Risk, uncertainty and life threatening illness: Analysing stroke survivors accounts of life after a stroke

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Abstract

Current policy on stroke and the majority of the research focuses on prevention and treatment. There is an emphasis on identifying risk factors and communicating risk information so that high-risk individuals, including stroke survivors can manage their risks more effectively. This paper examines the ways in which stroke survivors identify and manage the dangers and uncertainty of their situation. The paper draws on interview data from a UK study in East Kent of 31 stroke survivors. These interviews created accounts based on the experience of stroke and post stroke recovery. Stroke survivors experienced their stroke as an unexpected event in which there was a failure of foresight. The stroke made them aware of the dangers of every-day life such as those associated with crossing the road as well as the specific dangers of their situation such as having another potentially fatal stroke. Survivors used a variety of strategies to manage such uncertainties including relatively passive concentration on the present and more active management of the intermediate future. The more proactive strategies involved voluntary risk taking which when successful had benefits for survivors.
Introduction

Current policy on stroke and the majority of the research focuses on prevention and treatment. There is an emphasis on identifying risk factors and communicating risk information so that high-risk individuals, including stroke survivors can manage their risks more effectively. This approach is grounded in a rational approach to risk communication that focus on the transfer of risk knowledge from experts to patients. It is important to consider how stroke survivors respond to stroke and the ways in which they identify and manage the dangers and uncertainties of their situation.

1. Risk, uncertainty and serious illness

Preventing harm and risk communication In the United Kingdom, the health departments are committed to reducing the overall level of harm to the population and saving lives (Department of Health, 1999). Central to this strategy is the effective communication of risks to the population so that individuals can effectively manage their personal risk, for example by changing their life styles to reduce their exposure to dangers. The former Chief Medical Office of Health and his colleagues at the Department of Health have published a review of risk communication (Bennett and Calman, 1999) and there has been debate in the medical press on the most effective strategies for communicating risk (Edwards, 2003). Particular attention has been given to reducing the risks of diseases which cause high levels of harm such as cancer, heart disease and strokes.

Stroke is a major cause of long-term disability amongst adults and older people and a significant factor in the increase in disability associated with ageing in the United Kingdom. Government policy on stroke (Department of Health, 2001) has a strong emphasis on prevention by reducing population and individual risks:

The prevention of stroke depends on reducing risk factors across the whole population as well as in those at relatively greater risk of stroke (p. 63)

At population level the National Framework recommends reducing risk by

increasing levels of physical activity, encouraging healthy eating… supporting smoking cessation as well as identifying and managing high blood pressure (p. 63)
At individual level the National Framework specifies that services should identify individual who are at high risk of stroke, especially those who have has a previous stroke and TIA, identify their modifiable risk factors and provide appropriate advice, support and treatment to modify these risk factors (p. 64). The National Framework forms the basis of national clinical guidelines developed by expert working group. These guidelines emphasised the importance of secondary prevention in the following way:

*Patients who have suffered a stroke remain at an increased risk of a further stroke of between 30% and 43% within five years... The risk of completing a stroke after a TIA may be as high as 20% within the first month. Patients with TIA and stroke also have an increased risk of myocardial infarction and other vascular events. The risk of further stroke is highest early after stroke or TIA. Therefore there should be a high priority given to rapid delivery of evidence-based secondary prevention.*

**Recommendations**

- An individual strategy for stroke prevention should be implemented within a maximum of seven days of acute stroke or TIA.

While it is clear that the effective communication of health risks is seen as playing an important role both in reducing the overall level of harm in the population and improving the outcome for ‘high-risk individuals’, such as individuals who have survived a stroke, much of the current approach to risk communication is based on a rational approach to risk communication (Herxheimer, 2005 and Gigenenzer, 2003). This model emphasises the role and position of experts such as doctors who have the ability to identify relevant risk knowledge. In the context of medical decision-making this is knowledge about the probable consequences of different courses of action based on scientific research. The role of the doctor is to make such knowledge available so that the patient can then use it to make an informed decision. It is important to consider risk from the patient’s perspective

*Risk and uncertainty from the stroke survivor's perspective* Increasingly individuals in modern society are encouraged to actively manage their health by using information on health risks to construct a healthy lifestyle. They are encouraged to use the research-based evidence to reduce their personal risk factors and reduce the possibility that they will experience harm (Giddens, 1991). While an individual may not know for certain what will happen, he or she can assess the odds and take action to reduce the risk or odds of suffering from a harmful event such as a stroke (Adams, 1995, p. 25). Individuals who have had a stroke have an increased risk of having another and there is clear expert guidance on secondary prevention, the actions which stroke survivors can take to reduce the odds of having another stroke. For
example, the stroke association website provides the following guidance on secondary prevention for stroke survivors:

