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The paradox of hope for working age adults recovering from stroke

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Abstract

This article draws on data from a Stroke Association–funded longitudinal study in South East England (2003–2006) that explored the experiences and recovery of 43 stroke survivors under 60 years. Participants were invited to take part in four interviews over an 18-month period and to complete a diary for 1 week each month during this period. Here, we chart their shifting attitudes towards the process of their recovery. We bring a focus to how this transformed their views on the possible futures before them. We underline how hope was experienced as a deeply paradoxical and risk-laden notion. With energies concentrated upon the effort to live positively in the here and now, the very idea of hope for the future was met as an unwelcome distraction and in some cases even as a source of distress.

Keywords

hope, illness experience, paradox, recovery, sociological research, stroke

Introduction

The increased attention that is brought to the experience of stroke from the perspective of stroke survivors is also drawing debate towards the role played by ‘hope’ in their recovery. Put simply, it is observed that insofar as those recovering from stroke are positively orientated towards the future and live in the expectation they can learn to cope with any resulting disability, then they are also set to maximise their chances of rehabilitation (Barker and Brauer, 2005; Burton, 2000; Cross and Schneider, 2010; Tutton et al., 2011). When addressed as a ‘therapeutic factor’ in stroke recovery, hope is identified as a self-motivating and self-sustaining ‘life force’ that not only has a major influence over the ability of survivors to adapt to the initial trauma of experiencing stroke but also their engagement with longer term strategies of rehabilitation (Bluvol and Ford-Gilboe, 2004; Western, 2007).

Most studies of hope in the context of health care are preoccupied with its therapeutic value in primary care settings. Accordingly, as far as recovery from stroke is concerned, it is more with a focus brought to the role played by hope in the immediate stages of stroke rehabilitation rather than

to its influence over the longer term, that its condition, presence and force are held up for investigation and debate (Cross and Schneider, 2010). To date, moreover, it might be argued that the research in this area has been burdened by a struggle for conceptual clarification. A considerable number of articles are dedicated to defining 'the concept of hope' as an issue for the practice of clinical health care (Benzein and Saveman, 1998; Cutcliffe and Herth, 2002; Hockley, 1993; Morse and Doberneck, 1995; Stephenson, 1991). Here, researchers operate from the premise that it is by studying contrasting approaches to the conceptualisation of hope that nurses and doctors will be better equipped to work at promoting and instilling it among those in their care. It is suggested that by mapping out multiple experiences and dimensions of hope in relation to specific diseases, health problems and disabilities, it is possible to refine therapeutic techniques to guide people into adopting attitudes and behaviours in which they stand to acquire the types of positive feelings and goal orientations that are most suited to advance their healing and recovery (Benzein and Saveman, 1998). The overall effect of such studies, however, has been to lead researchers to an appreciation of the 'elusive' character of hope, the inherent complexity of its condition as a form of experience and the fact that its presence and force are subject to considerable variations through time and by context. While some take this as a cue to work at building theoretical models to 'capture' the full dimensions and dynamics of hope in a 'common framework', more often than not, researchers have turned to consider the peculiarities of hope as it features in relation to specific health problems and discrete health care settings (Nekolaichuk et al., 1999). By documenting distinct domains and cultures of hope as these arise and take shape in relation to contrasting experiences of cancer, traumatic forms of physical injury, varieties of mental illness, types of chronic illness and multiple forms of degenerative disease, it is assumed that a range of carefully targeted strategies can be devised to both enhance hope and fashion it as a means to promote health (Benzein and Saveman, 2008; Duggleby and Wright, 2005; Elliott and Olver, 2007; Little and Sayers, 2004; Lohne and Severinsson, 2005; Samson et al., 2009).

In this article, we follow Andrew Soundy et al. (2013) by highlighting how, for those struggling to live with debilitating neurological conditions, hope often takes place as an inherently paradoxical experience. The types of hope that are deemed useful for patients to commit themselves to the immediate task of adapting to and living with their situation also require them to guard against falling into the trap of hoping for too much. Soundy and colleagues argue that patients are frequently caught up in a paradox where, on the one hand, they are counselled by health care experts to work at combating the limitations met through their illness, while on the other hand, they are also advised to acknowledge their limitations lest excessive hopes for a full recovery draw them to the point of despair. As progress is made in processes of recovery and rehabilitation, patients may involve themselves in hoping for possible futures that are unrealistic and which make them vulnerable to experiences of hopelessness. Accordingly, at the same time as being encouraged to have 'realistic hopes', that is, hopes that are limited to their official prognosis, patients are often made to live through the distress of abandoning previous life ideals and aspirations.

On this account, hope is understood to take place as a dynamic process and as a multidimensional form of experience. An emphasis is also placed on the extent to which commitments to hope are bound to a burden of risk. Soundy and colleagues are inspired by the work of David Barnard (1995) and his concern to chart the 'dynamics of hoping' in the contexts of chronic illness. Here, a focus is brought to the extent to which talk of hope in medical settings tends to take place where individuals are involved in experiences of grave adversity. Where urgency is placed on the value hope, it is for

patients suffering conditions that are both highly negative and painfully disruptive for their lives. Bernard (1995) emphasises that under such circumstances, patients are set to live in the tension of a particularly troubling boundary situation; that is, 'the boundary between old formulations of the self and new formulations not yet born' (p. 50). It is here that illness narratives are held to perform a vital role in constructing possibilities to enable people to engage with different modalities of hope.

