

Poststroke trajectories: the process of recovery in the longer-term following stroke

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Poststroke Trajectories: The Process of Recovery Over the Longer Term Following Stroke

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Abstract

We adopted a grounded theory approach to explore the process of recovery experienced by stroke survivors over the longer term who were living in the community in the United Kingdom, and the interacting factors that are understood to have shaped their recovery trajectories. We used a combination of qualitative methods. From the accounts of 22 purposively sampled stroke survivors, four different recovery trajectories were evident: (a) meaningful recovery, (b) cycles of recovery and decline, (c) ongoing disruption, (d) gradual, ongoing decline. Building on the concept of the illness trajectory, our findings demonstrate how multiple, interacting factors shape the process and meaning of recovery over time. Such factors included conception of recovery and meanings given to the changing self, the meanings and consequences of health and illness experiences across the life course, loss, sense of agency, and enacting relationships. Awareness of the process of recovery will help professionals better support stroke survivors.

Keywords

grounded theory; illness and disease, chronic; illness and disease, experiences; recovery; research, qualitative; stroke

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Introduction

Worldwide there were almost 25.7 million stroke survivors in 2013, and globally stroke is the third most common cause of disability (Feigin, Norrving, & Mensah, 2017). In the United Kingdom alone, there are over 1.2 million stroke survivors, the vast majority of whom live at home, and stroke is the leading cause of disability (Stroke Association, 2017). People over 55 are the most likely to have a stroke, with the average age to have a stroke of 74 for men and 80 for women in England, Wales, and Northern Ireland (Stroke Association, 2017). It is important to understand the process of recovery poststroke to better support stroke survivors.

The concept of biographical disruption, the process whereby illness can disrupt the structures of everyday life, relationships, and expectations of the future (Bury, 1982), has been critically applied to debate the meaning and consequence of stroke in survivors' lives. Disruption is understood as being a consequence of the multiple losses people experience as a result of the stroke. Such losses might include disruption to their sense of self, and loss of control over their bodies, valued activities, meaningful skills, and social roles (Burton, 2000a; Ellis-Hill, Payne, & Ward, 2000; Faircloth,

Boylstein, Rittman, Young, & Gubrium, 2004; Nasr, Mawson, Wright, Parker, & Mountain, 2016; Robison et al., 2009). Survivors also report experiencing embarrassment, fear, and a sense of ongoing uncertainty (Becker & Kaufman, 1995). Stroke is known to affect mood, sometimes contributing to anxiety and depression (Burvill, Johnson, Jamrozki, Anderson, & Stewart-Wynne Chakera, 1995a, 1995b).

In managing the disruptive impact of stroke, literature suggests some survivors might actively adapt to their new situation by either reestablishing a sense of continuity with their life prestroke or by altering their expectations to create

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a new life (Ahuja et al., 2013; Becker & Kaufman, 1995; Faircloth et al., 2004; Pound, Gompertz, & Ebrahim, 1998a, 1998b). Studies vary, however, in the length of time survivors are followed up poststroke.

Not everyone who has a stroke, however, experiences a sense of biographical disruption (Becker & Kaufman, 1995; Faircloth et al., 2004; Pound et al., 1998). Literature has highlighted various biographical factors that might mediate the disruptive potential of the stroke. Pound et al. (1998) claim that in the context of an older and predominantly working-class sample, stroke is experienced as a continuation of a previous life of struggle. Similarly, Faircloth et al. (2004) argue that people who have had stroke might not experience the stroke as being disruptive, but understand the stroke as being part of their ongoing life experience. They refer to this as biographical flow. They identified three factors that might mitigate against the disruptive impact of the stroke: age, comorbidities and preexisting knowledge of stroke. The impact of the stroke is lessened, they argue, if illness is viewed as a natural part of growing older and if people are already managing existing comorbidities.

Although much research has focused on stroke as a disruptive event, the factors that might mediate disruption, and how survivors might adjust in the immediate aftermath of stroke, less attention has been paid to the process of recovery over time (Arntzen, Borg, & Hamran, 2015). Recovery can be understood as a dynamic process that is shaped by the interaction of physical, functional, emotional, and social domains (Dowswell et al., 2000; Kendall et al., 2007). In the context of stroke, "recovery" is often reduced to physical and functional rehabilitation (Arntzen et al., 2015; Burton, 2000a, 2000b; Easton, 1999). The process of recovery, however, stretches beyond the immediate aftermath of the stroke. The concept of recovery allows us to examine the dynamic nature of life over time poststroke, allowing us to acknowledge and move beyond disruption immediately poststroke.

This article explores the recovery trajectories of stroke survivors over time and examines the interacting factors that shape the meaning and process of recovery. Identifying what is understood to shape periods of stability and instability poststroke will help professionals to meaningfully assess how stroke survivors are managing and provide appropriate support.

Methodology and Method

In this study, we adopted a longitudinal, grounded theory approach (Charmaz, 2006) to explore poststroke trajectories and the factors that were understood to shape them. This study was part of a larger study, which aimed to improve outcomes after stroke by addressing the longer-term needs of community-dwelling stroke survivors and their carers in the United Kingdom (Forster et al., 2014).

Sample

We used a database of stroke survivors (Forster et al., 2015) to access potential participants. We employed a purposive sampling strategy to identify stroke survivors who were diverse in relation to various characteristics (socioeconomic status, age, gender, living circumstances, and changes in levels of function and independence as determined respectively by the Barthel Index and the Frenchay Activities Index). Stroke survivors who consented to be contacted were invited to participate and their family carers were also approached. Exclusion criteria were those living in 24-hr care settings and those receiving palliative care. In accordance with the grounded theory approach, we continued sampling participants until we reached data saturation (Charmaz, 2006). We defined data saturation as being the point at which no new recovery trajectories were being identified and we had sufficient data to explore facets of the recovery trajectories identified.