*After a stroke there is greater risk of another occurring. Treatments can help prevent this. Once someone has had a stroke or TIA they are more likely to have another one. There are a number of precautions which can be taken to reduce your risk of having another stroke. These may include:*

**Diet**

**Drugs to prevent blood clots**

**Exercise**

**Lowering blood pressure**

*To prevent another stroke occurring it is very important to continue with any of these measures for the rest of your life; if there are complications associated with any of them you should seek professional advice, as there may be alternative ways of dealing with the problem (The Stroke Association, 2005)*

The website provides more detailed information on each of the four areas of risk reduction. For example the following advice is provided on diet:

*Sensible eating can reduce the risk of stroke. Diets low in cholesterol and salt can help keep blood pressure within normal limits and prevent the build-up of fatty deposits in the wall of the arteries (The Stroke Association, 2005).*

This approach is based on the premise that scientific evidence gained from a study of past events, incidence of strokes, amongst groups of populations can be used by individual stroke survivors as a way of managing and reducing their personal risk of having another stroke. If stroke survivors do not have access to such knowledge or do not accept it is relevant to their situation then rather than managing risk, i.e. taking action reduce the probability they will have another stroke, they are managing uncertainty, managing a situation in which aware of the possibility of another stroke but not of the actual odds or probability (Adams, 1995, p. 25).

*Stroke, risk and uncertainty* While cerebrovascular accidents can vary from relatively minor events such as transient ischaemic attacks to major life threatening strokes such events have major impact on both the individual and their carers which may include psychological trauma
as well as varying degrees of mental and physical disability (see Anderson 1992). While more research is needed to fully explore the individual’s perspective, it is possible to identify some emerging themes from the current literature. It is clear that most stroke survivors experience their stroke as a major life event or defining moment. Such an event undermines basic trust in the world creating uncertainty about the future.

Survivors of strokes are increasingly recording their own experiences (see McCrum 1998, Bauby 1999, Jelks 2000) in books and recounting their stories on internet websites. Although there are hi-tech machines to diagnose stroke and doctors can provide advice on medications and life-style changes that reduce the probability of another stroke, such guidance tends to be generalised. Doctors are unable to give an accurate individual prognosis either of the likelihood of another stroke or of the degree of recovery. Burton (2000) found that each new stage in the treatment, especially discharge home, left survivors feeling unable to plan because of such uncertainties. The survivor was left in a rather unpredictable world that was full of uncertainties in which the future is difficult to plan and manage.

Stroke survivors not only have to manage the impact which stroke has had on their skills and abilities, but they also have to deal with impact of these changes on their wider social relations and activities, for example on their ability to engage in family activities or paid work. Dowswell et al (2000) investigating recovery from stroke found that almost all the participants in their study related how the stroke had drastically changed their lives, even those whose stroke had been mild and who had regained full physical function. The ramifications can be so broad that some stroke survivors see them in terms of having lost their social identity. For example McCrum reflected on the loss of a former self and the efforts to stick the pieces back together, ‘the cruel fact is that this former self is irretrievably shattered into a thousand pieces, and try as one may to glue those pieces back together again, the reconstituted version will never be better than a cracked, imperfect assembly, a constant mockery of one’s former, successful individuality’ (1998, p151).

Goals, strategies and time Research which has examined stroke survivors’ accounts of their experiences tends to emphasise the importance of social aspects of their recovery. For example Burton (2000) tracked six people over a year who had experienced stroke and
describes how re-engagement in the social world is more important to people who have survived stroke than physical function. He noted that:

Stroke is an intensely personal experience, involving the rebuilding and restructuring of an individual’s world. ...The social context of recovery was enabling participation in the social world through adaptation and the development of coping skills, rather than improvement in discrete physical function alone.

This process of recovery appears to place emphasis on short-term or immediate goals as opposed to longer terms plans and aspirations which are effectively left on hold. For example McCrum stressed the importance of setting short-term achievable goals in his recovery.

Reviewing the literature on people’s experience of stroke, Hafsteinsdottir and Grypdonck (1997) concluded that survivors set their own goals and measure their recovery in terms of returning to activities, which they value. Studies of people who have experienced stroke suggest that they develop their own strategies for overcoming challenges. Pound et al (1999) identified five ways in which people respond actively to stroke, by mobilising informal social support; creating new ways of doing things; taking things more slowly; beginning the process of relearning; exercising; ‘covering up’. They suggest that people who had experienced stroke developed creative ways of managing their lives by devising and employing new strategies to enable themselves to do things. They maintain that far from being victims they employ active strategies to manage their lives. Mr Jelks (2000), a stroke survivor, described in detail the strategy he used to stop himself thinking about all the activities he can no longer and to build his own self esteem. He set himself a task, to plant ten tomato plants, and then breaks activity down into small achievable units. Using his spade as a crutch he dug a hole a day – half in the morning and half in the afternoon. For some survivors recovery involves setting challenging goals that involved an element of danger. For example Robin Cant, a stroke survivor, described driving again:

