I just think "oh gosh it's ugly", so I lay the covers over it. (Ada, 2)

Feeling self-conscious and different in social situations was another aspect of self-image that was affected. Alan described his inability to assume and communicate a normal relaxed posture:

> I feel a bit embarrassed because you see everybody else out are showing their two hands, you know, and things like putting their hands in their pockets. I can't even put my hand in my pocket. (Alan, 6)

For some participants, their concern was not simply with the visibility of their dysfunction, but also with how others would make sense of it. Eve, for example, looked forward to wearing splints as it would help explain the altered appearance of her arm:

> I think the sooner the splints are on I'll feel a lot better and then at least people can see something. They might think "oh she's got a splint on there's a reason for that," you know, whereas to me when you look at this there's no reason for it like this. (Eve, 2)

Sub-theme 2.3: Changes in identity

Participants identified themselves according to their job or profession, their gender, and their roles within the family and society. Bob had a strong identity as a musician and performer. He described himself as such at the first interview, where he talked about his previous ability to both play his own instrument and simultaneously conduct. Following his stroke, whilst he still identified himself as a musician, this was challenged by his upper-limb dysfunction and, at both the 6- and 12-month interviews, he no longer identified himself as being a good performer:

> It's very sad … I used to be a pretty good [performer]. I mean I've been living in music all my life. It is a bit depressing you know. I mean that's my job isn't it, music? (Bob, 6)

> Without wanting to blow my own trumpet, I was a good performer and I would take the difficult parts myself. And now I'm just thinking of last Tuesday when I was conducting, erm, somebody else had to take the difficult part and I thought "I could have played that perfectly well", but in fact somebody else had to, and was having difficulty with it. (Bob, 12)

Having worked as a skilled manual worker before his stroke, Gordon was looking ahead to possibly returning to work; however, at six months he worried that he would "only be good for sweeping up" because of the poor function in his dominant hand. Unfortunately, by 12 months post-stroke he was unemployed because of his impaired manipulation skills. His job had been part of the purpose of his life and his sense of identity, and he was unsure now how to fill this void, saying: "Well you feel a bit lost" (Gordon, 12).

Ada saw herself as a cook, but at six months post-stroke she was clearly very upset at losing this skill because of loss of function in her arm and hand. She recounted how during a recent family bereavement she was frustrated because she would normally have looked after the family by cooking and providing food. Now, others were doing this for her and the emphasis she put on the word 'me' illustrates how her identity as the cook in the family had changed:

> My sister came at the weekend and brought *me* a chocolate cake. (Ada, 6)

A change of identity that affected one participant had to do with the notion of handedness − instead of identifying as being either right- or left-handed, he described himself as being "no-handed" (Harry, 12).

Discussion

It has long been acknowledged that stroke can bring about a fundamental change to a person's life [13–16,19–21,51–53]. However, the findings in this study have shown the specific ways in which upper-limb dysfunction, where a person no longer has two functioning hands that can work together, or is no longer 'two-handed', can contribute substantially to this change and can have wide-reaching consequences, altering many areas of a person's life. This study has explored some of these consequences, and highlights how, in the event of illness or disability, the body – normally absent [54] or transparent [55] – 'offers resistance' [56, p.81] within everyday life. It also illustrates how, using Bury's [57] distinction, stroke has both 'meaning as consequence' (the practical limitations that it imposes on an individual's functioning and activity) and 'meaning as significance' (its effect on the person's sense of self and the way in which others perceive and react to him or her).

Other studies have reported similar findings in people with stroke: stroke survivors have described themselves as less capable and more dependent after their stroke [17,18] and women have described feeling uncomfortable and exposed to the view of others when being

helped by carers [58]. A lack of mastery over personal care activities has been shown to leave people feeling vulnerable and embarrassed [12,15,31,32,59–61]. Resuming valued activities can be challenging, particularly those relating to employment [20,62,63], and a sense of identity and notions of the self can be disrupted [18–20]. While other studies have examined specific aspects of upper-limb impairment following stroke [38,59,64], our study is the first to explore the specific ways in which dysfunction in the upper limb and the loss of two-handedness may play an important part in these experiences.