Twenty-two stroke survivors, diverse in their demographic and stroke-related characteristics, and 12 carers took part in the study. The majority of participants were male ($n = 14$), aged 60 or older, and lived with others ($n = 14$). Most participants described themselves as being independent prior to their stroke ($n = 19$). Participants reported a range of stroke-related impairments, including mobility problems; reduced function; communication, visual, and cognitive impairments; fatigue; depression. In terms of support, all participants reported receiving informal support from family, friends, and neighbors, while 12 participants were receiving some form of formal support at the time of the first interview. Please see Table 1 for further details.

Data Collection Methods

We used a combination of qualitative methods comprising in-depth interviews at two time points, solicited diaries and network mapping techniques. In an initial interview, we explored survivors' experiences of stroke, and the daily pattern of life prior to and following the stroke. Please see Table 2 for further details about the topic areas covered. This interview took place, on average, 15 months poststroke (range of 14 to 24 months poststroke).

At the end of the initial interview, participants were asked if they would be willing to keep a written or audio diary over a period of 4 weeks. It was anticipated that as diaries can capture hidden accounts that do not emerge during interviews (Furness & Garrud, 2010), this data would aid our understanding of the complexities of living with impairments and reflections on daily lives. Participants were asked to write about any events and experiences that were meaningful to them, as well as their thoughts and feelings. The guidance provided to participants offered suggestions of what they might wish to write about, including routine experiences, challenges they faced, hobbies and leisure activities, interactions with others, their reflections

Table 1. Summary of the Characteristics of Participating Stroke Survivors.

| Characteristic | Number of Stroke Survivors (<i>n</i> = 22) |
|---|---|
| Gender | |
| Female | 8 |
| Male | 14 |
| Age at time of stroke (in years) | |
| 50–59 | 4 |
| 60–69 | 10 |
| 70–79 | 5 |
| 80–89 | 3 |
| Living circumstances at time of first interview | |
| Alone | 8 |
| With others | 14 |
| Comorbidities reported by stroke survivor at time of first interview | |
| Reported other health condition | 13 |
| None reported | 9 |
| Prior to stroke (not mutually exclusive categories) | |
| Independent prior to stroke | 19 |
| Working prior to stroke | 5 |
| Stroke-related impairments reported by stroke survivor at time of first interview (not mutually exclusive categories) | |
| Mobility | 20 |
| Paralyzed or limited use of hand/arm | 10 |
| Communication | 2 |
| Visual impairment | 4 |
| Cognitive impairment | 8 |
| Fatigue | 4 |
| Depression | 1 |
| Formal support provided at time of first interview (not mutually exclusive categories) | |
| Health and allied health professionals | 5 |
| Social care | 7 |
| Third sector | 1 |
| No formal support | 10 |
| Informal support provided at time of first interview (not mutually exclusive categories) | |
| Spouse | 13 |
| Son/daughter | 16 |
| Other relative, friend, and/or neighbor | 18 |
| No informal support | 0 |

on life after stroke. It was made clear, however, that these were only suggestions and they were encouraged to record anything they felt to be important. Participants were free to decide how frequently they recorded an entry and how much time they spent on the diaries. Once returned, we analyzed the diaries, and emerging categories and concepts were explored during a follow-up interview (Elliott, 1997; Jacelon & Imperio, 2005). Twelve survivors and three carers agreed to keep a diary.

A follow-up interview took place, on average, 4 months after the first (range of 3 to 6 months following the initial

interview), the topic guide was developed from our ongoing analysis of the initial interviews and diaries. In this interview, we examined any changes participants had experienced since the first interview, and explored further those issues raised by participants in the initial interview and diaries.

As the type and nature of support is known to be important, during the follow-up interview we also mapped participants' support networks using an adapted version of the hierarchical mapping technique (Antonucci, 1986). This involved participants identifying individuals or services that offered emotional, instrumental, informational, or other forms of support following their stroke. Participants indicated how important they had found the support of those identified by placing the individual or service on a diagram of three concentric circles. The closer to the center the individual or service was placed on the diagram, the more important the participant had found the support offered. Following this mapping exercise, we explored the values and meanings they attached to changing patterns of social relationships and support. We discussed issues such as the nature of support offered by those identified, changes in support over time, how such support was accessed, who they supported and how, changes in their relationships with individuals identified, if there was anyone or any form of support they felt to be absent from their network. Two survivors and one carer were unable or declined to take part in the second interview.

Permission was granted from NHS ethics to undertake the study. We worked to make the study as inclusive as possible, and obtained written informed consent from participants or, for those who lacked capacity to consent, we sought consultee assent in accordance with the Mental Capacity Act 2005 (England, Wales, and Northern Ireland). Interview transcripts were de-identified, all names were replaced with pseudonyms, and participants were given a unique identifier.

Analysis

We undertook simultaneous data collection and analysis (Charmaz, 2006). Analysis involved careful rereading of interview and diary transcripts, followed by open, focused, and theoretical coding to facilitate the development of categories, concepts, and theories (Charmaz, 2006). The software program NVivo 8 was used to organize data. Descriptive, analytic, and reflexive memos were recorded throughout.

Interpretations were developed and tested by the use of "constant comparison" (Glaser & Strauss, 1967). Data segments from different data collection methods were compared (interview and diary data) to add depth and complexity to the analysis. Developing codes and categories were also compared, and refined through the search for negative instances. This was carried out first within-case to produce an understanding of each individual's account of recovery and second, across cases to explore variation between participants.