When first allowed to drive again by the DVLC in Swansea after seven months I was thrilled but also somewhat frightened. At last, I was not dependant on others to get me from place to place (Cant, 1997, p. vi)

Comment
It is clear from personal accounts and research projects that having a stroke is a traumatic event that results in a major biographical disruption (Bury, 1982). Frank (1995) refers to this as narrative wreckage where previously taken for granted linear trajectories of self-development and life plans, anticipated activities in the future, are destroyed and replaced with uncertainty. Recovery from this ‘wreckage’ involves a process of reconstruction starting in many cases with a concentration on a short-term, manageable but at times challenging goals. In this paper we want to explore these processes further by examining how survivors construct and use risk as part of their process of managing their recovery.

The study

This article draws on interview data from a study in East Kent in which we interviewed 31 stroke survivors and informal carers in either focus group or individual interviews. (see Table 1)

Table 1 Interviews with Stroke Survivors and Carers

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender</th>
<th>Disability level (modified Rankin Scale)</th>
<th>Lived with</th>
<th>Interview</th>
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The main focus of our study was the impact of stroke on the lives of survivors, the coping strategies they developed and the effectiveness of professional support. Since we wished to access survivors’ own accounts of their experiences we used a flexible approach to interviewing, identifying key topic areas and only using prompts or supplementary questions when the natural flow of conversation was limited or dried up. Using focus group and individual interviews we explored:

- perceptions of the ways in which stroke changes individuals’ and their families or carers lives;
- the types of challenges and opportunities which they experienced when living independently in the community;
- the strategies which they developed to manage these threats and opportunities;
- how professionals’ interventions influence both the nature of the challenges and opportunities and the ways in which professional interventions could facilitate the rehabilitation of survivors.

We also invited stroke survivors to complete diaries recording the ways in which they managed day-to-day life. This part of the project was less successful as for a variety of reasons only four participants completed diaries and we focus our analysis on the interview data. Although risk was one of the topics we were interested in, we did not specifically use the term risk, as our previous studies had indicated that risk tended to be interpreted in negative or threatening ways (Alaszewski et al, 1998 and Alaszewski et al, 2000). Instead we sought to explore both the negative and positive dimension in terms of ‘opportunities and threats’. We used ATLAS.ti to content analyse the interviews.

**Stroke and Risk**
Stroke and foresight

Risk in modern society can be seen as a way of predicting and managing the future using evidence from surveillance of past events. In health care systems medical surveillance of populations is used to identify 'risk factors', which predict the increased likelihood of adverse events such as strokes and facilitate interventions. For example raised blood pressure is a risk factor for stroke and reducing blood pressure through medication reduces the risk of stroke. However for the survivors in our study this 'population' approach had not provided them with warning of impending danger and several survivors in our study saw their stroke as a failure of this approach. Most were unable to identify any 'risk factors' which would have given them warning of their increased susceptibility to a stroke which was experienced as an unexpected shock. For example Ms Beaton, a 40-year-old health worker, described her situation in the following way:

I had no disposition to having the stroke and I did smoke but I did not have high blood pressure, a bit over weight I grant you, but I couldn’t believe I had my stroke… I take things at my own pace because it has taken me over a year to get used to it the shock of it and things like that.

The unexpectedness and shock of having a stroke formed a common theme within individual accounts of stroke. The lack of warning was not restricted to individuals who felt their risk of a stroke was low but shared by the survivors who did acknowledge potential risk factors. For example Mrs Early, a 50-year-old railway worker who acknowledge a family history of stroke, responded to a prompt in the following way:

Mrs Early: It was a big shock although I suppose on afterthought I sort of, must have expected it really, I mean my mother had a stroke although it wasn’t the same as my one, she had a bleed stroke whereas mine was a blood clot stroke.

Some survivors also spontaneously mentioned the unexpectedness of their stroke. Mrs Miles, a very active 89 year old, responded to an early question in the following way:

Interviewer: How long is it since you had your stroke?
Mrs Miles: Sixteen months and I had no warning whatsoever.

While Mr Eden, a retired 63 year old, stated:

Oh Yes. I didn’t know I had a stroke, I just don’t know what happened, it’s just out of the blue, all of a sudden. I was sitting at this table actually.

The lack of warning meant that survivors experienced their stroke as a traumatic event, one which undermined the ‘taken-for-grantedness’ of everyday life. Mrs Garrett, an active 67-year-old woman, described the impact of her stroke in the following way:

Interviewer: Do you still feel able to take life for granted?
Mrs Garrett: No, most definitely not because it all happened so quickly, one minute I was sitting in the garden, walked in the house and collapsed. That’s how quickly it happened.

