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**Risk, Uncertainty and Life Threatening Trauma: Analysing Stroke Survivor's Accounts of Life after Stroke**

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**Abstract:** This paper examines the ways in which stroke survivors identify and manage the risks and uncertainties of their situation. It draws on interview data from a UK study in East Kent of 31 stroke survivors (aged between 38 and 89 years). The interviews created accounts based on the experience of stroke and post stroke recovery. Stroke survivors experienced their stroke as an unanticipated event in which there was a failure of foresight. The stroke undermined their ontological security and increased their awareness of and anxiety about everyday activities both in and outside the home, created awareness of a new danger, that of having another potentially fatal stroke, and could damage their social standing. Survivors used a variety of strategies to manage such uncertainties. They shortened their time horizons, either abandoning longer-term plans or discussing them in very vague and general terms. They concentrated either on the present, "taking each day as it comes" or developed goals to structure the short-term future. These short-term goals involved challenges and there was in some cases the possibility of a harmful outcome. Such voluntary risk-taking provided an opportunity for "centre work" which could re-establish the stroke survivors social standing.

**Key words:** *stroke, stroke recovery, risk, risk-taking, time, uncertainty*

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## 1. Introduction

This paper examines the nature of risk and risk management following a traumatic health event, a stroke. It contrasts experts' use of risk, evident in policy guidelines for stroke prevention and recovery management, with stroke survivors' accounts of their experience of uncertainty and the ways in which they manage it following their stroke. [1]

## 2. Risk and Uncertainty: Objectively Measured or Subjectively Experienced?

### 2.1 The expert approach

As ZINN has noted, although the term risk is used inconsistently in health discourses, there is a dominant "expert" approach that underpins epidemiology and much of clinical practice. In this approach risk is understood as: "an objective concept relating to the *management of future uncertainties* through rational action based on calculations of probability" (italics in the original, 2005, p.1). [2]

This approach fails to recognise how social context influences the ways in which risks are identified and managed. In particular it fails to recognise the agency of individuals in structuring risks. While this is evident in the ways in which "non-experts" respond to and structure risks, it is also evident in expert practice. PRIOR and his colleagues (2002), for example, examined the methods employed by clinicians using a computer-based programme to estimate patients' risk of cancer. Clinicians were compelled to make "sense" of results and images so that there was "a large chunk of "tacit knowledge" embedded in professional decision making" (p.256). [3]

The "expert" approach to risk currently underpins policy approaches to managing the risks of serious or chronic illness. As ZINN (2004, p.1) noted, the main emphasis is on helping individuals develop "coping strategies" by identifying the risk or harm which patients and their relatives should recognise and avoid. This expert approach is prominent in current health policy and dominates attempts to improve the health of nation (ALASZEWSKI forthcoming). However there is at present little evidence that expert assessments of risk influence the ways in which non-experts perceive and respond to risks and dangers (SLOVIC 2000) many individuals and groups persist with "high risk" behaviours (DENSCOMBE 2001 and DUFF 2003). [4]

This emphasis is also evident in current approaches to stroke, a traumatic event which is a major cause of long term disability. Government policy on stroke (Department of Health 2001) has a strong emphasis on prevention by reducing both 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) [5]

This policy guidance forms the basis of national clinical guidelines developed by an expert working group. These guidelines emphasise 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 [Transient Ischemic Attack] 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" (Intercollegiate Stroke Working Party 2004, p.40). [6]

In this approach to stroke, survivors are encouraged to use the research-based evidence to reduce their personal risk factors and consequently reduce the possibility of experiencing harm. 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). [7]

### 2.2 Lay accounts

Although qualitative studies on stroke survivors are currently limited, both published research and stroke survivors' own testimonies indicate that survivors respond to their stroke in a highly personal way. Survivors' accounts emphasise the ways in which their stroke is an important personal event and experience. In many accounts, the stroke is presented as a *fateful*

*moment* (GIDDENS 1991, p.112), a key personal event that irreversibly changes the ways in which the survivors perceive themselves and the world in which they live. Robert McCRUM, a stroke survivor who has published an account of his recovery described his experience in the following way:

"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, p.151). [8]

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. [9]