The participants in this study were very aware of the meaningful activities that they could no longer participate in because they no longer had bilateral hand function. This reflects a study by Poltawski et al [20, p.948] of internet-based accounts of upper-limb disability following stroke where people were frustrated by their inability to carry out simple tasks and 'cherished activities'. It is the ordinary and familiar things that a person does every day – what Charmaz [32] and Wallenbert and Jonsson [63] refer to as 'habits' – that build self-concept and identity and bring purpose and meaning to life; losing the ability to carry out these taken-for-granted activities, thereby failing to re-establish these former habits, can leave a void [65–68]. The loss of two-handedness can contribute to a change in self-image and a reduction in self-esteem [17,21]. Low self-esteem is associated with depression, which is common after stroke, and both low self-esteem and depression are related to poorer outcomes in rehabilitation [3,69].

These findings resonate with literature on hand trauma. People who suffered hand injury or trauma have reported similar experiences to those of the stroke survivors in this study, with their hand injuries altering their lives at many different levels. This included managing personal care and participating in meaningful activities in the home and in work [70–72]. Furthermore, they have reported altered perceptions of themselves, with low self-esteem being common, as they felt less competent and capable in activities and life roles [70–72].

This emphasizes the importance of the hands in activities that make up everyday life and supports the finding that no longer being two-handed is an important influence in the changes stroke survivors encounter in their life after stroke.

Hands play an important role in social interactions when meeting and communicating with people. However, for people with impairment or disfigurement of the hand, its normally unnoticed and taken-for-granted appearance may obtrude in social interaction and they may hide it away or camouflage it, in order to maintain social acceptability and to avoid feeling conspicuous [20,73]. Outward appearance of disability has been linked to people feeling conspicuous and ashamed of their disabled body, concerned about the reactions of others, and ultimately withdrawing from social contact [13,21,34,57]. Some people will strive to make their impairment less visible in social settings and, in keeping with Goffman's notion of 'passing' [74], will seek to appear able-bodied rather than disabled [59]; this may involve concealing any potentially visible impairments and making choices that avoid an impairment being seen, such as selecting food that can be eaten with just a fork in one hand as in the case of Meg. Her experiences are similar to those of a woman in the study by Poltawski et al [20] who had avoided eating out since her stroke because of her upper-limb disability. More broadly, the social effect of changes in bodily appearance reflect the way in which 'to be acknowledged as competent social performers we have to be able to give the impression of some degree of control, use and presentation of our bodies' [75, p.246]. However, for Eve, a desire for splints represented an attempt to accentuate, rather than conceal, her disability, so as to dispel ambiguity as to its cause, illustrating how individuals can strategically manipulate the visibility of their condition to ease social interaction and influence others' perceptions [76].

Being well dressed is part of looking well and attractive and makes one feel less conspicuous and more socially acceptable [66]. To achieve this, and to adorn the body with jewellery and

make-up independently, often requires one to be two-handed. Yet, in conventional stroke rehabilitation, simply achieving functional activity is often the priority, and relearning how to dress independently is achieved through the use of compensatory strategies such as wearing clothes that are looser fitting with fewer fastenings [63]. Relearning how to apply make-up and to fasten jewellery is not usually an important rehabilitation objective, as noted by Doyle et al [59] in their study on upper-limb sensory loss after stroke, as this requires fine manipulative control and acute sensitivity of the digits. Retraining these skills is resource-intensive and improvements in fine control to the level of skilled dexterous function are only achieved gradually. Nevertheless, the psychosocial consequences that arise from dissatisfaction and disillusionment with one's appearance and self-image [54,77,78] should be considered and addressed in stroke rehabilitation.

Occupational science makes a connection between the activities in which individuals participate, otherwise known as 'doing' [66], and their perception of themselves as a competent and capable person; the full extent of no longer having two hands working together, and of no longer being someone capable of 'doing', offers some explanation for stroke survivors describing themselves as only "half a person" [79, p.728]. Furthermore, Whalley-Hammell [66] suggests that 'doing' – completing tasks and activities – brings a sense of satisfaction and pleasure in life. Restoration of two-handedness in order to be able to engage in occupations, or learning to adapt to one-handedness and find new occupations, could contribute to stroke survivors regaining some sense of being a whole person again, and some restoration of their sense of self.