Perceptions of danger after a stroke The taken-for-grantedness of everyday life meant that for stroke survivors dangers that had previously been ‘bracketed out’ now need to be explicitly considered and managed. This meant that for some survivors their home, which they had previously treated as a safe environment, now became a source of danger. However for most of the survivors, it was environment outside the home that had become full of dangers. Every day activities such as crossing the road involved negotiating dangers. For Mr Timms, a 76-year-old man, continuing problems with his balance made crossing the road a hazardous activity:

It’s affected my confidence a lot. I go to step down from the kerb and it’s only about two or three inches and yet to me, mentally, it seems as if I’m going down into a well. So I’ve lost the confidence in stepping off the kerb.

While for Ms Quick, a 50-year-old woman who had returned to work at the time of her interview, it was the difficulty of dealing with traffic coming from two directions at the same time:

Going out, crossing roads, I still don’t like crossing roads, even now. It’s just there’s too much going on but it’s alright if I stand and wait. I either cross the road with somebody else
or if there is an island in the middle of the road then I’ve only got to cope with one lot of traffic and then I can cope with the other lot of traffic, I hate roads that I’ve got to look both ways. I can’t, I still don’t like it.

While such dangers have to be managed by everyone who wants to cross a busy road, stroke survivors were also aware of a danger that particularly related to their experience, the danger of having another potentially fatal stroke. Mrs Quick described her fear of another stroke contrasting it to an every-day hazard, a road traffic accident:

Interviewer: Is there anything specific since you had your stroke that has made you anxious?
Ms Quick: Only the fear that I might have a major stroke. And I think at first, I wouldn’t even go out of the house in case it happened again and in the end you just begin to think, ooh this is stupid because I could go out of the house and get run over, you know, I can’t let it dominate my life.

Some survivors sought reassurance from experts. For example Mrs Kellor, a 80-year-old woman who lived alone and presented herself as an ‘anxious’ person, sought reassurance from an expert, the stroke nurse who visited her at home.

Interviewer: Has it made you more anxious about anything?
Mrs Kellor: I think generally, yes… I mean I always had a bit of a worrying nature but yes, I think I am more anxious. I mean things like, can this happen to me again? I was saying to the nurse the other day when she came to see me, can it happen again? Because she was telling me about one of the ladies who was in the ward with me had had another stroke, and she said, she felt it could happen to people who perhaps didn’t get back into the stride or that do their very best to get back into the stride of things, maybe sat back and were anxious about it.

Several survivors reported that they were more sensitive to their body and were vigilant in seeking to identify any body signs or changes that could be an early warning of another stroke. Mrs Dean and Mrs Garrett were both sensitive to changes close to their brain, but they reacted in different ways to episodes of facial numbness:

Interviewer: Is there anything in particular that makes you anxious?
Mrs Dean: I get anxious when I get a sensation in the side of my face like it’s gone a bit numb or something that it will happen again, and the advice from the stroke foundation is if that happens you should go straight to the hospital. I’m not going to hospital, it’s got to be worse that just this feeling of numbness now and then (50-year-old former health worker).

Interviewer: So does that still make you feel a bit anxious?
Mrs Garrett: Yes, it does and the other week I wasn’t particularly well and I had the sensation going down my face and my left side so it was down to the doctor’s and I had to go to the emergency doctor but he assured me that it wasn’t another stroke, but because I only remember the feeling in my face it was an automatic reaction that it was happening again. So I think that we wake up each morning and we say thank you for another day, we mustn’t take life for granted (an active 67-year-old woman).

The limitations of risk management While survivors did recognise the possibility of another stroke, most were fatalistic, they did not believe that they could manage the risk by taking action to reduce the odds of having another stroke. For example Mr Charles, a 72-year-old man with a family history of stroke, noted that since precautions, such as taking medication, failed him before they were likely to fail him again. While Mrs Price, a 38-year-old woman who ran her own business, drew on her childhood experience to suggest a second fatal stroke was inevitable:

Mr Charles: That I might, you know, fall ill again and that’s basically it. It is one of these things that has happened, and as I told my doctor, I feel I am living on borrowed time now because I never know when something might happen again and having taken precautions beforehand. I was a bit surprised it happened.