As we progressed, the analytic notions of biographical disruption (Bury, 1982), and illness and recovery trajectory

Table 2. Summary of the Topics Covered in the Initial Qualitative Interview.

| Topic Areas Covered | Examples of Further Questions and Prompts |
|--|--|
| Could you tell me about your life before stroke? | <ul style="list-style-type: none"> • Could you describe an average day? • What kinds of activities and events were important to you? • Have you had previous experience of illness or disability and what impact did this have on your life? • Did you receive or provide any help or support to others prior to your stroke? |
| Could you tell me about your stroke? | <ul style="list-style-type: none"> • Could you describe the stroke? • How did the stroke affect you? • What was your experience of being in hospital? • What was your experience of returning home? • Could you describe what an average day was like when you returned home (good days/bad days)? • What support did you receive once you returned home? |
| Could you tell me about your life following your stroke? | <ul style="list-style-type: none"> • Could you describe what an average day is like for you now? How has this changed over time? • What activities and events do you do now? Could you tell me about what it was like to return to doing XXX [specific activity]/taking up XXX [specific activity]? • Could you tell me about your experiences of going out and about since your stroke? • What help and support have you received? • What are the ongoing affects of your stroke and how do you feel about these? • Do you feel you have adapted to the affects of your stroke? • Could you describe how you have recovered since your stroke? • What do you feel has helped or hindered your recovery? |
| Could you tell me your hopes and plans for the future? | <ul style="list-style-type: none"> • Do you anticipate any further recovery? • What are your plans for the future? Do these plans differ to those you had prior to your stroke? |

(Corbin & Strauss, 1985, 1987, 1991; Godfrey & Townsend, 2008; Strauss, 1984) from the literature on chronic illness became important as sensitizing concepts with which to think through the data. The concept of recovery, as a dynamic and ongoing process shaped by multiple domains, became increasingly important as the analysis progressed. In this instance, we used the phrase “recovery trajectories” to capture the interplay evident between the course of the stroke and rehabilitation, the work required to manage and live with impairments, and the subjective experience.

Our analysis led to the exploration of recovery trajectories evident in participants’ accounts and the factors that shaped them. Exploration of negative instances facilitated the identification of different recovery trajectories. For example, the trajectory that was eventually labeled “cycles of meaningful recovery and decline” has many similarities with the trajectory of “meaningful recovery” in how stroke survivors narrated their experiences, in particular their initial experience of disruption and recovery poststroke. By searching for negative instances in the data, however, important differences between experiences were noted. In particular, the importance of a second disruptive event in shaping survivors’ experience of poststroke recovery. Such differences shaped the overall experience of recovery for these survivors and led to the formation of two separate recovery trajectories.

Reflexivity formed an important element of both data collection and analysis, as we wrote reflexive memos after each encounter with participants and throughout the process of analysis. Such memos formed an important part of data

analysis, as is common in grounded theory (Charmaz, 2006), and our memos and interpretations of the data were discussed among the research team. Emerging findings were presented to academic audiences, health care professionals, as well as stroke survivors and their carers.

Results

Poststroke Trajectories

From the accounts of participating survivors, we identified four poststroke recovery trajectories: (a) meaningful recovery, (b) cycles of meaningful recovery and decline, (c) ongoing disruption, and (d) gradual, ongoing decline (please see Table 3 for a summary of the four recovery trajectories).

Meaningful recovery. This trajectory was characterized by stroke survivors experiencing the stroke and related impairments as disruptive, in terms of its significance for their identity and its consequences for their daily lives. This disruption was understood to be followed by a process of, often gradual, recovery in which people worked to create a new and meaningful life. The experience of recovery was marked by several key factors: initial disruption, giving meaning to small improvements and learning to manage impairments, reestablishing a way of being in the home, successfully reentering the public sphere, engaging in meaningful occupation, coming to terms with loss, maintaining the relational self. Nine participating stroke survivors described this trajectory.

Table 3. Overview of the Recovery Trajectories Identified.

| Recovery Trajectory | Key Features of the Recovery Trajectory Narrated by Stroke Survivors |
|--|--|
| Meaningful recovery | <ul style="list-style-type: none"> Initially experiencing stroke as being disruptive to the structures of everyday life, relationships, and sense of self Considering small physical and functional improvements as being meaningful Gaining familiarity with the changed body and learning to manage impairments Reestablishing acceptable ways of being in and moving around the home Successfully reentering the public sphere Developing strategies and being supported to resume (some) everyday life routines and engage in old or new meaningful occupations Maintaining important relationships through engaging in everyday tasks and leisure activities Coming to terms with losses experienced following stroke |
| Cycles of meaningful recovery and decline | <ul style="list-style-type: none"> Initially experiencing disruption poststroke and a process of recovery as described by those narrating a meaningful recovery Experiencing a subsequent event as being disruptive to their everyday life, relationships, and sense of self. This event could be related to their health, a shift in social support, or a loss of meaningful activity Going “backwards” in their stroke recovery Having to relearn how to manage stroke-related impairments given new circumstances Experiencing the process of recovery following the second disruptive event as being at a slower pace |
| Ongoing disruption | <ul style="list-style-type: none"> Experiencing stroke as continuing to cause disruption to the structures of everyday life, relationships, and sense of self Focusing on returning to prestroke (unimpaired) body Small physical and functional improvements were not viewed as being meaningful as they did not mark a return to their prestroke body Experiencing things they are no longer able to do as being particularly meaningful. Feeling restricted in their home and public spaces Daily life depicted as restricted and monotonous, with limited/no meaningful occupation Changes to and loss of important relationships Sense of insurmountable loss caused by their stroke |
| Stroke as part of gradual, ongoing decline | <ul style="list-style-type: none"> Gradual decline in health prior to stroke that had had an impact on daily life Declining routines and engagement in meaningful occupation prior to stroke Stroke understood as being a continuation of their unfolding biography (so, not experienced as being a disruptive event) Stroke-related impairments ascribed little meaning Acceptance and expectation of ongoing decline in health and subsequent impact on daily life |

Initial disruption. Participants spoke of experiencing disruption most acutely postdischarge home. Their accounts typify “biographical disruption”—in the meaning of the stroke on their identity and biography, and in the difficulties and challenges stroke impairments had on their daily lives. “It [the stroke] is very hard, I’ve had serious illnesses in my life when it has been touch and go and I’ve got over it, but even that, it’s not like a stroke” (ID02, Female stroke survivor, meaningful recovery trajectory).