Christiansen [65] suggests that a person's identity is closely linked to his or her occupations, in the wider sense of valued activities and life roles, and this was very much the case for participants in this study. Day-to-day, routine occupations are an important part of people's lives, and through these occupations they build an image of who they think they are and how

they think other people perceive them. People create an identity around meaningful activities, or 'doing' [66,79,19,62], such as employment and professional activity, and the life roles that people occupy – often defined as important relationships such as wife, husband, mother or father – are intertwined with their identity [17,60]. However, if that identity is associated with a meaningful activity that is no longer achievable as a result of upper-limb dysfunction, then the sense of identity derived from that activity is likely to be altered, as Bob's experience illustrates. What may be regarded as traditional male roles are challenged by the effect of stroke on physical capability [12,13,49,80,81], and what may be seen as traditional female roles, such as caring for the family, are similarly altered [82].

A person's daily occupations are closely connected with family members, co-workers and friends [83]. An essential sense of belonging and connectedness in a relationship is associated with the contribution a person feels that he or she brings to that relationship, and helping one another creates bonds and connectedness, and a sense of fulfilment and pleasure [66,84]. Upper-limb dysfunction has, therefore, the potential to adversely affect that belonging and connectedness in people with stroke, as they can no longer complete the tasks or fulfil the responsibilities associated with their role in a relationship; their contribution to social and personal relationships is thereby undercut, as was the case for Eve, who could no longer fulfil her role of grandmother in the same way as before her stroke.

This has implications for the type and quantity of rehabilitation that is provided after stroke to improve functional activity in the arm and hand, particularly as the disruption to life and the altered sense of self did not seem to improve over time for the participants in this study. A more sustained approach to rehabilitation, as suggested by Robison et al [62], could improve function over the longer term and enhance participation in valued activities. Where this is not possible, helping the person to adapt to the challenge of hemiparesis – possibly using compensatory strategies for the upper limb, such as assistive technology – may provide more

useful function, ameliorate some of the negative effects of dysfunction, and facilitate development of new, meaningful occupations. Furthermore, it is important to recognize that upper-limb dysfunction can be a significant contributor to a person's low self-esteem and loss of identity and this, in turn, could affect overall motivation to engage and participate in rehabilitation.

Limitations

The participants in this study were all recruited from one stroke rehabilitation unit and so the findings could reflect particular aspects of the model of care adopted within the unit, or certain social or cultural circumstances in that part of the country. People with dysphasia or cognitive problems were excluded, resulting in more people with left-sided hemiplegia, and consequently fewer people with their dominant right hand affected by stroke. Additionally, the age range of participants (62 to 87) was somewhat limited. However, qualitative research aims primarily at the theoretical generalizability, or transferability, of insights, rather than the empirical generalizability of specific findings [85,86]. The description of the participants in this study should allow others to determine how and to what extent the insights that have emerged are transferable to different contexts.

A concern within phenomenological research is to preserve the individuality of participants' unique perspectives within a more 'aggregate' analysis of their accounts at a broader thematic level (as exemplified by the case-oriented approach utilized within interpretive phenomenological analysis [87]). We have attempted to strike an appropriate balance here through our use of quotations and providing a biographical context in which they can be interpreted.

Conclusion

This research has contributed new insights to the existing literature on the experience of stroke survivors and has brought to the fore how a dysfunctional upper limb, and the consequent loss of two-handedness, can profoundly affect many areas of a person's life. The effect of being unable to manage personal care and participate in meaningful activities and life roles and relationships can permeate through into a person's sense of self, disrupting his or her identity and self-image, and cause lowered self-esteem. The findings have shown that there is much for practitioners to learn from listening to people's experiences of upper-limb dysfunction. The participants' accounts in this study highlight the importance of restoring upper-limb function or providing compensatory strategies in stroke rehabilitation. The long-term nature of upper-limb dysfunction and its associated psychosocial consequences suggest that more intensive and specific upper-limb therapy should be provided in the early stages of stroke recovery, and this should extend beyond the usual six weeks of rehabilitation, to maximize potential for restoration of function and to enable a person to regain a meaningful life and a more positive sense of self.