Soundy and colleagues aim to be particularly attentive to processes of narrative self-reconstruction where living with renewed hope also involves patients resigning themselves to the fact that it is no longer possible to recover their former selves and recognising that their projected horizon of self-expectation needs to be significantly modified. To this end, they aim to expose the forms of 'narrative employment' deployed by therapists involved in helping patients to navigate a course through the distress of this transition (Mattingly, 1994). They argue that paradoxically, the practically useful types of 'hope' sought for in health promotion often involves therapists guiding their patients through experiences of hopelessness so that they can be brought to a point where they accept their new health condition and recalibrate their expectations in a more 'realistic' frame (Soundy et al., 2013: 193–203).

In this article, we further contend that when interviewing stroke survivors, at the very point where they venture to raise this as a matter for inquiry through interview, sociological researchers are also involved in the reconfiguration of participants' hopes. It is not only that the sociological invitation issued to stroke survivors to reflect on their experience involves them in a further recognition of their suffering and loss, but also that it serves as a prompt for them to work at understanding how their hopes either have been, or still must be, re-aligned in response to their diminished state. Moreover, the very fact that such interviews often involve painful processes of self-reflection and self-articulation that are exacerbated by the ongoing effects of stroke serves to bring volume to the fact that here the process of collecting data is weighted with moral meaning. These are contexts where participation in sociological research is a high-stake activity for participants and where researchers bear a considerable responsibility to conduct themselves with care.

In what follows, we also argue that these critical issues and moral concerns are liable to be encountered in a particularly virulent form among the type of stroke survivors and experiences featured in this study, namely, working age adults who have suffered stroke and are now dealing with the longer term consequences of this event. This is due to the fact that for those struggling to maintain positions in paid employment, and perhaps even more so for those with responsibilities of care for young children, the effects of stroke are particularly devastating for their accustomed and ongoing roles, activities and responsibilities. Working age stroke sufferers are often left contending with economic difficulties as a consequence of their inability to resume their established roles in paid employment. Those with dependent children are also made to confront the brute fact that they are no longer physically and emotionally equipped to discharge their parental duties and responsibilities (Daniel et al., 2009). Under these circumstances, the existential tensions aroused in face of the 'paradox of hope' are made particularly voluminous and extreme, not least due to the scale of the life investments made in the risk of hope.

Methods

Design

The data we use in this article come from a study funded by the UK Stroke Association of stroke survivors in South Eastern England. The study was funded from 1 September 2003 until 30 September 2006 with most of the data collected in 2004 and 2005. Most studies of stroke survivors have used a biomedical frame to measure physical and mental changes linked to stroke and how these change over time (see, for example, Kwakkel et al.'s (2008) review of the impact of therapy on upper limb recovery). Most studies using a social science frame have used one-off interview surveys. For example, in an earlier study, we interviewed 31 stroke survivors and close family members in individual and group interviews (Alaszewski et al., 2006). The ages and background of the participants varied considerably as did the time since the stroke. While this study provided insight into the ways stroke disrupted everyday life, it could only provide limited insight into how individuals responded to stroke and the different ways in which they managed the practicalities of everyday life and sought to rebuild their lives. Therefore, we decided to develop this work by focussing on 'younger' stroke survivors (those under 60 years old), individuals who at the time of their stroke were likely to be engaged in domestic, social and work activities. This would enable us to examine how issues such as domestic, social and work commitments shaped the ways in which these individuals experienced life after and recovery from stroke. We adopted a longitudinal approach so that we could explore how survivors' experiences and perceptions changed over 18 months after their stroke.

We sought to develop a relationship with the participants in our study, establishing initial contact and providing information and explanation while they were undergoing active post-stroke treatment, usually in hospital. However, a condition of ethical approval for the study was that we did not approach stroke survivors directly, so service providers, usually a senior nurse, initially identified and approached potential participants. If these stroke survivors were interested, then service providers passed their details to the research team who then arranged an initial meeting to explain the study again, obtain their informed consent and conduct the first interview. We aimed to have this first interview within 3 months of the stroke and then to meet and interview each survivor a further three times. In addition, we invited all participants to record a diary completing entries for a week each month.

In this article, we draw on data from the interviews. In both the interviews and diaries, stroke survivors were invited to describe their experience of everyday life and

[Insert Table 1.]

reflect on the impact of the stroke. However, the interaction between the researchers and the survivor and therefore the type of data recorded differed. The interview was a guided conversation in which stroke survivors reflected on the past (life before and after the stroke), the present (experiences of everyday life) and the future (predictions and plans). The diary was a document completed and owned by the stroke survivors (indeed two survivors decided they did not want to

give their diaries to the team). The research time invited stroke survivors to make regular entries for a month describing and reflecting on their everyday. Since this article focuses on hope and the nature of time, especially the relationship between the present and the future which underpins hope, the interview material with its interlinking between past, present and future provides a rich source of data. By contrast, the diary entries tend to concentrate on the present; they contain reflections on the past and future but these tend to be less systematic (Alaszewski, 2006b). Elsewhere we have used the diary data to explore issues related to the time-present, but in this article we draw on data from the interviews (Alaszewski, 2006a).