A common theme in the personal and research accounts is the ways in which stroke undermines ontological security, "the sense of continuity and order in events" (GIDDENS 1991, p.243). This may be evident in the ways in which the normal activities of every-day life, such as crossing a road or making a cup of tea, which prior to the stroke are taken for granted or performed without conscious effort require conscious planning, preparation and are even challenging or risky. For example BURTON (2000) found that each new stage in the treatment, especially discharge home, left survivors feeling unable to plan. The survivor was left in a rather unpredictable world that was full of uncertainties and in which the future was difficult to both plan and manage. [10]

Just as the impact is highly personal and individual so are the ways in which individuals seek to reconstruct their lives. 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 regaining 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" (p.307). [11]

One common theme in these accounts is the use of personal goals to set targets and monitor progress. Robert McCRUM for example stressed the importance of setting short-term achievable goals in his own recovery. HAFSTEINSDORRIR and GRYPDONCK (1997) in their review of the literature concluded that survivors set their own goals and measured their recovery in terms of returning to activities which they valued. 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 suggested 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 and far from being victims employed active strategies to manage their lives. [12]

## 2.3 Comment

While expert-based approaches to risk management emphasise the importance of identifying and reducing personal risk factors, especially those of another stroke, accounts grounded in stroke survivors own experiences tend to emphasise the uncertainties of post-stroke life and the individual strategies which survivors use to reconstruct life. In current accounts there is little explicit consideration of risk, especially that of another stroke. In this article we focus on stroke survivors accounts, and consider the issues related to a possible further stroke and the ways in which survivors use time and risk to manage uncertainty. [13]

### **3. Methods**

#### **3.1 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 a focus group or individual interviews (see Table 1). [14]

#### **3.2 The sample**

The sample was purposive and designed to include a range of ages, residual disabilities, living circumstances and genders.

Pseudonym	Age	Disability level (modified Rankin Scale)	Lived with	Interview
Mr Eden	63	moderately severe	wife	wife
Mrs Roberts	72	moderate	partner	partner
Mrs Gordon	80	moderately severe	husband & daughter	husband & daughter
Mr Moore	79	moderate	wife	wife
Mr Tucker	76	moderately severe	wife	wife
Mrs Arnold	74	moderately severe	husband	husband
Mrs Early	50	slight	husband	aunt
Mrs Best	87	slight	daughter	group
Mr Neville	79	slight	alone	group
Mr Charles	72	slight	wife	group
Mr White	66	moderately severe	wife	alone
Mrs Hunt	89	moderately severe	husband	husband
Mrs Kellor	80	moderate	alone	alone
Mr Green	68	not significant	wife	alone
Mr Nail	81	moderate	daughter	daughter
Ms Beaton	40	moderate	alone	alone
Mr Jones	77	moderately severe	wife & daughter	wife & daughter
Mr Timms	77	moderate	wife	wife
Ms Quick	51	slight	daughter	daughter
Mrs Dean	50	slight	husband & son	alone
Mrs Garret	69	slight	partner	partner
Mr Peters	43	moderate	alone	carer
Mr Davies	73	slight	alone	group
Mrs Kilby	66	slight	husband	group
Mrs Miles	89	moderate	son	group
Mrs James	79	moderate	alone	group
Ms Harper	55	slight	alone	alone
Mrs Dalton	79	slight	husband	alone
Mrs Price	38	slight	husband	alone
Mr Isles	54	moderately severe	alone	alone
Mr Bryant	57	moderately severe	wife & daughter	alone

Table 1: Interviews with stroke survivors and carers [15]

### 3.3 Issues addressed

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 challenges 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. [16]

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 this article mainly uses 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 is often interpreted in negative or threatening ways (ALASZEWSKI et al. 1998, 2000). Instead we sought to explore both the negative and positive dimension in terms of "opportunities and challenges". [17]

### 3.4 Analysis

The research team analysed the content of the interviews and diaries thematically using constant comparison to identify the different aspects of the stroke experience. The approach was based on the grounded theory (see STRAUSS & CORBIN 1990) with three linked stages, an initial stage of open coding to identify themes, a second phase to explore theme properties and relationships and a final phase involving the organisation of themes around a prioritised core category. [18]

## 4. Stroke Survivors Accounts

### 4.1 Reflecting on the past: Stroke and the failure of foresight

The expert approach to risk involves using evidence from past events to predict and provide foresight of future harmful events so that they can be managed by "rational actions based on calculations of probability" (ZINN 2005, p.1). For the participants in our study this approach had failed. Reflecting on their stroke they were unable to identify any warning of impending danger. 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." [19]