Giving meaning to small improvements and learning to manage impairments. People spoke of having focused on their changed body, their physical and functional impairments in the period postdischarge, which became starkly apparent following the transition to home. Over time, however, they noted small, but meaningful, improvements. Their ability to ascribe meaning to these subtle changes was, in part, because of the comparison they drew with their immediate poststroke body and in part, because of the possibility of working toward further improvement.

My eyesight had been affected (. . .) when you’ve got the herbs shelf, well they’re all the same color, I couldn’t tell the difference (. . .) I couldn’t find things (. . .) when you’re in a hurry trying to find the thyme or something, I’d have to call somebody to come and look for it for me. But no, that’s better, much better. (ID13, Female stroke survivor, meaningful recovery trajectory)

Concurrently, people talked of gaining familiarity with this new, changed body and devising strategies for managing the effects of impairments, sometimes with the support of health care professionals.

Now I’ve learned, I fasten it [bra], I put it over my head, put my arms in, which I’ve got to be careful of because my bones creak and I don’t want to put my arm out. So you find ways of doing things, and they [health care professionals] teach you a lot of odd things, to do things, but dressing is very hard at the beginning, and I mean really hard. (ID02, Female stroke survivor, meaningful recovery trajectory)

This increased knowledge about how to manage their body, which was often established through a process of trial and

error, contributed to their growing sense of control and confidence.

Reestablishing a way of being in the home. People described feeling lost in their home when they first left hospital and, in some cases, being restricted to a single room. This previously familiar space became one of new obstacles and challenges. For a time, their home became a semipublic space, as professionals came and went, altering the space as they did so. Although the input of these professionals was often perceived as vital to their rehabilitation, for some it also contributed to the “strangeness” of this once private space.

The subtle but meaningful improvements stroke survivors noted and their knowledge of how to manage their impairments contributed to them reestablishing a way of being within their own home. Being able to move around and “be” in this space in a way that was acceptable to them was often considered to be a major achievement.

Well when I first came home I couldn't get up the stairs, I had a bed down here (. . .) I don't know about you but I don't like sleeping in the same room I do me business in and eating, sleeping, and eating in the same room, not very pleasant. So first thing I did when they put the hand rail up was went upstairs to the toilet and since then I've been going to bed every night with her upstairs [his partner], me own bed and no doubt that we all know that you have a tendency to miss if you've not had your own bed for a while. (ID17, Male stroke survivor, meaningful recovery trajectory)

People related the practical and pragmatic steps they, or those that supported them, had taken to reorder the environment so they were able to use the space in an acceptable way.

I couldn't get up the stairs (. . .) me brother came and fitted me an extra banister on so I can drag myself upstairs now, one each side and yeah (. . .) there's a big difference to what (. . .) I was when I first came out. (ID01, Male stroke survivor, meaningful recovery trajectory)

Successfully reentering the public sphere. Leaving the home was also described as an important milestone in their recovery trajectory. For some it was fraught with challenges, as people had to devise very practical strategies to overcome environmental barriers including physically managing to leave the house and then navigating certain spaces and buildings.

I don't feel too bad [going out on his own], if I take my time, I have a little walking frame with wheels on that's in the car (. . .) And so I'll get my sticks and I've got some clips on, I can stick clips in and push that round, yeah, a bit more confident than I was. I was glad they were there before [his wife and son], (. . .) but now (. . .) I have to have a go myself, got to try and do it myself. (ID01, Male stroke survivor, meaningful recovery trajectory)

Reengaging with the public sphere was almost always facilitated by some form of support at first (sometimes from professionals, but often from family or friends) before they ventured out alone.

I didn't go out of the house for about what, three month, (. . .) and then I just, Fred me mate, I said, “Fred come on, walk me to the shops,” and it was a job to walk to the shops, but I stuck with it, (. . .) I stuck with it, so I got better and better, now I can go out on me own. (ID03, Male stroke survivor, meaningful recovery trajectory)

For some, reentering the public sphere required the assistance of others and was facilitated by having family who lived nearby or with the help of friends, neighbors, or professionals.

Engaging in meaningful occupation. By taking charge of their situation and changing the way they went about doing routine activities, survivors resumed everyday life routines and tasks, for instance getting dressed, cooking, and cleaning. Carrying out such tasks was valued and provided a sense of accomplishment.

I put all my skirts and that in the drawer, I did that myself (. . .) I've got my clothes on a rail like and then on a Sunday I usually look on the rail to see what I wear on Monday, my clothes, I get them out, I get them off the coat hanger and then on the Wednesday I have another look to see what I'm going to wear on a Wednesday, yeah I do that alright (. . .) I mean I've even manage to sometimes change my quilt cover. (ID15, Female stroke survivor, meaningful recovery trajectory)

Pacing was an important strategy for engaging in everyday tasks, by doing a little at a time and scheduling in time for rest, they had the physical energy and strength to complete tasks. People also spoke of how they would meticulously plan their routines.

(. . .) now I section myself, I time myself and I get through it all. I think right now I am and I put all my clothes ready, get a shower and I get myself showered and dried and all that, do my face which doesn't take much, (Laughs) (. . .) And um I get there, it takes me an hour to get up. (ID02, Female stroke survivor, meaningful recovery trajectory)

Reentering the public sphere enabled stroke survivors to engage in meaningful occupation outside the home. Attempts were made to resume previously valued leisure activities. This resulted in mixed success, shaped in part by the degree and nature of their impairments, the level of support they received, and the types of activities they engaged in prior to the stroke. Many, however, took up some form of meaningful leisure pursuit by adapting, substituting, or discovering new activities.