Interviewer: How do you see the future?
Mrs Price: I don’t really know, I’d just like to be confident in my recovery, that’s what I’d like to know, because I recall being a child and elderly people around you having a stroke and then having another stroke and then dying and I can recall adults saying things like, ‘well, it’s his second stroke, he did have a stroke before’. So I just assume that when you’ve had a stroke another stroke will follow and I don’t know any different to that because that’s what it was like in my past. I don’t know, do you know?
Comment
The suddenness and unexpectedness of a stroke indicated a failure of foresight, perhaps that personal risk-factors were not identified and managed. Having had one stroke, most survivors could no longer take their future health and well-being for granted. Their basic trust in the world was undermined. They recognised a number of new dangers or threats especially that of having a further and fatal stroke. Given previous failures of foresight and lack of relevant risk information, most survivors were in a state of uncertainty. In the next section we will consider how they managed this uncertainty.

Identifying and managing every-day risk
We interviewed survivors approximately one year after their stroke. They were past the initial trauma and associated medical investigations and care but had generally not yet re-established routine every-day life. Most of the survivors in our study were actively and consciously seeking to re-establish their every-day life.

Goals: Personal Challenges
As with many survivors of serious illness, the survivors in our study experienced a biographical disruption. The conditions of uncertainty meant that they could no longer consider the longer term future and instead focussed on a far shorter time horizon. For example both Mr While, a 66-year-old mechanic, and Mrs Keller, a 80-year-old woman, responded to a question about taking life for granted by emphasising the uncertainty and unpredictability of the future and therefore the need to take life day-by-day.

Interviewer: Do you still feel able to take life for granted?
Mr White: (pause) I wish I had, Er, no I take it from day to day… because you don’t really know what is round the corner, do you?

Interviewer: Do you still feel able to take life for granted?
Mrs Kellor: No, I don’t. No, each day is a blessing, isn’t it? I used to say that to the therapists in the hospital, to think all this while I’ve taken things for granted which I can no longer do.

In most interviews the uncertainties of the future were unspecified though in some it was more clearly linked to a further stroke. For example Mr Green a 68-year-old who felt that he had had a mild stroke and was back to normal said:
Mr Green: I’m taking life as it comes, if it happens again, it happens again.

However uncertainties about the long-term future did not prevent most survivors from seeking to actively manage their situation by thinking about and planning for the immediate future. The majority of survivors 21 (68%) focussed on managing the immediate future by setting goals. Some survivors reported they started planning immediately after their stroke. In a group interview, Mr Neville, a 79-year-old man explained the importance of recording progress and how achieving his goal of walking 400 hundred steps made him feel he was making progress and changed his sense of himself:

I think from the moment I came round in the hospital my mind told me I was going to get better and I still have a life to live and so I used to keep a record on my calendar every day, like a diary and for improvements and any advances I had made and one day I was able to write down that I had taken four hundred steps and Oh it really does something to you when you are able to do that…… so it was very important for me to get back because the quality of life means such a lot. It means such a lot.

Some goals were vague and aspirational. For example three of the survivors phrased their goals in very general terms of, ‘getting over the effects of it’, ‘to get back into the normal run of things’, ‘being able to do simple things’. Most survivors identified specific goals which they could achieve in the short-term or immediate future. One survivor preferred to set herself short-term goals everyday such as making the bed or cooking a meal to ensure that she actually carried out these activities. The goals were often related to the recovery of specific skills that were part of personal competence and identity. Of particular importance was mobility with 13 (42%) of respondents citing walking or getting out and about independently as their personal goal, and 3 (10%) driving. For some of those in the study, the personal goals they set themselves centred around their personal space and accomplishment of everyday tasks such as cooking and personal care; for others it involved recovering enjoyment in a hobby or interest and for some of the younger survivors going back to work. Mrs Dalton, a 79-year-old, had three linked goals and at the time of the interview had achieved the first two but had recognised she was not making progress with the third, driving:

Interviewer: Did you actually set yourself any personal goals?
Mrs Dalton: Yes, it was walking, to feel that sense of independence again, and the bowls and
the driving, the three priorities. They were my target things and my physiotherapy has been
directed at all that. It is only the driving that...

The emphasis on immediate and achievable goals can be seen in the following extract. Mr
Bryant, a 57-year-old who prior to his stroke had taken early retirement with a career change
and at the time of the interview was housebound, described the goals he set himself in the
following way:

Interviewer: Did you set yourself any personal goals when you were in hospital or when you
came home?
Mr Bryant: Yes, my goals I set, I'd try and get myself to walk as far as the computer and as
far as the toilet so I could take a wee without my wife having to change the commode for me.
That's my goals.

For Mr Bryant achievement of this short-term goal was a means to longer-term goals.
Walking a small distance could achieve a wider range of goals, access to the computer would
enable him to have contact with the world outside the house, and access to the commode
would reduce his dependence and stress for his wife. Similarly Mr Tucker, a 76-year-old, had
set himself a goal to propel his wheelchair independently. This would enable him to control
access to his computer, files and his CD collection.