The participants

We recruited participants through three separate NHS stroke services who agreed to approach all new admissions who were suitable for the study (individuals who had a stroke, were aged between 21 and 60 years and who were able and competent to provide consent to take part in the study). Although the services covered an area with nearly 500,000 residents, it took over a year to recruit the participants. Our target was 40 stroke survivors. We recruited 43 participants, but there was a bias in the recruitment towards the older 'younger survivors', that is, survivors aged between 50 and 59 years, and towards men (see Table 1).

All the participants completed the first interview but there was a dropout during the course of the study with 38 completing the second interview, 34 the third and 33 all four.

Method of data collection

Interviews were tape-recorded with the participants' permission, and the tapes and diaries were transcribed for analysis. The local research ethics committee granted ethical approval in accordance with research governance frameworks (ref. 175/10/03). All names used in this article are pseudonyms to maintain anonymity of participants and we have changed some details which could identify individual participants. Interviews had a flexible structure and took the form of a guided conversation in which we encouraged participants to describe their experiences and feelings in their own words. As Jacqueline Low (2013) notes, such interviews enable researchers to access 'experiences of health and illness where people already feel disempowered by their illness' (p. 88). In their interviews, stroke survivors were invited to reflect on their stroke experience in terms of past events, current life and the future. As we moved from the first to the final interviews, the context of the interviews changed and this influenced the content and structure of the interviews. The first interview took place shortly after the survivors had completed initial treatment, usually in hospital and usually within a month of the stroke. In this interview, the events surrounding the stroke tended to loom large and the survivors wanted to talk about the stroke and the ways it had affected their lives. We did invite them to talk about the future but at this stage survivors often found it difficult to articulate a clear view of the future. As the interviews progressed, for most though not all survivors, the stroke and its impact on their lives remained an important topic of conversation, and when we invited them to reflect on the future, they usually had a more developed

view of what could be hoped for in this regard. At this point, it was possible to move from a discussion of realistic hopes relating to the challenges of the present to one that brokered with possible hopes for the future and how these were implicated in how they now related to themselves as a 'stroke survivor'. The ways in which stroke survivors negotiated with these contrasting modalities of hope provide the key data for this article.

Analytic approach

Our analytic approach included both deductive and inductive elements. The interviews generated a rich body of data based on survivors' accounts of their experience. We wanted to explore the different ways in which individual survivors made sense of what had and was happening and how they sought to manage these experiences. From our reading of the literature and from our own previous research, we anticipated that survivors' accounts would highlight themes such as post-stroke acute care, relationship with family and friends and work relations but we were also aware of possible unanticipated themes. For example, we did not anticipate that some survivors would make sense of their experience in terms of 'luck', paradoxically reconstructing misfortune in terms of good fortune because the consequences of their stroke were not more severe or because they were less seriously affected than other stroke survivors.

To make sense of our data, we used a three-stage process to identify and code themes (see Saldana, 2009). We started by reading and annotating each interview transcript and identifying (coding) such units every time they appeared. This coding created the building blocks of the subsequent analysis. The project researcher (Helen Alaszewski) read all the interview transcripts making an initial categorisation, marking sections of the texts and attaching a coding category using the data management package ATLAS.ti to facilitate subsequent management of the data. Two other members of the research team (Andy Alaszewski and Jonathan Potter) read and coded a sample of the transcripts and compared the coding for consistency. We then examined the relationship between the coding categories, both in terms of the ways in which categories appeared in different interviews and also the apparent relationship between coding categories. We finally examined the content of each of these extracts to identify linkages to other coding categories and where there were important links, we then included extracts relevant to these linked coding categories.

Through this process, we were able to examine the ways in which participants in our study responded to their stroke and identify responses, some of which could be grouped together while others were more idiosyncratic. We found four broadly shared responses: (a) rational planning, (b) minimisation, (c) enduring illness and (d) rational planning with disappointed expectations. One of the key differences between individuals in these groups related to the ways over time they positioned their stroke within their biography and its relationship to their current life. Both the minimisation and enduring illness groups tended for different reasons and in different ways, to minimise, the stroke became a minor disruption in their biography and was not the most important aspect of their everyday life. The minimisation individuals emphasised their personal resilience and past experience of overcoming misfortune. (In this article, we draw on data from the rich case of Mr Trueman who was 49 years old when he had his stroke.) In contrast, the enduring illness individuals

emphasised their adverse circumstances; their experience of ill health prior to their stroke enabled them to subsume the stroke within their overall illness biography. (In this article, we draw on data from the rich case of Ms Temple who was 45 years old when she had her stroke). For the individuals who adopted a rational planning approach or who experienced disappointed expectations, the stroke became a crucial turning point in their biography and formed a prominent part of their everyday life. Those adopting a rational planning approach sought to manage their bodies and lives through a rational regime drawing on expert advice and support. (In this article, we draw on data from the rich case of Mr Riley who was 58 years old when he had his stroke.) In contrast, individuals who experienced disappointed expectations would have liked to rebuild their bodies and lives but felt their recovery was undermined by continuing complications and health problems following their stroke. (In this article, we draw on data from the rich case of Mrs Jenner who was 43 years old when she had her stroke.)¹

There were also individuals whose post-stroke life was more difficult to categorise. For example, in the case of Mr Philpott (44-year-old at the time of his stroke), his stroke and post-stroke acute care seemed to engender a sense of anxiety so that at the time of the final interview, these experiences were still vivid, forming part of present reality not past biography. Similarly, Mrs Jarman who was 34 years old at the time of her stroke experienced enduring difficulties that she struggled to specify and manage. She felt exhausted and unable to rebuild her life. In this article, we draw on data from these rich cases to examine how hope was evident in and shaped survivors' accounts of their lives after stroke.