I made loads [greetings cards] (. . .) I made one for Julie for her niece's birthday and I made one (. . .) for Mary for her friend's birthday and it's got "Best Friend" on it, I made one for her, and I made some Easter cards for Julie and Sammy, because Sammy's going to treasure it, and oh I've made lots; yeah. (ID15, Female stroke survivor, meaningful recovery trajectory)

When talking about these new activities, people emphasized opportunities they provided for social interaction, which for some acted as a substitute for the social engagement they had previously enjoyed. One stroke survivor, who had given up working following his stroke, drew parallels between conversations at the gym he now attends and the banter he used to engage in with his work colleagues.

It's a massive gym, the equipment there is very good as well (. . .) yeah, I enjoy it. I have a bit of a crack [laugh] with the lads who are there, we mainly talk about football and things (. . .) I enjoy it. (ID17, Male stroke survivor, meaningful recovery trajectory)

Stroke survivors were often supported to (re)engage in everyday and leisure activities by their family, friends, and formal services, who offered encouragement, discovered and created opportunities, and provided practical help.

Maintaining the relational self. Emphasized throughout the interviews was the relational importance of doing everyday tasks and leisure activities. Through the doing of such activities, stroke survivors performed relational ties. Such action was key to creating a meaningful recovery.

I've always been used to, because my son's got a special diet, serving up two or three different meals at the same time. But I'd get to Sunday dinner and I couldn't handle plating up for six people. I'd forget the sprouts on one, I'd go, "Oh." That really threw me. That's gone. (ID13, Female stroke survivor, meaningful recovery trajectory)

Engaging in family events and celebrations, and doing activities with friends were seen as being particularly important. This enabled them to perform family and friendship through their participation in such events.

It [the art group] consists of about 15 of us, we work together, we have a good crack [laugh], lighten each other up a bit, torment each other a bit like you do, there's a bit of wisecracking and that (. . .) we're all friends with each other because we all know each other so long. (ID05, Male stroke survivor, meaningful recovery trajectory)

By engaging in meaningful occupation, and, therefore, maintaining their relational self, survivors worked to create a new life which, although different from their prestroke existence, was valued and meaningful.

Coming to terms with loss. An important element of this trajectory was making sense of loss. All but one spoke of their lives now as being quite different to their lives prior to the stroke. Many still missed elements of their previous life, in particular, the loss of freedom, independence, and spontaneity.

But, yes there's a lot of things you miss. You miss slipping out in the car and going to the shops. You miss walking over to the shops because you've got to think about it now, can I manage that today. All the things that are nothing really and (. . .) you've got to be determined to try and do them. (ID02, Female stroke survivor, meaningful recovery trajectory)

Some used the concept of an aging self to make sense of changes, deal with losses, and reevaluate their expectations of the future. "I haven't quite got the stamina I had before. I tend to fall asleep in the evenings, but I mean, I suppose for 60 I'm not too bad" (ID13, Female stroke survivor, meaningful recovery trajectory).

The creation of a meaningful recovery was a continuous "work in progress" as they still faced challenges because of fluctuations in the severity of their impairments, and the social and material resources at their disposal. Ways of managing occasionally had to change, frustrations continued to exist, and the new way of being often had limitations and constraints. This process of recovery took place over varying periods of time, and for those with severe or communication impairments the process of recovery was experienced as being especially elongated.

Cycles of meaningful recovery and decline. For five participating stroke survivors, the challenges and fluctuations they faced had substantial implications for their recovery. This group, who initially presented their poststroke trajectory as that of *meaningful recovery*, subsequently encountered a further disruptive event. Typically, this related to another health condition interacting with the effects of the stroke. For instance, worsening arthritis or acute periods of ill health that they felt undermined their ability to manage stroke-related impairments.

Well not too [good] to be honest with you, my legs (. . .) started getting better, [then] seemed to get worse (. . .) Yeah I've got some arthritis in my knee (. . .) Backwards, I'm going backwards with these legs, especially my left leg. (ID22, Male stroke survivor, cycles of recovery and decline trajectory)

The disruptive event could also be precipitated by significant shifts in their social worlds. Loss of support from a family member on whom they had relied to manage day-to-day, or the loss of a meaningful occupation, could contribute to the sense of disruption.

I mean, don't get me wrong, [daughter], rings up every day, (. . .) to see how I am, especially since I've had this cold. But she doesn't

come and see me as much (. . .) and she doesn't do things with me as much. (ID06, Male stroke survivor, cycles of recovery and decline trajectory)

They spoke about going "backwards" in their recovery, requiring that they start again to reestablish ways of managing. This took place in conditions of heightened vulnerability, undermining confidence.

I dislocated my shoulder so that's put me back quite a bit, but I am now going forward again, because I lost my confidence, obviously, didn't dare walk without my husband (. . .) so it really, it put me back to how it was when I had the stroke in other words. My mind said "oh no, I've gone back a whole year" but now it's back to normal, to how I was, I think, almost. (ID14, Female stroke survivor, cycles of recovery and decline trajectory)

For some, this phase of recovery was felt to be at a slower pace and they never quite got back to where they were before the second disruptive event.

Ongoing disruption. Here, poststroke disruption assumed the same meaning and consequences for survivors as that for people in the previous two trajectories. The difference was that they perceived no sense of movement toward meaningful recovery. On the contrary, their sense of disruption persisted and they conveyed selves and lives in terms of continued suffering and struggle. Sustained disruption was marked by several key processes: focusing on the prestroke body, restriction in the home and in the public sphere, lack of meaningful occupation, disrupted relational self, and insurmountable loss. Six participating stroke survivors presented this trajectory.