Comment While many survivors saw the long term-future as uncertain even threatening, the
short-term or immediate future was potentially more manageable. Some survivors respond to
the threat of the future with a passive, fatalistic emphasis on the present, taking each day as it
comes. There was an alternative approach which was to focus on the short-term and to use
personal goals which facilitate the immediate structuring of every-day life and to a sense of
progress and a return to a more normal life.

Goals and risk: setting and meeting challenges
While survivors defined their goals in terms of activities that they particularly valued, they
often noted the challenge or risk associated with goals. For example 80-year-old Mr Neville
described the challenge associated with his goal in the following way:
Mr Neville: Four months after coming out of hospital I put the ladder against the wall and it is very high, and I thought, right you can paint this room, you can do it and I painted it so I got my confidence back again and I bought a bicycle you know for... An exercise bike, I bought that and I worked out a regime of exercises and I do those every day.

Interviewer Why do you think it was important to you to get back to these activities?

Mr Neville: Well unless I could do them it was going to be, life was going to be very dull. I didn’t want to sit down all day

When goals were defined in terms of risk, achieving goals meant not only progress towards a more normal life but also a personal challenge and, if achieved, a sense of personal accomplishment and a more positive personal identity. Mr Isles, a 54-year-old man who lived alone, referred to Douglas Bader, fighter pilot, who had heroically struggled to overcome severe disability to fly again in his interview:

Interviewer: Did you actually set yourself any personal goals?

Mr Isles: Yes, I want to be able to walk without a stick by Christmas, that’s one of my goals.

Interviewer: So how are you going about that?

Mr Isles: I just every so often, on occasions, I walk without a stick, but I have to be careful where it is in case I fall over.

Interviewer: Do you do that inside the house then?

Mr Isles: In the house, yes.

Interviewer: Have you taught yourself how to get up?

Mr Isles: No I haven’t. I saw the film ‘Douglas Bader’... He refused a stick, he would not use a stick, he was such a brave man. He had both legs cut off and he just fell down all the time and he would just pull himself up by sheer determination. But I mean, he had both his arms, of course. But I think it was determination.

While survivors described the ways in which they built up their skills to achieve goals, there was a parallel discourse about risk. They recognised the risks involved in achieving a particular goal but showed how they were willing and able to overcome this risk so that they could achieve the desired activity. The risks which survivors identified were context specific. They related both to the specific characteristics of the environment as well as to the specific consequences of the stroke. For example for survivors with a severe hemiplegia their home was potentially a dangerous environment and managing the risks of falls was an important
goal. Mr Eden, a retired 63-year-old, who had been discharged without being taught how to get up following a fall described how he taught himself:

*Mr Eden: I’ve tried to get up, I’ve done it myself. I’ve put myself down (laughs), well, you have to laugh, it’s frightening. ‘Cos I know, If I can’t get up, she can’t get me up, you have to work out a way of getting up. I’ve done that myself so I know if I go on the floor, slip or something, ‘cos this leg has got a nasty habit of giving way and I’m frightened that one day it’ll go when I can’t hold on to anything.*

Mobility outside the house was both more highly valued and more risky. Being able to get about independently, whether on foot, in a car or wheelchair was an activity which respondents valued highly but presented them with risks and challenges that they had to manage. Outside the home there were a variety of risks, not only was there the risk of falling but also potential embarrassment of doing this in public as well as the difficulties created by fatigue and inability to walk far enough.

Survivors developed a variety of strategies to increase their mobility. Most sought to build up their skills incrementally developing their strength and stamina by walking a little further each day and by practising, for example on stairs. Some individuals started with professional assistance and supervision but many respondents missed out on such care and had to develop their own strategies. Transferring these skills was a challenge, especially from practice in and around the home to mobility outside the home. A number of respondents related how they started by walking short distances, usually accompanied, and built this up slowly until they could reach the shop or the bus stop. Mrs Garrett, a 68-year-old woman, chose to use a combination of walking and a taxi:

*… and my walking wasn’t particularly good either and so it was just small distances. What we did to begin with was to just go to the supermarket and then I’d walk round a bit because that’s what I could cope with and I could hang onto the trolley and then as I say, I’ve twice on my own, I’d get the taxi and then have a walk. And before that I couldn’t have done, there was always somebody with me.*

Fear of being in crowded places and busy shops engendered anxiety in some respondents and they coped in various ways. For example, one 55-year old lady, Ms Harper, who had poor balance and a speech deficit, chose to go shopping at ‘quiet’ times as she felt people jostled
her and were impatient with her. Ms Quick, a 50-year-old woman who had returned to work at the time of her interview, explained that she found it hard to admit to herself that there were times when she could not cope, but when the shops seemed too frenetic, she gave the shopping list to her friend and sat outside.