The unexpectedness and shock of having a stroke was 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 was also shared by the survivors who did acknowledge potential risk factors. For example Mrs Early, a 50-year-old railway worker who acknowledged a family history of stroke, responded to a prompt in the following way:

"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." [20]

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." [21]

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." [22]

#### **4.2 Undermining the present and the future: Experiencing every-day life as hazardous, anxiety about another stroke and concerns about social standing**

The lack of warning meant that survivors experienced their stroke as a traumatic event, one which undermined the confidence which they had in 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." [23]

Stroke survivors could no longer take-for-granted every day activities and perceptions of dangers that had previously been "bracketed out" now needed 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. Respondents spoke of dislike of being alone, being frightened to bathe or shower when nobody else was in the house, or restricting themselves to certain areas of the house. In some cases this resulted in virtual immobilisation within the home. For example Ms Price, 38-year-old woman described how

"I couldn't sit at the table, for weeks and weeks to eat my food, I had to have it on somewhere like this (the settee in the living room), where it was comfortable, I couldn't sit on those chairs. Because I was used to being in here, so I didn't really like going into other parts of the house." [24]

For most of the survivors, the environment outside the home was especially dangerous and needed very careful management. 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." [25]

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." [26]

The failure of foresight created uncertainty not only about every-day life but also about the continuation of life itself. Mr Charles 72-year-old man with a family history of stroke emphasised the uncertainty of the present in terms of living on borrowed time:

"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." [27]

A number of stroke survivors noted the ways in which their lack of confidence in every-day life was linked anxieties about another stroke. For example Mrs Quick :

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." [28]

Some survivors felt that another stroke was inevitable, Mrs Price (38-years-old a shop owner and manager) commented on the future:

"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?" [29]

The link between anxiety and concern about a further stroke was explicit in a number of accounts. Mrs Kellor, an 80-year-old woman who lived alone, presented herself as an "anxious" person, and reported that the nurse she had consulted advised her to get on with every-day activities:

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." [30]

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)." [31]

Lack of confidence in the ability to perform everyday activities and the uncertainties created by the threat of another stroke combined to undermine stroke survivors' social standing. Most felt that they were unable to sustain their previous social relations and activities. Some survivors felt that role reversal had occurred not only in relation to their spouses but also with their children. Where they had provided support for their spouse or children, they now received such support, sometimes even intimate care. Mrs Dean, a previously active 50-year-old woman reflected, "*I'm more dependent on than being depended on*". Some interviewees felt a loss of status and role within the family, a sense of feeling diminished. An 89-year-old lady felt that she had been marginalized within the family and was no longer "the queen-bee":

Mrs Hunt: "I won't be here for years now anyway (laughs). I can't lead the same sort of life as I used to. I can't pass an opinion to anybody like I would do at one time."

Interviewer: "Why is that?"

Mrs Hunt: "Well, because I'm now the one who sits in a corner and does nothing. I've got no control over anything now." [32]

Others felt that the stroke had undermined their broader relations and social activities and had also resulted in social isolation. Physical disabilities sometimes prevented previous forms of mobility such as driving:

Interviewer: "What about your social life, do you feel that has been affected?"

Mr Isles: "Totally, devastating. I'm totally reliant on people coming here, I can't get out at all. I've got no means of getting out." [33]

Mr Isles lived in a fairly isolated area with minimal public transport and his mobility was very limited until he was able to drive again. He thus experienced exclusion from his local community. [34]

Mr Bryant a late middle aged man had previously been a musician but following his stroke he could no longer get out or play his instrument and had lost both the pleasures of playing in a band but also the friendships and support that went with this activity. In his interview he described the ways in which the professionals who came to help him were unable to understand his loss:

"I've played in many bands. They're all very good to me, came to see me so I don't think they can understand playing in a band, it's not like playing music by yourself, you play in a band you're playing in a team and it's wonderful." [35]

The suddenness and unexpectedness of a stroke created uncertainty. For many stroke survivors this undermined their confidence both in the present, i.e. the every-day world they live in and also in the future. They became more sensitive to existing hazards such as crossing the road and aware of new dangers or threats especially that of having a further and fatal stroke. Thus stroke and its consequences can have major impacts on their social networks undermining their standing as competent adults. 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. [36]

