

09/02/2010
Stroke and identity

Title: The impact of early stroke on identity: A discourse analytic study

Keywords: Stroke, identity, discourse analysis, computer-mediated communication

Word count: 8,000

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Biographical Notes

Jennie Guise is a lecturer in Health Studies at the University of Abertay Dundee. Her research interests involve aspects of different chronic illnesses, and in particular the ways in which chronic illness, and its treatment, can affect the sufferer's identity and relationships with others. She is also interested in wider issues of identity, well being and patient experience.

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Sue Widdicombe is a lecturer in Psychology at the University of Edinburgh, UK. She is interested in conversation and discourse analysis, in their utility in exploring matters of identity and applying conversation analysis (eg to therapy). She is also interested in personal and social identity, and cultural variations in self conception and individuality.

Abstract

This paper examines the ways in which sufferers talk or write about early stroke and the effects this chronic condition has on identity. Traditional research into chronic illness has largely used medical, psychiatric or cognitive models. We adopt a social constructionist perspective and use a discourse analytic methodology to study data collected via computer-mediated email communication, and focus group interaction. Participants showed sensitivity about a potentially 'damaged' sense of self by highlighting positive features of their experiences, and attended to the issue of whether their accounts were persuasive or believable. In focus group discussions, some carers were present. Although there were some similarities between focus group and email participants, there were some differences. Principally, focus group participants did not produce highly positive evaluations of their experience. Moreover, they displayed sensitivity to the way that carers might respond to mitigation of the negative aspects of stroke.

Introduction

Our aim is to examine the construction of identity and change in identity, and to show how identity constructions are sensitive to interpersonal issues in different interactional contexts. Participants are relatively young stroke sufferers (aged 55 or less).

Stroke is debilitating and prevalent. In 2006, the estimated number of stroke patients seen in General Practice in Scotland was approximately 53,000 people - 1% of the population (ISD, 2007). Approximately 10% of stroke sufferers in Scotland are under the age of 55 (ISD, 2007). The initial stage can involve anything from mild confusion to complete loss of consciousness for a number of days. As many as 35-40% die within the first month; those who survive may be left with moderate to severe neurological impairments that can affect speech, sight, movement and memory. For many, stroke also results in overwhelming fatigue and/or depression.

There is very little in the way of pharmacological or surgical treatment for stroke. The emphasis instead is on rehabilitation, aimed at enabling the patient to relearn the practical skills necessary to prevent physical degeneration - such as that caused by restricted movement - and to regain functional competence through repetitive exercise. The stroke literature, too, is dominated by a concern with identifying and measuring indicators of physical abilities (Pound, Gompertz, & Ebrahim, 1977). This approach has been criticised because it can fail to take into account the psychological and emotional effects of this condition (White & Johnstone, 2000). Moreover, the emphasis on physical rehabilitation may not match the concerns of the patient. Kaufman & Becker (1986), for example, found that as well as losing functional independence,

stroke sufferers missed their former ease of movement, energy and sense of wholeness. They noted that medical practitioners' preoccupation with the observation and measurement of rehabilitative tasks was shared by sufferers only in the first few months post-stroke. Thereafter, stroke sufferers co-operated, but were not 'engaged', their main interest having moved to recovery, "a non-specific, diffuse goal which implies notions of normality, continuity and identity" (Kaufman & Becker, 1986: 83). Kaufman reports that sufferers "believe that they are physically, emotionally, or cognitively different from their former selves, in spite of "perfect" performance in therapy" (Kaufman, 1988: 86). Similarly, in a phenomenological study, Burton (2000) writes that participants focused on engagement in the social world rather than physical performance. Ellis-Hill (1998) found that two years after their stroke, participants saw themselves as less active, satisfied, independent or interested than they had been pre-stroke. These perceptions did not appear to be related solely to the severity of the physical symptoms. Thus, the observable level of physical impairment is not a reliable indicator of the stroke sufferer's experience of illness.

Other research suggests that sufferers experience a major disruption in their lives. Thus Ellis-Hill and her colleagues found in their study that "[a]ll of the respondents described their lives as having undergone a change that could be likened to entering a new foreign world" (Ellis-Hill, Payne, & Ward, 2000:727). Similar findings are reported by Becker (1993) in a study in which 100 people were interviewed up to one year post-stroke. Glass and Maddox (1992) describe the post-stroke experience as a psychosocial transition in which the effect of sudden change is to cast doubt on the sufferer's previous assumptions about the world and how he or she is to live in it. Stroke can also bring about feelings of uncertainty as to the future (Bendz, 2000).