(7677words)

Acknowledgements

The authors are grateful to the participants who were involved in this study, without whose time and willingness to share their experiences this research would not have been possible. Thanks, are also due to the Physiotherapy Research Foundation for a grant that part-funded the research.

Declaration of interest statement

The authors report no conflict of interests.

References

1. World Stroke Organization https://www.world-stroke.org/component/content/article/16-forpatients/84-facts-and-figures-about-stroke [accessed Jun 2019]
2. National Institute for Health and Care Excellence. Stroke Rehabilitation: Long Term Rehabilitation after Stroke. Clinical Guideline 162. London: NICE; 2013.
3. Intercollegiate Stroke Working Party. National Clinical Guideline for Stroke,5th ed. London: Royal College of Physicians; 2016.
4. Schieber MH. Individuated finger movements: rejecting the labeled-line hypothesis. In: Wing AM, Haggard P, Flanagan JR, editors. Hand and brain: the neurophysiology and psychology of hand movements. London: Academic Press; 1996. p. 81–98.
5. Wiesendanger M, Kazennikov O, Perrig S, et al. Two hands – one action: the problem of bimanual coordination. In: Wing AM, Haggard P, Flanagan JR, editors. Hand and brain: the neurophysiology and psychology of hand movements. London: Academic Press; 1996. p. 283–300.
6. Rosenbaum DA, Meulenbroek RGJ, Vaughan J. Three approaches to the degrees of freedom problem in reaching. In: Wing AM, Haggard P, Flanagan JR, editors. Hand and brain: the neurophysiology and psychology of hand movements. London: Academic Press; 1996. p. 169–186.
7. Tubiana R, Thomine J-M, Mackin E. Examination of the hand and wrist, 2nd ed. London: Martin Dunitz; 1996.
8. Champion J, Barber C, Lynch-Ellerington M. Recovery of upper limb function. In: Raine S, Meadows L, Lynch-Ellerington M, editors. Bobath concept: theory and clinical practice in neurological rehabilitation. Oxford: Blackwell; 2009. p. 154–181.
9. Yekutiel M. Sensory re-education of the hand after stroke. London: Whurr; 2000.

10. Raine S. The Bobath concept: developments and current theoretical underpinning. In: Raine S, Meadows L, Lynch-Ellerington M, editors. Bobath concept: theory and clinical practice in neurological rehabilitation, Oxford: Blackwell; 2009. p. 1–22.
11. Barreca S, Wolf SL, Fasoli S, Bohannon R. Treatment interventions for the paretic upper limb of stroke survivors: a critical review. Neurorehab Neural Repair. 2003;17(4):220–226.
12. Burton CR. Living with stroke: a phenomenological study. J Adv Nurs. 2000;32(2):301–309.
13. Dowswell G, Lawler J, Dowswell T, et al. Investigating recovery from stroke: a qualitative study. J Clin Nurs. 2000;9(4):507–515.
14. Kirkevold M. The unfolding illness trajectory of stroke. Disabil Rehabil. 2002;24(17):887–898.
15. Salter K, Hellings C, Foley N, et al. The experience of living with stroke: a qualitative meta-analysis. J Rehabil Med. 2008;40(8):595–602.
16. Shapiro AB. A story to create: stroke survivors' broken narratives. Top Stroke Rehabil. 2011;18(1):18–23
17. Williams S, Murray C. The experiences of engaging in occupation following stroke: a qualitative meta-synthesis. Brit J Occup Ther. 2013;76(8):370–378.
18. Ellis-Hill CS, Horn S. Change in identity and self-concept: a new theoretical approach to recovery following a stroke. Clin Rehabil. 2000;14(3):279–287.
19. Clarke P, Black SE. Quality of life following stroke: negotiating disability, identity and resources. J Appl Gerontol. 2005;24(4):319–336.
20. Poltawski L, Allison R, Briscoe S, et al. Assessing the impact of upper limb disability following stroke: a qualitative enquiry using internet-based personal accounts of stroke survivors. Disabil Rehabil. 2016; 38(10):945–951.