Results

Reeling under shock

The early interviews with participants, that took place shortly (usually within a month) after the event of stroke, document the fact that they were all still heavily involved in making sense of the radical disruption of everyday life that had befallen them. Most testified to being deeply shocked by the dramatic and sudden loss of their physical and mental abilities. Stroke had been met as a terrifying and violent intrusion upon the normal flow of day-to-day life. While there were marked differences in the strategies adopted as a means to make narrative sense of their experience, in early meetings most sought to underline the fact that the shock of stroke had been met as traumatic assault on their personhood and on the relationships that they cared for the most. For example, one declared,

And then all of a sudden, bang, this happened. I felt helpless, I felt like I was dying. I felt like I was leaving my two children without me and I didn't want that. I knew that I was sending fear across the whole of the house for a week because nobody knew what was wrong. (Mrs Jarman)

Another repeatedly emphasised,

It's certainly come as a huge shock ... I would say probably the shock element of it is hard to come to come to terms with. Like I said before, you do have a tendency to think you're indestructible. (Mr Philpott)

In this regard, however, there was a noticeable difference between the majority of our interviewees who were not experiencing any obvious illness before their stroke and one who was already chronically ill with a range of different incapacitating health problems. In this case, she sought to emphasise that, in itself, the stroke was more of an inconvenient disruption of her routine experience than a life-changing disaster. When asked how she felt in the early stages of her recovery she explained,

I was scared. I didn't know what was happening. It scared me. But I didn't feel ill at all. I was just scared. (Ms Temple)

After this, however, she claimed that it was not so much the effects of the stroke that she found so upsetting as the experience of being in hospital, which had disrupted her normal routine. Already suffering from problems with chronic fatigue and fibromyalgia, she was more distressed by the fact that she was made to get up early and how this further exacerbated her tiredness and physical discomfort.

More generally, when it came to explaining what was either particularly shocking or upsetting about the initial experience of stroke, it was also striking to note the extent to which participants explained their condition with reference to the distress met in their encounters with health professionals or through the experience of hospitalisation. In almost every instance, they reflected on the experience of being treated as a victim of stroke in hospital as horrific and very distressing. Some recognised their treatment at the hands of doctors and nurses as bringing volume to the seriousness of their situation and as serving to further frighten them by alerting them to further possible negative consequences of being a 'stroke victim'. For example, Mr Philpott in particular sought to make clear:

I found the whole casualty experience traumatic, it really upset me. I was scared. Very very scared.

And when transferred to the ward he further emphasised,

I found going to the stroke ward extremely distressing. If I had been in a ward with four blokes the same age as me or thereabouts, I wouldn't have found it quite so distressing but to see old ladies who had obviously had very serious strokes, I found very distressing ...

Another confessed that the distress of being in hospital, and in particular the fact that he was totally dependent on nurses for the maintenance of his bodily hygiene, had driven him into a state of delusion where he believed that he was being deliberately imprisoned. He declared,

I went through ... times when I was mentally unstable ... I was convinced they [nurses] were holding onto me deliberately to keep themselves in business. It was a really weird sort of theory and I was going to break out through a hole in the wall and go off with this gang who were outside ... (Mr Riley)

All those involved looked back upon their experience of being in hospital as deeply unpleasant and, further, made clear that far more than any positive thought for their recovery, it was far more due to the immediate distress of the experience of being treated as a stroke patient that they were motivated to do whatever they could to be discharged. In this regard, our findings lend further support to other studies that suggest that the psychosocial stress and adverse effects of the experience of hospitalisation and being in the hospital environment warrant study as matters making a significant contribution to how people negotiate with the meaning of what is happening to them (Parke and Chappel, 2008; Robison et al., 2009; Stone, 2007). At this stage in their recovery, there was no positive thought of hope involved. Our participants' attentions were entirely caught up in projects of escape from what were entirely negative and often deeply upsetting sets of experiences.

Living in the process of stroke

It was the experiencing of returning home to resume family life and positions at work that prompted participants to dwell more substantially upon the meaning of their experience of stroke and how it had left them. In many ways, it might be argued that it was only when directly challenged or pressed to resume pre-stroke roles and activities that they were brought to a point where they could begin to recognise the consequences of stroke for their lives; or indeed, it was only from here on in that they were set on a course that enabled them to contextualise what had happened to them. Following a range of other studies, we found that, as far as the lived experience of stroke is concerned, it is only through being immersed in the struggle to readjust to life once discharged from hospital that stroke survivors are made to face up to the scale of their impairments and their effects (Jones et al., 2008; Koch et al., 2005; Murray et al., 2003). It was in being actively forced to compare their former selves to how they found themselves in their ongoing processes of recovery that it was made possible for them to discern the personal and interpersonal consequences of their stroke.