Others survivors, who did not have someone to support them, sought the help of agencies such as the Red Cross who provided befrienders for a defined period to accompany them whilst building up their levels of confidence in their mobility or being outside alone. A number of respondents mentioned the hazards involved in crossing the road and how difficult they found mastering this following the stroke.

Electric wheelchairs could provide a source of independence for individuals and, Mr Jones, a 77-year-old man who lived with his wife and daughter enjoyed the sense of freedom his wheelchair gave him even though his main goal was to walk:

*Mr Jones: Yes, I can go where I want in the electric wheelchair. If I want to go from here into another room it is very difficult but if I use the one with the motor, they can push me outside and leave me and I can go off on my own then.*

Mobility or the ability to get about independently was important for survivors in a number of ways, increased independence, improved confidence levels and re-gaining some of their pre-stroke identity. While most of our data was derived from interviews in which individuals reported on their goals and how they achieved them we did also get data from two diaries. In one of these Mr Jones recorded one of his trips out and his sense of accomplishment from overcoming the challenges of his trip:

*Extract from Mr Jones Dairy:*

*April Easter Monday*

*Got up quite early and go at doing exercises with mum [his wife] supervising. Afterwards I was put in the wheelchair and left to go around the orchard. I was looking over the fence when suddenly the wheelchair stopped. One of the small wheels went into a rabbit hole and would not move. The big driving wheel just kept spinning. Eventually I put my good foot on the ground and pushed and then I got out and got away without getting help from home.*
**Important point:** Getting the wheelchair out of the rabbit hole and got away myself as it made me feel independent.

This sense of achievement through successfully meeting a challenge or accomplishing a risky activity was also evident in interviews. Ms Beaton, a former health worker, who had major residual disabilities including sight impairment, felt that meeting such challenges made her feel like her old 'self'.

**Interviewer:** Do you feel it has affected your confidence?

**Ms Beaton:** Yes, absolutely, yes. I feel this year I've been better but last year was the hardest year I have ever had to go through and face challenges like last year because I have achieved something about my walking and I think we all like I feel part of the getting well process is being able to do something...

**Interviewer:** What about preparing food in the kitchen?

**Ms Beaton:** Yes that was a bit aggravating to begin with. I have got better at that. Because I live on my own I don't really cook an awful lot. If I have friends round and I cooked a meal last week which I actually surprised myself, one it was edible but it was home cooked I did really well and actually felt like, it might probably sound a bit strange but I felt like my old self really.

**Comment**

It is clear from survivors’ accounts that most saw themselves as playing an active role in reconstructing their lives after their stroke. Their stroke had disrupted their sense of security and they were facing an uncertain future, and many were aware that they could have another stroke. In this situation, some survivors avoided thinking about the future by concentrating on the present and taking things day by day. Other survivors were more proactive. They identified ways in which they could plan and structure the immediate future through goals and strategies. In some respects these strategies involved replacing uncertainty with risk. The achievement of many goals involved a deliberate and calculated exposure to danger, for example resulting from falls or social embarrassment, but the successful management of such risks played an important part in the development of confidence and of more normal living.

**Discussion**
The accounts, which stroke survivors give, can be seen as narratives which help them explain, make sense of and control the situation. Williams in his analysis of individuals’ accounts of chronic illness argues that such narratives can be seen as:

*a process of continuous accounting whereby the mundane incidents and events of everyday life are given some plausible order.*

Giddens argues that such narratives are an essential mechanism by which individuals establish and maintain their identity in modern society (Giddens, 1991, p. 243) and from our study it is possible to identify a number ways in which stroke survivors in our study used their accounts to rebuild their identities. Survivors tended to present their strokes as *fateful moments* which undermined *their basic trust* in the world. While most survivors recognised that the future was uncertain, they could actively manage and control some but not all risks and the *successful management of the risks* associated with everyday activities was a positive accomplishment.

**Fateful moments and basic trust**

Stroke survivors presented their stroke as a defining event. An event which changed their lives and after which nothing was or would be the same. Giddens characterises such events as fateful moments which he describes in the following way:

*Fateful moments are highly consequential for a person’s destiny* (Giddens, 1991, p. 112.)

Giddens argues that while the individual concerned has to deal with the consequences of a fateful moment, such as in the case of a stroke, experts such as medical practitioners play a key role in identifying the fateful character of the event through expert investigation and diagnosis.

Fateful moments form an important part of individual’s narratives as they threaten to undermine basic trust or the certainty that things will continue as before. Such trust is an important personal defence mechanism providing a ‘protective cocoon’ that filters out dangers which threaten the individual:

*Fateful moments are threatening for the protective cocoon which defends the individual’s ontological security, because the ‘business as usual’ attitude that is so important to that cocoon is inevitably broken through* (Giddens, 1991, p. 114).
In such circumstances individuals were exposed to uncertainty and took action to manage this uncertainty.