Focus on returning to prestroke body. For this group of stroke survivors, their focus continued to be on returning to their prestroke body, which was often presented as being unimpaired. The severity of the poststroke impairments they reported varied, but did not differ greatly from other participants. Typically, they spoke of having had high expectations of rehabilitation and what health care professionals could achieve.

I thought well, I'll soon be out of here [hospital] (. . .) and he [health care professional] said "No, we'll sort you out, we'll sort you out" and to be quite honest, I mean, I didn't think they'd let me out again until I could walk. (ID18, Female stroke survivor, ongoing decline trajectory)

Small improvements were not viewed as being particularly meaningful, being regarded as insignificant steps toward attaining their ultimate goal of their "normal" prestroke self. The perceived lack of improvement often led to feelings of frustration. Although by the time of the interview they acknowledged that returning to their prestroke body was unachievable, they struggled to make sense of this

perceived failure and adjust their expectations for recovery. Indeed, some survivors here were unable to envision a meaningful life with impairment. "I keep asking the same question, is everything going to come back to normal? And the question [*sic*] they keep giving me, 'no,' and I can't take no for an answer [bangs right hand on the table]" (ID10, Male stroke survivor, ongoing decline trajectory). Survivors who recounted this trajectory neither recounted having developed nor described what they regarded as meaningful strategies for managing their impairments.

Ongoing restriction. Although there was some talk of changes that had occurred since their stroke, the emphasis was most often placed on what they were no longer able to do.

It's just ruined me really, totally, I was so active before, because as I say, I can't turn me own fire on, I can't put a plug in the bath, I can't pick up me kettle. They might seem damn silly things but they're so frustrating, that you can't do them. No, it hasn't been very nice [she begins to cry]. (ID21, Female stroke survivor, ongoing decline trajectory)

Barriers to accessing and engaging in the public sphere were highlighted. For some, this was because of problems with transport, which they felt dramatically curtailed their ability to engage in leisure activities. If the survivor had prior to the stroke been the driver in the household, the spontaneity and freedom of driving was a particular loss. The work involved in getting out of the house and accessing different places was elaborated on. "So that was like cutting my legs off, because I'd been driving for sixty odd years and then suddenly to lose it, you lose your means of transport and we can't get anywhere now, this is the problem" (ID09, Male stroke survivor, ongoing decline trajectory).

They perceived that others acted differently toward them on account of their impairments and recounted incidents in which they felt diminished. "I find everybody was the same, (. . .) [they] talk to you different, you don't get the same treatment, you know" (ID18, Female stroke survivor, ongoing decline trajectory).

Lack of meaningful occupation. Survivors spoke of a lack of routine and struggling to carry out everyday tasks and valued leisure activities.

[You] think about the things that you've done before, which you can't do now (. . .) Same as taking his mum out, I'd love to keep going up there two or three times a week like I used to, sometimes I used to go up there nearly every day, and I'd love to do it but I can't (. . .) I can't do anything, that's the thing, I can't think about doing anything, I can't do it. (ID19, Male stroke survivor, ongoing decline trajectory)

Daily life was depicted as restrictive and often monotonous.

Up, coffee, telly [television], [next door neighbor's daughter] came in and did a bit of cleaning, telly [television] all afternoon, tea, bed by six. Another lovely day [said in a sarcastic tone] and I am totally, totally bored to death. (ID21, Female stroke survivor, ongoing decline trajectory, extract from audio-diary)

Disrupted relational self. Of importance through all the interviews with survivors in this trajectory was changes to and loss of important relationships. For some being restricted in the manner in which they inhabited the home and being unable to perform certain everyday tasks was understood as having an impact on their ability to enact family ties, which in turn contributed to tensions within relationships.

Carer (C): Since [name] had both strokes, her ability to do anything in the house has been highly . . .

Stroke survivor (SS): Grrrr, yeah, I didn't think it would be as hard to [do] the little jobs that I want to do.

C: Yeah, and of course, anything I do, I do my way, which is not . . .

SS: (Makes screeching sound).

C: And under our strict demarcation, she's responsible for in the house, so you can see the problems, and it is a problem (ID18, Female stroke survivor and male carer, ongoing decline trajectory)

Some withdrew from friends and family, others felt people had distanced themselves from them because of their impairments. "When you're actually disabled nobody really wants to know you, where you thought you had friends you don't have 'em anymore" (ID21, Female stroke survivor, ongoing decline trajectory).

Although all participating stroke survivors described the complexities of having to rely on others, this group seemed to particularly struggle with accepting help, as this was an explicit marker of their changed self. Their reactions toward those who offered assistance were often complex.

I don't like to gain sympathy, I don't want sympathy, like I said before, if people aren't helpful and it's obvious I need that if, I get cross, and if they're too helpful, I get cross (. . .) it is a stupid mind set, I know that (. . .) You want to be normal, you don't want to be treated different, but you do need help sometimes. (ID18, Female stroke survivor, ongoing decline trajectory)

Insurmountable loss. These stroke survivors narrated life poststroke as being a series of losses. They felt passive in their own rehabilitation and recovery, and unable to shape a meaningful life. The future was imagined as either a continuation of the unsatisfactory present, or a continued decline. "My life to me it's started to deteriorate. I have always said, I've got this, this and this, the next thing what's going to happen that'll be it, [makes a cut throat gesture] end of story"

(ID10, Male stroke survivor, ongoing decline trajectory). Lacking meaningful occupation, and experiencing disrupted relationships, survivors mourned a life lost and experienced ongoing disruption.

Stroke as a part of gradual, ongoing decline. This poststroke trajectory was characterized by stroke survivors presenting the stroke as another step in a slow process of declining health. Their poststroke trajectory was part of a broader deteriorating trajectory marked by declining health and reduced involvement in meaningful occupation; the stroke not being experienced as disruptive; stroke-related impairments ascribed little meaning; and an acceptance of ongoing decline. Two survivors presented this trajectory.