21. White JH, MacKenzie L, Magin P, et al. The occupational experience of stroke survivors in a community setting. OTJR (Thorofare NJ). 2008;28(4):161–167.
22. Charmaz K. Loss of self: a fundamental form of suffering in the chronically ill. Sociol Health Illness. 1983;5(2):168–195.
23. Owens TJ, Samblanet S. Self and self-concept. In: De Lamater D, Ward A, editors. Handbook of social psychology, 2nd ed. Dordrecht: Springer; 2013. p. 225–250.
24. Callero PL. The sociology of the self. Ann Rev Sociol. 2003; 29:115–133.
25. C. Swain J. Interpersonal communication. In: French S, Sim J, editors. Physiotherapy: a psychosocial approach, 3rd ed. Oxford: Butterworth-Heinemann; 2004. p. 205–219.
26. Goffman E. The presentation of self in everyday life. New York (NY): Anchor Books; 1959.
27. Owens TJ. Self and identity. In: Delamater J, editor. Handbook of social psychology. Boston (MA): Springer; 2006. p. 205–232.
28. Stone GP. Appearance and the self. In: Rose AM, editor. Human behavior and social processes: an interactionist approach. London: Routledge & Kegan Paul; 1962. p. 86–118.
29. Rosenberg M. Conceiving the self. New York (NY): Basic Books; 1979.
30. Gecas V, Schwalbe ML. Beyond the looking-glass self: social structure and efficacy-based self-esteem. Soc Psychol Quart. 1983;46(2):77–88.
31. Stets JE, Burke PJ. A sociological approach to self and identity. In: Leary MR, Tangney JP, editors. Handbook of self and identity. New York (NY): Guilford Press; 2003. p. 128–152.
32. Charmaz K. The self as habit: the reconstruction of self in chronic illness. OTJR (Thorofare NJ). 2002;22(suppl):31S–41S.

33. Burke PJ. The self: measurement requirements from an interactionist perspective. Soc Psychol Quart. 1980;43(1):18–29.
34. Stets JE, Burke PJ. Identity theory and social identity theory. Soc Psychol Quart. 2000;63(3):224–237.
35. Pound P, Gompertz P, Ebrahim S. A patient-centred study of the consequences of stroke. Clin Rehabil. 1998;12(4):338–347.
36. Secrest JA, Thomas SP. Continuity and discontinuity: the quality of life following stroke. Rehabil Nurs. 1999;24(6):240–246.
37. Murray CD, Harrison B. The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis. Disabil Rehabil. 2004;26(13):808–816.
38. Carlsson H, Gard G, Brogårdh C. Upper-limb sensory impairments after stroke: self-reported experiences of daily life and rehabilitation. J Rehabil Med. 2018;50(1):45–51.
39. Finlay L. Phenomenology for therapists; researching the lived world. Chichester: Wiley-Blackwell; 2011.
40. Hammersley M. Phenomenology. In: Lewis-Beck MS, Bryman A, Liao TF, editors. The SAGE encyclopedia of social science research methods, volume 2. Thousand Oaks (CA): Sage; 2004. p. 815–816.
41. Giorgi A, Giorgi B. Phenomenology. In: Smith JA, editor. Qualitative psychology: a practical guide to research methods. London: Sage; 2003. p. 25–50.
42. Lopez KA, Willis DG. Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. Qual Health Res. 2004;14(5):726–735.
43. Silverman D. Interpreting qualitative data: methods for analysing talk, text and interaction, 2nd ed. London: Sage; 2001.

44. Shudak NJ. Phenomenology. In: Frey BB, editor. The SAGE encyclopedia of education research, measurement, and evaluation, volume 3. Thousand Oaks (CA): Sage; 2018. p. 1246–1249.

45. Finlay L. “Outing” the researcher: the provenance, process and practice of reflexivity. Qual Health Res. 2002;12(4):531–545.

46. Hunt D, Smith JA. The personal experience of carers of stroke survivors: an interpretative phenomenological analysis. Disabil Rehabil. 2004;26(16):1000–1011.