Under these pressures, it soon became apparent to all concerned that it was extremely difficult for them to cast the experience of stroke as a discrete 'event' that could be readily consigned to the past; rather, their stroke was an ongoing lived condition. The remaining physiological and neurological complications that they all experienced were often accompanied by a deep-felt sense of vulnerability and protracted bouts of anxiety. Their stroke had committed them to an uncertain process of ongoing social frustration, bodily discomfort, frequent weariness and disappointment.

Typically, participants found that the emotional distress and physical difficulties encountered in their return to work and/or to parental responsibilities placed them under an immense pressure to modify the boundaries of self-expectation. Quite simply, they discovered themselves incapable of fulfilling the roles they were accustomed to perform. There were, however, marked differences in how these were interpreted and addressed. One (Mr Philpott) found that while having coped with a measure of optimism through the first 12 months of his renewed life, as time progressed, this became more difficult to maintain and that he was increasingly overcome with feelings of anxiety and an ever more pronounced loss of self-confidence. The trauma of the initial experience seemed to grow in magnitude the more he was moved to reflect on what it meant for him and the more exhausted he became through the effort to resume work. He was now prone to depression and to experience surprising bursts of emotion that often disrupted his social interactions and activities. At one point he confessed,

When I went back to work I that I was very, very tired very easily. I still feel tired half the time ... I can cry now at the drop of a hat. I could cry now. I could make myself cry now. Watching things on the TV, things that before I would have considered ... I don't know, like a nature film or something ... you know, it upsets me. And you know, I would hate to watch Lassie Come Home or something like that because I would be a complete wreck ... Quite often just driving along the road sometimes I have to wipe tears out of my eyes because I'm thinking of something that's upset me.

In this instance, after 18 months of attempted recovery, a 44-year-old man who had previously held down a successful career in the army and had been actively involved in combat situations without suffering significant inner turmoil or grief was increasingly inclined to relate to himself as 'frightened', 'scared' and emotionally fragile.

Others were also concerned to underline the fact that under the effort involved in their attempts to return to their pre-stroke lives, they had experienced major transformations in their character and outlook. For example, as Mrs Jenner and Mrs Jarman grew ever more exhausted and wearied by the physical and mental effort expended in the struggle to recover their former selves, the more they grew resigned to being lost to themselves. Moreover, here such recognition was accompanied by pronounced feelings of low self-esteem, inner loneliness and loss of self-confidence. Mrs Jenner felt that she had changed from a 'happy-go-lucky, self-confident woman' to someone who now 'dreads' going out 'even to places like Asda and B&Q in case I bump into somebody I know'. Mrs Jarman made clear that she had come to regard the stroke as 'the most horrendous' turning point in her life and that she felt deeply 'bereaved' as she came to realise that she was no longer able to continue her work or maintain the appearance of being a 'happy mother'. When asked how she saw herself at 18 months following her stroke, she explained,

I feel older. I look in the mirror and my eyes have lost their sparkle which sounds like a vanity thing but it's not. I see my Mum's eyes coming through which isn't a horrible thing; but my Mum had angina and high blood pressure all through her life and she was never well. She used to walk but I never saw her like jog across the street or anything and I look at me and see the sadness coming

through and I can't get it off and I know I had eye trouble but it seems to be coming from ... whatever's going on in my body is taking away the sparkle ... and all of a sudden you realise that it has aged me. I've not aged. It has aged me.

By contrast, some participants, while admitting to many ongoing difficulties and complications in their recovery, appeared to be making considerable efforts to present themselves as actively working to deny their stroke recognition as a disruptive factor in their lives. For example, one of the men (Mr Trueman), who worked in the building trade, was only prepared to go so far as to admit that the stroke had served as a 'wake up call' to the fact that he was no longer 'indestructible'. He sought to announce himself as 'belligerent', 'cantankerous' and 'bloody-minded' in his determination to resume life as normal and took this to the point where he disregarded the advice to give up smoking and made very little to guard against placing his body under too much physical stress. Another of our male participant (Mr Riley) had a tendency to portray his stroke as a 'one-off accident', and despite the fact that he was being increasingly alerted to the fact that he was left with many permanent physiological problems and psychological difficulties, repeatedly declared that he retained confidence in his ability to tackle these as a series of challenges that could be mastered through careful rational planning and the refined techniques of self-mastery. While at 18 months following the stroke he was more prepared to admit to the fact that he had lost some of his physical abilities, he still took considerable efforts to stress that he expected to make further progress with his recovery and that overall he regarded his life as 'business as usual'.

For the purposes of the argument pursued in this article, the important thing to appreciate in these contrasting approaches and responses to the process of recovery is that all those involved in our study were left deeply preoccupied by the ongoing task of negotiating with their various impairments and ongoing difficulties. Their energies were heavily invested either in managing highly negative experiences of loss or in marshalling available resources at their disposal towards the effort of maintaining a positive approach to their rehabilitation. While adopting markedly different relationships towards their condition and adopting contrasting interpretations of its life meaning, nevertheless, their bodies and minds were consumed by the effort of living through the process stroke, and this became an ever more pronounced tension and self-defining lesion in their lives.