#### **4.3 Managing uncertainty: Time, goals and risk**

Time played an important role in ways in which stroke survivors talked about their situation. When we discussed the future, some survivors were willing to discuss the longer term but did so in vague or generalised terms, such as "getting over the effects of it" (Mr Moore 79-year-old) and "to get back into the normal run of things" (Mrs Kellor, 80-year-old). When they did discuss the longer term in more concrete terms it was to indicate that they had effectively "put it on hold" by cancelling planned activities. For example Mr Charles who had been used to regular holidays abroad initially decided things were too uncertain for holidays:

Mr Charles: "Well first of all I wouldn't go on holiday. I didn't feel that we could. Well actually, the only thing we have done is coach trips to Torquay ... and that was no problem."

Interviewer: "What was it about going on holiday that worried you?"

Mr Charles: "That I might, you know, fall ill again and that's basically it." [37]

A minority of survivors responded to uncertainty by avoiding all consideration of the future. This passive even fatalistic approach emphasised the present, as the future was unpredictable. Both Mr White, a 66-year-old mechanic, and Mrs Keller, an 80-year-old, 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." [38]

This fatalistic approach was in some cases explicitly linked to the threat presented by fear of another stroke. Mr Green a 68-year-old who felt that he had had a mild stroke and was back to normal commented that "I'm taking life as it comes, if it happens again, it happens again." [39]

However most of the survivors adopted a more proactive approach. They presented themselves positively as managing uncertainty by self-consciously setting goals and personal targets to monitor and measure their progress over specific time periods. Mr Isles, a 54-year-old man who lived alone, used the image of Douglas Bader, fighter pilot, who had heroically struggled to overcome severe disability when describing his goal setting:

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." [40]

Mr Neville an 80 year old man set himself the target of walking unaided by the time he left hospital:

"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." [41]

He kept a diary of his progress which he made available to the research team.

Extract from Mr Neville's diary for June

"Sunday 3 <sup>rd</sup>	Took 400 steps unaided
Monday 4 <sup>th</sup>	20 times across wash room floor
Tuesday 5 <sup>th</sup>	30 times across wash room floor
Wednesday 6 <sup>th</sup>	35 times across wash room floor
Thursday 7 <sup>th</sup>	40 times across wash room floor
Friday 8 <sup>th</sup>	Walked back from physio – two flights of stairs and long corridor
Saturday 9 <sup>th</sup> – Wednesday 13 <sup>th</sup>	Walking without aid
Thursday 14 <sup>th</sup>	Cooking 11.15
Friday 15 <sup>th</sup>	Walking without aid
Tuesday 19 <sup>th</sup>	Home visit with physios." [42]

Stroke survivors presented their goals as an aspiration or a challenge. By definitions they were activities that were important or valued and they could not perform. 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 the focus was on 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 ..." [43]

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." [44]

For Mr Bryant achievement of this short-term goal was a means to longer-term goals. Walking a small distance meant he 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 CD collection. [45]

While all goals implicitly contained a challenge and the possibility that the stroke survivor would fail to meet that challenge, with some goals there was also a risk of harm. Survivors defined their goals in terms of activities that they particularly valued but often noted the risk associated with their particular goals. 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." [46]

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 survivors with a severe hemiplegia their home was a potentially dangerous environment and managing the risks of falls was often an important goal both for themselves and their carers. Mr Eden, a retired 63-year-old, who had been discharged from hospital without being taught how to get up following a fall described how he taught himself:

"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." [47]

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 and negotiate. Outside the home there were a variety of risks, not only was there the risk of falling but also the potential embarrassment of doing this in public as well as the difficulties created by fatigue and inability to walk far enough. Mobility or the ability to get about independently was important for survivors in a number of ways; it increased independence; improved confidence levels and helped in re-establishing some of the person's 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 on this aspect 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." [48]

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." [49]

## 5. Discussion

The accounts, which stroke survivors give, can be seen as narratives which help individuals to 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" (WILLIAMS 1984, p.175). [50]