47. Emmel N. Sampling and choosing cases in qualitative research: a realist approach. London: Sage; 2003.

48. National Institute of Health Stroke Scale (NIHSS) [Internet]. Rockville (MD): National Institute of Neurological Disorders and Stroke; [2010, accessed Jun 2019] available from: https://www.ninds.nih.gov/sites/default/files/NIH_Stroke_Scale_Booklet.pdf

49. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG, editors. Analyzing qualitative data. London: Routledge; 1994. p. 173–194.

50. Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013; 13:117.

51. Becker G. Continuity after stroke: implications of life course disruption in old age. Gerontologist. 1993;33(2):148–158.

52. Hilton EL. The meaning of stroke in elderly women: a phenomenological investigation. J Gerontol Nurs. 2002;28(7):19–26.

53. Ch’ng AM, French D, McLean N. Coping with the challenges of recovery from stroke: long term perspectives of stroke support group members. J Health Psychol. 2008;13(8): 1136–1146.

54. Leder D. The absent body. Chicago (IL): University of Chicago Press; 1990.

55. Carel H. Phenomenology of illness. Oxford: Oxford University Press; 2106.

56. Svenaeus F. The hermeneutics of medicine and the phenomenology of health: steps towards a philosophy of medical practice. Dordrecht: Kluwer; 2001.

57. Bury M. Meanings at risk: the experience of arthritis. In: Anderson R, Bury M, editors. Living with chronic illness: the experience of patients and their families. London: Unwin Hyman; 1988. p. 89–116.

58. Kvigne K, Kirkevold M, Gjengedal E. Fighting back – struggling to continue life and preserve the self following a stroke. Health Care Women Int. 2004;25(4):370–387.

59. Doyle SD, Bennett S, Dudgeon B. Upper limb post-stroke sensory impairments: the survivor's experience. Disabil Rehabil. 2014;36(12):993–1000.

60. Pilkington FP. A qualitative study of life after stroke. J Neurosci Nurs. 1999;31(6):336–347.

61. Kvigne K, Kirkevold M. Living with bodily strangeness: women's experiences of their changing and unpredictable body following a stroke. Qual Health Res. 2003;13(9):1291–1310.

62. Robison J, Wiles R, Ellis-Hill C, et al. Resuming previously valued activities post-stroke: who or what helps? Disabil Rehabil. 2009;31(19):1555–1566.

63. Wallenbert I, Jonsson H. Waiting to get better: a dilemma regarding habits in daily occupations after stroke. Am J Occup Ther. 2005;59(2):218–224.

64. Barker RN, Brauer SG. Upper limb recovery after stroke: the stroke survivors' perspective. Disabil Rehabil. 2005;27(20):1213–1223.

65. Christiansen CH. The 1999 Eleanor Clarke Slagle Lecture. Defining lives: occupation as identity: an essay on competence, coherence and the creation of meaning. Am J Occup Ther. 1999;53(6):547–558.

66. Whalley-Hammell K. Dimensions of meaning in the occupations of daily life. Can J Occup Ther. 2004;71(5):296–305.
67. Bourland ELR, Neville MA, Pickens ND. Loss, gain and the re-framing of perspectives in long-term stroke survivors: a dynamic experience of quality of life. Top Stroke Rehabil. 2011;18(5):437–449.
68. Wolf TJ, Baum CM. Improving participation and quality of life through occupation. In: Gillen G, editor. Stroke rehabilitation: a function-based approach. St Louis (MO): Elsevier Mosby; 2016. p. 46–58.
69. Vickery CD, Sherer M, Evans CC, et al. The relationship between self-esteem and functional outcome in the acute stroke rehabilitation setting. Rehabil Psychol. 2008;53(1):101–109.
70. Bylund SH, Ahlgren C. Experiences and consequences for women with hand-arm vibration injuries. Work. 2010;35(4):431–439.
71. Chan J, Spencer J. Adaptation to hand injury: an evolving experience. Am J Occup Ther. 2004;58(2):128–139.
72. Kingston GA, Judd J, Gray MA. The experience of living with a traumatic hand injury in a rural and remote location: an interpretative, phenomenological analysis. Rural Remote Health. 2014;14(3):2764–2776.
73. Meyer TM. Psychological aspects of mutilating hand injuries. Hand Clin. 2003;19(1):41–49.
74. Goffman E. Stigma: notes on the management of spoiled identity. London: Penguin; 1963.
75. Kelly MP, Field D. Medical sociology, chronic illness and the body. Sociol Health Illness. 1996;18(2):241–257.