Preexisting trajectory of declining health and meaningful occupation. Stroke survivors here spoke of a gradual decline in their health prior to the stroke, which, although not unique among those interviewed, was different to the extent that previous ill health had exerted a significant impact on their daily lives. One stroke survivor, who retired from work because of ill health several years prior to his stroke, noted that since giving up driving, prior to his stroke, he has done less and less.

No I think it's been coming on gradually over the last four years or so. It all seemed to start (. . .) when we finished with the motor [car] and getting out and about (. . .) and ever since then it seemed to quietly go down, downhill if you will (. . .) I don't know it's a weird sort of thing, but as I say the telly's [television's] here, telly's [television's] on. (ID11, Male stroke survivor, gradual decline trajectory)

Stroke not experienced as disruptive. Prior experience of ill health and impairment, and resulting consequences for their sense of self, meant that they did not depict the stroke as being disruptive. Instead, it was understood as being a continuation of their unfolding biography. Another survivor understood the stroke as being just another complication of his diabetes.

I mean from a medical point of view, yeah well diabetic (. . .) which will lead to this, which will lead to this, which will lead to this, so it's obvious that as a diabetic you're going to have trouble with your eyes, you're going to have trouble with your feelings, and things like that and you're going to have all this, that and the other and you're going to, be more liable to have a stroke or a heart attack or whatever. (ID12, Male stroke survivor, gradual decline trajectory)

Stroke-related impairments ascribed little meaning. Although they noted various impairments caused by the stroke, they were not considered particularly debilitating, nor had they altered their lives significantly. When one participant was asked about the impact the stroke had had on his life, he replied, "I mean it weren't as though we were dashing about a hundred miles an hour [before the stroke]"

was it?" (ID11, Male stroke survivor, gradual decline trajectory). Even noteworthy changes to their daily routine, such as having to give up work, were not considered to be particularly life changing.

I started to get the medical problems due to the diabetic thing which were getting to the stage where, (. . .) I couldn't operate as efficiently shall we say, was still doing the job but I'm getting more and more on light duties you know. And then of course when this happened that was the end of it all. (ID12, Male stroke survivor, gradual decline trajectory)

For those who narrated this trajectory, there seemed to be an acceptance of ongoing decline.

Conclusions

Recovery for stroke survivors has been presented as somewhat uniform and linear (Ahuja et al., 2013; Burton, 2000a; Easton, 1999; Kirkevold, 2002), and is often reduced to physical and functional rehabilitation and adjustment in the first few months following stroke. Recovery, however, is best understood as a complex and dynamic process comprising of the interrelationship between physical, functional, emotional, and social domains (Dowswell et al., 2000; Kendall et al., 2007), which is embedded in socially constructed contexts (Kendall & Buys, 1998). The concept of recovery allows us to acknowledge and then go beyond the immediate disruption and adjustments survivors might make.

Our findings further the understanding of recovery trajectories as presented in the accounts of stroke survivors. In the current study, the variability across different experiences is highlighted, conceptually depicted here as a typology of recovery trajectories. Of importance are the meanings people give to their health, impairments, and treatment (Moerman, 2002), which can change over both the short and longer term (Llewellyn et al., 2014).

There has been critique of "flat temporalities" and assumptions of "orderability" in discussions of illness trajectories (Ahuja et al., 2013; Arntzen et al., 2015; Shubin, Rapport, & Seagrove, 2015), and calls for greater attention to be given to the subjective experiences of living with the everyday consequences of impairments over time. The recovery trajectories discussed above are far from fixed, neatly ordered, or illustrative of a cohesive process, but are dynamic, shifting, multifaceted, and temporally uneven. These trajectories are not mutually exclusive, a stroke survivor might narrate an experience akin to "meaningful recovery," and later reconceptualize their recovery following, for example, an unanticipated health event or loss of support, giving new meaning to past and present events, and future predictions. For many, recovery is experienced as continually ongoing, long after the stroke itself, and clinical signs of functional and physical rehabilitation have ceased (Arntzen et al., 2015).

Stroke survivors differed in the version of themselves they drew on to illustrate their experience poststroke. Some referred to their self immediately poststroke when discussing the, sometimes small, changes they recounted in the time since their stroke marking a meaningful recovery. Others drew on their selves immediately prestroke in giving meaning to the contrast between their lives before stroke and now, their prestroke self having been the anticipated future self following a successful, but now unachievable, recovery. Others drew on multiple versions of the self poststroke in marking cycles of meaningful recovery punctuated by unanticipated occurrences that were experienced as having set their recovery back. Others referred to distant selves in marking an ongoing, gradual, but now anticipated, deterioration in health. The findings not only illustrate that stroke survivors emphasize different aspects of their experiences and compare different versions of themselves (Nasr et al., 2016), but that the present meanings given to their past selves and projected future selves, which might differ between people and across time, are important in shaping their experiences of recovery. This adds complexity to the understanding of experiences of rehabilitation and recovery common in the literature that stroke survivors assess their recovery only in light of their prestroke lives, and that their expectations and experiences of rehabilitation and recovery are somewhat static (Dowswell et al., 2000).

The meaning of the stroke and recovery was also shaped by the different meanings and consequences survivors' attributed to previous health events. Those who narrated an experience of gradual ongoing decline did not present the stroke as having had a disruptive impact on their lives echoing some of the work on biographical flow (Faircloth et al., 2004; Pound et al., 1998). These survivors, however, did not differ from those who presented an alternative trajectory in relation to the factors that are often understood to mitigate against the disruptive impact of having a stroke: age (Pound et al., 1998), poverty (Pound et al., 1998), and the presence of other health conditions (Faircloth et al., 2004). Instead, the stroke was not viewed as significant as it was understood in light of an earlier disruptive event and the consequences this had had on their lives. Their declining health was accepted and expected to continue. This suggests that it is the meanings that people give to health, illness, and their present, past, and predicted future selves, and the consequences health and illness has on their everyday lives, that are important. Such meanings and consequences might be shaped by features, such as age and socioeconomic status, but are not reducible to fixed biographical or environmental factors.