Flight from future hope

One of our most consistent findings in our study was that at 18 months into the process of recovering from stroke, participants recognised that they had significantly modified their attitudes towards the future. Either as a consequence of the distress aroused by the thought of possibilities now denied to them or as a result of the sheer physical and mental effort involved in managing their day-to-day affairs, most declared the future to be largely absent from their thoughts as a matter for serious consideration. For example, one declared,

I tend not to think so much as my own future ... I more or less have to confront myself with my own future so I don't think about it very often ... I sort of live in the moment really I suppose. (Mr Riley)

Another (Mrs Jarman) regarded her reluctance to think about the future as a standpoint that mirrored the strength of her commitment to live for now. She feared the damaging effects that feelings of anger or depression might have on her family relationships and therefore made strenuous efforts to push thoughts of the long-term future from her mind.

Indeed, more generally, it seemed that thoughts of the future were readily identified as a potential source of distress; for in addition to these being liable to immerse them in a deep-felt sense of disappointment, they also raised the possibility that a further experience of stroke or similar condition might lie ahead. For example, one declared,

I tend not to think of the long-term future for me personally. I mean I am frightened to death that it will happen again. I tend not to make great plans or anything like that. I don't sort of say oh I'm gonna buy a house in Spain for my retirement or anything like that ... I don't make any great plans for the future. (Mr Philpott)

We found others in a position where they saw the reflection on the future as a matter to be delayed until they could better cope with living in the present. They liked to think that thoughts for the future might be entertained at some point, but only in a context where they were experiencing improved health conditions. For instance, Mrs Temple explained,

I would get back to work at some stage but not at the moment ... [but] I know that I just wouldn't be able to ... I plan day-to-day because I don't know how I'll be feeling tomorrow and I can't. If somebody said 'shall we go so-and-so in a week's time?' I'd have to say 'well, no, I can't say now ... I haven't got any plans as such for the future but whatever happens will happen ... Other people might think I'm in a rut or something but I don't think ... personally, I don't think I am. It's just me being me. (Ms Temple)

We found that in almost every instance, the experience of stroke recovery over the longer term had not only left survivors with diminished horizons of self-expectation, but further, with an attitude in which the future was cast as ominously threatening, and indeed as a matter best avoided both in thought and conversation. In this regard, they had no positive relationship to hope. Indeed, if anything it was negotiated with as an encumbrance that, if anything served only to disrupt their efforts at living in the here and now. Particularly for those such as Mrs Jenner whose experience of recovery was thwarted by many setbacks and complications, thoughts were entirely dominated by immediate struggles and needs. It was not just the case that they struggled to see beyond the possibility of forever remaining ill, but that the very negotiation with any thought of future hope was damaging for their recovery; quite simply, it risked too much upset and disappointment.

Conclusion

The overall incidence and prevalence of stroke is widely recognised as a leading cause of death and disability in the United Kingdom (Bhatnagar et al., 2010; Lee et al., 2011; Saka et al., 2009). It is estimated that around 25% of strokes occur in people below the age of 65 years, but the majority of studies have focussed on its incidence, effects and treatment among older people. In every case, studies that concentrate their attentions on stroke in working age adults underline the need to understand this experience in quite different terms to those applied to older sections of population. Most notably, it is not only recognised that these 'younger' stroke survivors are faced with the possibility that they shall be dealing with the effects of their stroke for a much longer period of their lives but also that this will involve them in the effort to cope with the negative impacts of their condition in terms of their ability to engage in paid work, to carry out parental responsibilities and their potential to plan for the future (Daniel et al., 2009; Kersten et al., 2002; Lawrence, 2010). Here, not least due to the sheer scale of the existential situation presented by the challenge of recovery, the experience of biographical disruption and process of narrative self-reinterpretation is liable to be more extensive, and where the effects of stroke are experienced as long-lasting or permanent, then its significance for a person's life orientation and purpose is set to be magnified (Williams, 1984).

All the participants in our study were involved in dealing with stroke as an ongoing condition of social impairment. The experience of stroke varied considerably in each case and changed over time. While some were able to manage their recovery more effectively and efficiently than others, there was no doubting the fact that they were all immersed in a process that was often very difficult to endure and at times was experienced as unendurable. Survivors were compelled to devote their attentions to the task of monitoring their condition and were regularly preoccupied with the task of adapting to new challenges, possibilities or setbacks.

While most therapeutic interventions in stroke rehabilitation are designed to meet short-term needs in people's recoveries and readjustments and are overwhelmingly committed to the assessment and monitoring of physiological measurements of recovery, our study joins with that of Fiona Jones et al. (2008) in underlining the need for more caring concern to be brought to stroke as a debilitating social process over the long term. We contend that it is only under this recognition that it is possible to gain an appreciation for the fact that the lived experience of stroke is made brutally real to work age adults in disruptions of their social roles and activities in contexts of paid employment and family life. In this regard, the practice of sociological research holds the potential to be applied to the task of exposing the care needs of 'younger' stroke survivors, and it might even have a useful role to play in their ongoing attempts at narrative self-reconstruction. Indeed, at the end of the study featured in this article, when participants were asked to reflect on their experience of being interviewed through their process of recovery, we were struck by how many confessed to finding it a self-revelatory experience which they had valued as an opportunity for personal reflection on their condition outside of being subject to the condition of meeting with health experts. A value was placed on the experience of being listened to without the need for an engagement in some officially prescribed therapy or treatment.