GIDDENS argues that such narratives of the self are an essential mechanism by which individuals establish and maintain their identity in modern society (GIDDENS 1991, p.243) 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. Some survivors presented their strokes as *fateful moments* which undermined *their basic trust* in the world. While most recognised that the future was uncertain, they were able to actively *manage and control* a proportion of the risks associated with everyday activities and such positive accomplishment assisted in the reconstruction of individual identity. [51]

### 5.1 Controlling the controllable

Most of the stroke survivors in our study presented their stroke as a fateful moment, an event which changed their lives and after which nothing was or would be the same (GIDDENS 1991, p.112). 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). [52]

The participants in our study described how they were exposed to uncertainty. They could no longer take for granted every-day activities and their own continued existence was under threat from another potentially fatal stroke. [53]

The interviews contained different accounts of the individuals' responses to risk. 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. RITTMAN and her colleagues noted that stroke survivors in their study used time to manage the uncertainties of discharge from hospital by "passing time", "waiting on time" or "killing time" (2004, p.259). However our interviews also

contained other responses. Other survivors accepted that the future was uncertain and contained dangers, especially that of another stroke, but identified ways of structuring time and the (immediate) future through setting goals and creating and managing risks. [54]

In his study of mental health service users, RYAN (2000) identified three distinct approaches to risk management, no risk strategy, passive and proactive. The difference between no risk strategy and passive strategy was one of degree. Both were characterised by an emphasis on the present and an apparent acceptance that dangers and therefore the future were essentially uncontrollable. In the no strategy approach there was an apparent failure to acknowledge the dangers whereas in the passive approach the dangers were addressed as they arose and were recognised and dealt with by adopting the line of least resistance. The proactive approach was characterised by the user's recognition that the dangers could and should be controlled and managed and the user played an active role in both exposing themselves to dangers and managing the consequences (RYAN 2000, p.279). [55]

## **5.2 Risk-taking, identity and social standing**

While RYAN recognised the possibility and benefits of focussing on risk, he saw it in terms of danger and did not consider the benefits of voluntary risk taking which some of the stroke survivors used to manage their recovery. As LUPTON and TULLOCH noted in their study of voluntary risk taking most of the expert and media accounts of risk present it as something negative and thus 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 & TULLOCH 2002, p.113). [56]

This approach to risk underpins the "expert approach" which perceives recovery from traumas such as strokes as coming primarily from a risk and harm minimisation strategy enabling individuals re-establish their skills and function and develop a sense of personal security. In contrast, LUPTON and TULLOCH showed how voluntary risk or exposure to dangers could be a source of pleasure and increased self-awareness and identity. By setting and successfully overcoming challenges, individuals could develop an improved sense of self. Cultivated risk-taking in this context was 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 & TULLOCH 2002, p.122). [57]

LUPTON and TULLOCH referred to such risk taking as edgework as individuals often used dangerous activities to provide the necessary challenge and danger, such as surfing in rough seas. These activities could form the basis of a risk-taking community or distinctive subculture and membership of such a community formed an important part of individual identity and an escape from the dull everyday life and activities. PARKER and STANWORTH (2006) also examined voluntary risk-taking and engagement in dangerous activities such as a charity parachuting but this tended to be a one-off activity that could be used by an individual to establish their standing in a mainstream group such group of work colleagues. They referred to this form of risk-taking as "centre-work". They suggested it could be used to deal with social change, for example when an individuals starts a new job and needed to establish their social position and standing. The survivors in our study can be seen as engaging in centre-work when they engage in challenging every-day activities, such as cooking a meal for friends or going out for a walk. [58]

Following the experience of stroke, the period of recovery can be seen as one in which some stroke survivors engaged in risk- to reconstruct their individual identity and social standing. Successful negotiation of risk and accomplishment of challenges served an important function in regaining a real sense of agency for individuals. [59]

## 6. 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 & 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. [60]

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 negotiate and manage it. In particular it is important to see how the risks associated with the management of disabilities are placed in the contexts both 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, well-being and rehabilitation. [61]

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 this 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) and found little evidence that professionals were either 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 & HARRISON 1998 and ALASZEWSKI, ALASZEWSKI, MANTHORPE & 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 either reconstructing life or re-establishing identity, which are arguably the most important tasks facing individuals who experience and survive stroke. In our view it is important that professionals acknowledge such perspectives as these and incorporate them into their practice in order to more effectively assist individual survivors and where necessary their caregivers in successfully negotiating and re-building life after stroke. [62]

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