Loss also shaped recovery trajectories. For many, feelings of loss persisted over the long-term and were integral to the ongoing process of recovery. Previous literature has highlighted the multitude of losses and uncertainty experienced by stroke survivors (Becker, 1993; Becker & Kaufman, 1995; Burton, 2000a; Nilsson, Jansson, & Norberg, 1997; O'Connell et al., 2001; Secrest & Thomas, 1999) and the

importance of acceptance in the process of recovery (Ahuja et al., 2013). Some survivors were better placed to make sense of the multiple and ongoing losses experienced, working to create a different but meaningful life.

It has been highlighted that the initial disruptive impact of the stroke might be mitigated by the survivor's age and their expectations that illness is a normal part of aging (Faircloth et al., 2004). In our study, aging was employed as a device by some after the stroke and initial disruption to make sense of their changed circumstances by reframing their current impairments and need to "slow down" as being a normal part of aging (rather than as a consequence of the stroke). This confirms the importance of the concept of aging for some stroke survivors in enabling them to manage loss by normalizing poststroke limitations (Nasr et al., 2016).

Subsequent losses poststroke, including noteworthy health events that impacted on survivors' existing impairments and/or strategies for managing impairments, were understood as contributing to periods of instability. This suggests that recovery trajectories are vulnerable to unanticipated changes in health and social context (Burton, 2000a).

Viewing themselves as being agents in their own recovery was important. Those who narrated a meaningful recovery placed value on small successes both within and outside the home and spoke of developing knowledge of how to manage their impairments and increasing confidence. They described actively reordering the home environment, creatively solving problems, establishing routines, and adapting, substituting, or discovering leisure activities. Literature suggests the importance of self-efficacy in recovery poststroke (Ahuja et al., 2013). Further work is required on whether giving meaning to small successes, and a sense of agency and control, perpetuates physical and functional rehabilitation.

Existing literature also highlights the range of strategies survivors use to manage their impairments in the months immediately poststroke, including experimentation, trial and error, altering their expectations, finding new opportunities (Ahuja et al., 2013; Becker, 1993; Becker & Kaufman, 1995; Doolittle, 1992; Faircloth et al., 2004; Kubina, Dubouloz, Davis, Kessler, & Egan, 2013; Nilsson et al., 1997; Pound et al., 1998; Robison et al., 2009). Such sense of agency and expertise in managing impairments, however, is vulnerable to shifts in health and support structures in the longer term. Furthermore, some survivors did not view as meaningful small successes, nor did they manage to develop ways of managing impairments that are acceptable for them, experiencing life as unmanageable and out of control.

Talk of the importance of enacting relationships in shaping experiences of recovery was evident across the interviews. Some survivors spoke of working to (re)build a life that was meaningful through enacting friendship and family ties by engaging in meaningful occupation. Those who experienced ongoing disruption depicted lives that were monotonous, lacking in meaningful occupation comprising of disrupted relationships with family, friends, and others.

Relationships, and survivors' roles and responsibilities in relation to others, are recognized as important in how stroke survivors (re)construct their sense of self poststroke (Arntzen et al., 2015; Green & King, 2009; Lou, Carstensen, Jørgensen, & Nielsen, 2017; Nasr et al., 2016; Secrest & Thomas, 1999). Here highlighted is the role of meaningful occupation, including everyday routines and leisure activities, in supporting survivors to maintain the relational self over time.

With this study, we add new understanding to the process of recovery among stroke survivors by highlighting points of difference within and between participants' narratives, including variability in the disruptive impact of the stroke over time and how various factors shape the experience of recovery. The findings illustrate recovery as a process that involves meaning making, agency, and relational resources, which might shift over the short- and longer term, and might be affected by unanticipated contingencies. This goes beyond the uniform process of rehabilitation and recovery, and points of disruption and flow between life prestroke and poststroke, that much literature tends to focus on (Faircloth et al., 2004; Lou et al., 2017; Nasr et al., 2016; Pound et al., 1998; Secrest & Thomas, 1999).

Limitations

We acknowledge the limitations of our research. Our participants were purposefully sampled to be diverse in relation to various characteristics; however, our sample consisted entirely of people who identified as White British. Stroke is known to affect mood, and conditions such as anxiety disorders and depression are likely to shape the process of recovery over time. We were unable to explore such factors in depth, as we did not measure mood or have access to survivors' medical records.

We have explored the recovery trajectories and the factors that shaped them in the data we collected; however, we acknowledge that there might be many other factors that shape differing experiences of recovery across time and individuals. One such factor that warrants further investigation is the importance of gender-related influences in shaping recovery trajectories. Our findings highlight the importance of relationships, roles, and meaningful occupation in shaping recovery trajectories; however, we did not explicitly explore the role of gender in shaping experiences of recovery.

Implications for Policy and Practice

Stroke survivors are best supported when recovery is viewed holistically (Kendall et al., 2007; Robinson, 1990). This study suggests that meaning making, agency, and relational resources are important in shaping survivors' experiences of recovery, and that these might shift over time and particularly in response to unanticipated health events or changes in support. Services need to be attuned to this ongoing and shifting recovery experience, and be able to support people

through this process. Professionals should routinely explore with survivors their recovery trajectories, and the key features known to shape different experiences in clinical reviews. This would facilitate the provision of timely and tailored support in the longer term, with the potential to positively impact on experiences of recovery.

Authors' Note

Permission from NHS ethics was obtained for this research. Participants with capacity gave informed consent to take part in the research. For those who lacked capacity to consent to take part (under the Mental Capacity Act, 2005), a consultee declaration was obtained.

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