On this point, we would further add that this certainly involves the practice of sociological research in moral tensions that are, perhaps, both more voluble and volatile than in many other settings. This

is not least due to the fact that the demands placed on people to reflect on their experience of stroke and to give vocal expression their thought and feelings also involve them in the struggle to master their condition. While the effort of reflecting on their various impairments and difficulties often involved our participants in many unpleasant feelings and distressing emotions, these were also compounded by the fact that the very act of thinking about and giving voice to what stroke meant to them further gave rise to a difficult negotiation with it as an ongoing and present condition. Moreover, such tensions were perhaps most forcefully made present on occasions where they were asked to reflect on their hopes for the future; for when posed, sometimes even the question itself was identified as a source of considerable distress and as an issue best avoided. Here, we believe that we found further evidence in support of the contention that 'hope' is an intrinsically paradoxical notion for those recovering from stroke, and perhaps even more so for younger people faced with thinking about their long-term futures under the shadow of this experience (Soundy et al., 2013).

Soundy et al. (2013) note that particularly in the context of recovery from stroke, people's ability to adapt themselves to living with their debilitating condition requires considerable commitments of pragmatism (p. 182). This was readily acknowledged by the participants in our study; although at the point of interview, they were not always alert to longer term consequences of these commitments. Over time, as they became more heavily involved in and acquainted with the process of modifying their horizons of self-expectation in line with the pursuit of more 'realistic' hopes for themselves, they came to recognise other dimensions of hope as a source of anguish and discomfort. Longer term hopes of the future, particularly insofar as these evoked the ideal aspirations of their lives before stroke, made them vulnerable to experience feelings of distress as they were made to re-evaluate their existing social state and lived condition in light of the transition following stroke. It may well be the case that here the unintended consequence of the commitment to 'realistic' hopes was to aggravate existential tensions surrounding what might be hoped for over the longer term. We suggest that this should draw further research and debate to the ways in which the successful induction of stroke survivors into the limited hopes set for their rehabilitation over the short and medium term hold the potential to beget an ever more troubling negotiation with the meaning and possibility of hope in the long term.

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Note

1. For a fuller discussion of these groups and their response to work issues, see Alaszewski et al. (2007).

References

Alaszewski A (2006a) Diaries as a source of suffering narratives: A critical commentary. *Health, Risk and Society* 8(1): 43–58.

Alaszewski A (2006b) *Using Diaries for Social Research*. London: SAGE.

Alaszewski A, Alaszewski H and Potter J (2006) Risk, uncertainty and life threatening trauma: Analysing stroke survivor's accounts of life after stroke. *Forum Qualitative Sozialforschung [Forum: Qualitative Social Research]* 7(1): Article 18.

Alaszewski A, Alaszewski H, Potter J, et al. (2007) Working after a stroke: Survivors' experiences and perceptions of barriers to and facilitators of the return to paid employment. *Disability and Rehabilitation* 29(24): 1858–1869.

Barker RN and Brauer SG (2005) Upper limb recovery after stroke: The stroke survivors' perspective. *Disability and Rehabilitation* 27(20): 1213–1223.

Barnard D (1995) Chronic illness and the dynamics of hoping. In: Toombs SK, Barnard D and Carson RA (eds) *Chronic Illness: From Experience to Policy*. Bloomington, IN: Indiana University Press, pp. 38–57.

Benzein E and Saveman BI (1998) One step towards the understanding of hope: A concept analysis. *International Journal of Nursing Studies* 35: 322–329.

Benzein E and Saveman BI (2008) Health-promoting conversations about hope and suffering with couples in palliative care. *International Journal of Palliative Nursing* 14(9): 439–445.

Bhatnagar P, Scarborough P, Smeeton NC, et al. (2010) The incidence of all stroke and stroke subtype in the United Kingdom, 1985–2008: A systematic review. *BMC Public Health*. Available at: <http://www.biomedcentral.com/1471-2458/10/539>

- Bluvol A and Ford-Gilboe M (2004) Hope health work and quality of life in families of stroke survivors. *Journal of Advanced Nursing* 48(4): 322–332.
- Burton CR (2000) Living with stroke: A phenomenological study. *Journal of Advanced Nursing* 31(2): 301–309.
- Cross A and Schneider M (2010) A preliminary qualitative analysis of the impact of hope on stroke recovery in women. *Stroke Rehabilitation* 17(6): 484–495.
- Cutcliffe JR and Herth K (2002) The concept of hope in nursing 1: Its origins, background and nature. *British Journal of Nursing* 11(12): 832–840.
- Daniel K, Wolfe CD, Busch MA, et al. (2009) What are the social consequences of stroke for working-aged adults? A systematic review. *Stroke* 40(6): 431–440.
- Duggleby W and Wright K (2005) Transforming hope: How elderly palliative patients live with hope. *Canadian Journal of Nursing Research* 37(2): 70–84.
- Elliott JA and Olver IA (2007) Hope and hoping in the talk of dying cancer patients. *Social Science & Medicine* 64: 138–149.
- Hockley J (1993) The concept of hope and the will to live. *Palliative Medicine* 7(3): 181–186.
- Jones F, Mandy A and Partridge C (2008) Reasons for recovery after stroke: A perspective based on personal experience. *Disability and Rehabilitation* 30(7): 507–516.
- Kersten P, Low JTS, Ashburn A, et al. (2002) The unmet needs of young people who have had a stroke: Results of a national UK survey. *Disability and Rehabilitation* 24(16): 860–866.
- Koch L, Egbert N, Coeling H, et al. (2005) Returning to work after the onset of illness: Experiences of right hemisphere stroke survivors. *Rehabilitation Counselling Bulletin* 48(4): 209–218.
- Koehn CV and Cutcliffe JR (2007) Hope and interpersonal psychiatric/mental health nursing: A systematic review of the literature – Part one. *Journal of Psychiatric and Mental Health Nursing* 14: 134–140.