76. Hoppe S. Visibility and invisibility in chronic illness. Medische Antropologie. 2010;22(2):361–373.
77. Garner J. Identity and Alzheimer's disease. In: Kelleher D, Leavey G, editors. Identity and health. London: Routledge; 2004. p. 59–77.
78. Fox KR, Wilson PM. Self-perceptual systems and physical activity. In: Horn TS, editor. Advances in sport psychology, 3rd ed. Champaign (IL): Human Kinetics; 2008. p. 49–64.
79. Ellis-Hill CS, Payne S, Ward C. Self-body split: issues of identity in physical recovery following a stroke. Disabil Rehabil. 2000;22(16):725–733.
80. Baumeister RF. The self in social psychology. Hove: Psychology Press; 1999.
81. Rittman M, Boylstein C, Hinojosa R, et al. Transition experiences of stroke survivors following discharge home. Top Stroke Rehabil. 2007;14(2):21–31.
82. Eilertsen G, Kirkevold M, Bjørk IT. Recovering from a stroke: a longitudinal, qualitative study of older Norwegian women. J Clin Nurs. 2010;19(13–14):2004–2013.
83. Eklund M, Orban K, Argentzell E, et al. The linkage between daily occupations and occupational balance: applications within occupational science and occupational therapy practice. Scand J Occup Ther. 2017:24(1):41–56.
84. Prigatano GP. The importance of the patient's subjective experience in stroke rehabilitation. Top Stroke Rehabil. 2011;18(1):30–34.
85. Firestone WA. Alternative arguments for generalizing from data as applied to qualitative research. Educ Res. 1993;22(4):16–23.
86. Sim J. Collecting and analysing qualitative data: issues raised by the focus group. J Adv Nurs. 1998;28(2):345–352.
87. Smith JA, Flowers P, Larkin M. Interpretative phenomenological analysis: theory, method and research. London: Sage; 2009.

Table 1: Data analysis process

Step 1	Adopting a phenomenological attitude to be open to all possibilities in the data.
Step 2	Listening to the interview several times, referring to any field notes, to remember the interview as a whole.
Step 3	Reading and re-reading the transcript several times.
Step 4	Annotating the transcript where recurring ideas of interest are identified and coded as such.
Step 5	Reviewing the coded data within the transcript to identify and label the broader themes and to look for similarities between them.
Step 6	Clustering of similar themes into a table of themes and sub-themes for each interview with every participant.
Step 7	Organizing tables of themes into framework charts to provide overview of data within and across participants
Step 8	Second researcher analysis of a sample of three transcripts from each interview point.
Step 9	Discussion between researchers and review of data analysis and development of tables of themes.
Step 10	Discussion between researchers and review of development of charts.

Table 2: Participant demographics

Participant	**Age**	**Hemiparetic side**	**Dominant hand**	**NIHSS score**
Ada *	74	Left	Right	5
Barbara	67	Left	Right	2
Alan	62	Left	Right	12
Cath *	84	Left	Right	8
Doris	84	Left	Right	2
Eve	65	Left	Right	8
Jenny	76	Right	Right	4
Lily	77	Left	Right	3
Bob	70	Right	Right	6
Meg	80	Left	Right	16
Colin	71	Left	Right	14
Gordon	62	Right	Right	Not Available
Harry	86	Left	Left	15

* participant died before end of study

NIHSS = National Institutes of Health Stroke Scale

Table 3: Themes and subordinate themes

Main themes	**An altered way of life**	**The disrupted self**
Subordinate themes	Challenges in personal care	Feeling devalued
	Meaningful and valued activities	Disrupted self-image
	Managing life roles and relationships	Changes in identity