*Controlling the controllable*

The interviews contained different accounts of the individuals’ response to their stroke and the ways in which it introduced uncertainty into their lives. As Zinn notes an individual's capacity to manage a situation depends on their capacity 'to transform (unmanageable) contingencies somehow into (manageable) complexities. (Zinn 2004, p. 203). In some accounts the response to uncertainty was to accept that the dangers were essentially uncontrollable. In such circumstances the rational response was fatalism, to concentrate on the present and take each day as it came. However the accounts also contained other responses. Other survivors accepted that the future was uncertain and contained dangers, especially that of another stroke, but identified ways of managing the (immediate) future through setting goals and creating and managing risks.

Ryan (2000) in his study of the ways in which mental health service users identified three approaches to risk management, no risk strategy, passive and proactive. The difference between no risk strategy and passive strategy seems to be one of degrees. Both are characterised by an emphasis on the present and an apparent acceptance that dangers is essentially uncontrollable. In the no strategy approach there is an apparent failure to acknowledge the dangers whereas in the passive approach the dangers are addressed as they arise and are recognised with the person adopting the line of least resistance. The proactive approach is characterised by the user’s recognition that the dangers can and should be controlled and managed and the user playing an active role in exposing themselves to dangers and managing the consequences. (Ryan, 2000b, p. 279).

*Successful management of risk and individual identity*

While Ryan recognises the possibility and benefits of focusing on risk, he sees it in terms of danger and does not emphasise the benefits of voluntary risk taking which formed part of the strategies of some of the stroke survivors in our study. As Lupton and Tulloch note in their study of voluntary risk taking in Australia most of the expert and media accounts of risk
represent risk as something negative and individuals in contemporary society are represented as:

"Living in fear, constantly dogged by feelings of anxiety, vulnerability and uncertainty in relation to the risks of which they are constantly made aware (Lupton and Tulloch, 2002, p. 113)."

Within this framework the development of personal identity and wellbeing comes through a rigorous and dynamic avoidance of dangers facilitating personal control of the self and the future avoiding a passive dependence on fate. In contrast Lupton and Tullock show how voluntary risk or exposure to dangers can be a source of pleasure and increased self-awareness and identity. By setting and successfully overcoming challenges, individuals can develop an improved sense of self:

"Cultivated risk-taking in this context is seen to provide an opportunity for individuals to display courage, to master fear, to prove something to themselves which allows them to live life with a sense of personal agency (Lupton and Tulloch, 2002, p. 122)."

While the participants in Lupton and Tullock’s study often had to undertake special activities to provide the necessary challenge and danger, such as surfing in rough seas, the survivors in our study could achieve the same challenge and sense of control through every-day activities, such as cooking a meal for friends or going out for a walk.

Conclusion

There is increasing understanding of the importance of effective risk assessment and management to both minimise the harm experienced by vulnerable individuals and maximise the quality of their lives (see for example Kemshall and Pritchard, 1997). There is a general acceptance that strokes in particular increase an individual’s vulnerability by impairing physical and/or mental capacity. However this has not always extended to the consideration of the ways in which vulnerable individuals and their carers manage their own risk. Indeed to our knowledge there has not been a study examining risk in relation to individuals who have had strokes and their carers.
One way of facilitating more effective rehabilitation is to ensure that professionals' interventions are grounded in a clear understanding of the ways in which users and carers define and perceive risk and the strategies they use to manage it. In particular it is important to see how the risks associated with the management of disabilities are placed in the contexts of everyday life and the range of challenges and opportunities which users and carers are seeking to manage and at times reconcile. From this basis it should be possible to develop more sensitive and effective ways of providing individuals with enhanced security and rehabilitation.

However not only have researchers neglected the ways in which individuals perceive and manage the uncertainties of their lives, so have service providers. Ryan has examined the in his study of the ways in which individuals with mental health needs and their carers managed the uncertainties and challenges of everyday life (Ryan, 2000) found little evidence that professionals were aware of user or carer strategies or had assisted or influenced them in the development of such strategies. Buri and Dawson, in their study of carers supporting vulnerable older people concluded that professional interventions designed to help carers should be based on a collaborative approach and that professionals should ‘discover individual carers’ strategies’ for managing risks (2000, p. 291). Our own work with vulnerable adults and their carers (see Alaszewski, Manthorpe and Harrison, 1998 and Alaszewski, Alaszewski, Manthorpe and Ayer, 2000) confirmed that every day life posed considerable challenges to people with disabilities which they sought to actively manage. Much professional practice is based on prevention and on protecting vulnerable individuals from dangers. In the case of stroke survivors there was little evidence that this approach contributed to reported strategies for reconstructing life.

References