Kwakkel G, Boudewijn J, Kollen BJ, et al. (2008) Effects of robot-assisted therapy on upper limb recovery after stroke: A systematic review. *Neurorehabilitation and Neural Repair* 22(2): 111–121.

Lawrence M (2010) Young adults' experience of stroke: A qualitative review of the literature. *British Journal of Nursing* 19(4): 241–248.

Lee S, Shafe ACE and Cowie MR (2011) UK stroke incidence, mortality and cardiovascular risk management 1999-2008: Time-trend analysis from the General Practice Research Database. *BMJ Open* 1(2). Available at: <http://bmjopen.bmj.com/content/1/2/e000269.full.pdf+html>

Little M and Sayers EJ (2004) While there's life ... Hope and the experience of cancer. *Social Science & Medicine* 59: 1329–1337.

Lohne V and Severinsson E (2005) Patients' experiences of hope and suffering during the first year following acute spinal cord injury. *Journal of Clinical Nursing* 14: 285–293.

Low J (2013) Unstructured interviews and health research. In: Saks M and Allsop J (eds) *Researching Health: Qualitative, Quantitative and Mixed Methods*. London: SAGE, pp. 87–105.

Mattingly C (1994) The concept of therapeutic 'emplotment'. *Social Science & Medicine* 38(6): 811–822.

Morse JM and Doberneck B (1995) Delineating the concept of hope. *Image – The Journal of Nursing Scholarship* 27(4): 277–285.

Murray J, Ashworth R, Forster A, et al. (2003) Developing a primary care-based service: A review of the qualitative literature. *British Journal of General Practice* 53: 137–142.

Nekolaichuk CL, Jevne RF and Maguire TO (1999) Structuring the meaning of hope in health and illness. *Social Science & Medicine* 48: 591–605.

Parke B and Chappel NL (2008) Transactions between older people and the hospital environment: A social ecological analysis. *Journal of Aging Studies* 24(2): 115–124.

Robison J, Wiles R, Ellis-Hill C, et al. (2009) Resuming previously valued activities post-stroke: Who or what helps. *Disability and Rehabilitation* 31(19): 1555–1566.

Saka O, McGuire A and Wolfe C (2009) Cost of stroke in the United Kingdom. *Age and Aging* 38: 27–32.

Saldana J (2009) *The Coding Manual for Qualitative Researchers*. London: SAGE.

Samson A, Tomiak E, Dimillo J, et al. (2009) The lived experience of hope among parents of a child with Duchenne muscular dystrophy: Perceiving the human being beyond the illness. *Chronic Illness* 5: 103–114.

Soundy A, Smith B, Dawes H, et al. (2013) Patient's expression of hope and illness narratives in three neurological conditions: A meta-ethnography. *Health Psychology Review* 7(2): 177–201.

Stanghellini SB and Slade M (2008) Hope in psychiatry: A review of the literature. *Acta Psychiatrica* 118: 421–433.

Stephenson C (1991) The concept of hope revisited for nursing. *Journal of Advanced Nursing* 16: 1456–1461.

Stone SD (2007) Patient concerns posthaemorrhagic stroke: A study of the Internet narratives of patients with ruptured arteriovenous malformation. *Journal of Clinical Nursing* 16(2): 289–297.

Tutton E, Seers K and Langstaff D (2009) An exploration of hope as a concept for nursing. *Journal of Orthopaedic Nursing* 13: 119–127.

Tutton E, Seers K, Langstaff D, et al. (2011) Staff and patient views on the concept of hope on a stroke unit: A qualitative study. *Journal of Advanced Nursing* 68(9): 2061–2069.

Western H (2007) Altered living: Coping, hope and quality of life after stroke. *British Journal of Nursing* 16(20): 1266–1270.

Williams G (1984) The genesis of chronic illness: Narrative re-construction. *Sociology of Health & Illness* 6(2): 175–200.

Wolinsky FD, Gurney JG, Wan GJ, et al. (1998) The sequelae of hospitalization for ischemic stroke among older adults. *Journal of the American Geriatrics Society* 46(5): 577–582.

Wood JP, Connelly DM and Maly MR (2010) Getting back to real living: A qualitative study of the process of community reintegration after stroke. *Clinical Rehabilitation* 24: 1045–1056.