A central theme here appears to be a change in identity, and consequently a need to rethink the self in interactions with others. Thus, Kirkevold (2002) argues that sufferers may be more concerned about their changed roles and relationships than recovery of physical function (Banks & Pearson, 2004). In addition, the fact that the responsibility for rehabilitation is on the patient rather than the clinician can be particularly problematic for sufferers, who can be held accountable by carers for their recovery. This can affect the sufferer's identity (Kaufman, 1988; Pound, Gompertz, & Ebrahim, 1998). Stroke sufferers who experience aphasia may find that this affects their interactions with others, and that successful adaptation may involve a renegotiation of identity (Shadden 2005; Shadden & Agan, 2004). Higher quality of life post-stroke has been reported for people who prioritised activities they felt to be particularly salient to their identity (Clarke & Black, 2005). Parry (2004) shows that identity is an issue even when the focus is on physical rehabilitation. She showed, for example, that physiotherapists were sensitive to the negative identity-related consequences of physical incompetence and tried to avoid this in their interactions.

However, there are few, if any, studies of how young stroke sufferers negotiate their own identities, how they account for change in self, and how they attend to related interpersonal issues in accounting for self. In this study we therefore examine sufferers' accounts given in two different interactional contexts: one-to-one email correspondence with the first author, and focus groups in which other early-onset stroke sufferers were present, as well as carers. We adopt an approach - discourse analysis – that is well-suited to examining constructions of identity, how particular constructions are achieved through the language used (including linguistic devices), and how identity constructions

have an action-orientation, that is, they have particular effects which it is the analysts' job to identify (e.g. to do with accountability, blame). Discourse analysis involves a detailed analysis of the interaction within and through which identity work is done, as well as identifying why a particular identity or meaning is invoked on this occasion. However, Hutchby and Wooffitt (1998) note that speakers' utterances may be designed to respond not simply to the interviewer, but to the wider community. Thus, explanations or excuses are provided in a social context in which the function of utterances is understood because there is a level of shared social understanding. When they speak, participants draw on culturally available resources, and we can assume that these resources are not employed exclusively in the context of interviews but have a currency beyond that setting. We can also assume that the discursive resources found in these data are not specific to this community of speakers. Discourse analysis, then, affords a deeper understanding of socially available descriptions of stroke and identity.

Previously, discursive analysis has been used successfully to elucidate the interactional consequences of stroke by examining conversational exchanges between health professionals and stroke sufferers (Martinovski, Traum, & Marsella, 2007). Using a related technique - conversation analysis - Horton (2007) examined the way in which therapists control topic generation in conversations with aphasic patients and how this is used to establish a particular therapeutic identity for themselves and a 'patient' identity for their clients. Other researchers (Grainger, Masterton, & Jennings, 2005) have relied upon conversation analysis to tease apart the interactional subtleties of conversational episodes between therapist and client in which the therapist talks about the difficulties and problems which the client will face as a result of experiencing a stroke.

However, few studies have used discursive analysis to explore questions of illness and identity. Where studies of this sort have been carried out (Bowker & Tuffin, 2004; Giles, 2006; Guise, Widdicombe & McKinlay,), this has been in relation to conditions other than stroke. This is despite the fact that questions of identity in general have been a topic of long-standing interest in the area of discursive research (Benwell & Stokoe, 2006). The present paper addresses this current lack by focusing directly on issues of identity as they arise in the talk of stroke sufferers.

Methods

Data collection

Participants were recruited via support groups for people who had suffered stroke at a young age (defined as aged 55 or less). There can be practical problems in arranging face-to-face interactions with people who suffer chronic illness. They may, for example, have problems of mobility, or difficulties in producing speech. People were also recruited via a web-based support group. This ran as a message board, and provided the means to initiate one-to-one email contact with sufferers willing to participate. All respondents were given assurances of confidentiality and contact details in case they wished to withdraw at a later stage (none did). All personal and place names were changed. Where hospitals were named, this was replaced by a numerical code. Some stroke sufferers were accompanied by a carer, and these people also joined the focus group discussion. This paper examines participants' responses to the question "in what ways has your illness affected you as a person?" in order to explore issues of identity.

Focus group data were recorded and transcribed using conventional notation (ten Have, 1999). Email communication was copied to separate file, to ensure anonymity. Spelling and layout, however, were left unchanged.

Participants

The total number of stroke participants was 22 (12 in focus groups; 10 one-to-one emails), and in the focus groups there were 5 carers.

Analytic procedure

The analysis synthesised guidelines provided by Potter & Wetherell (1987) and Schegloff (1996). First, transcripts were read through and inspected closely to identify recurrent patterns or features in the data. Next, the analysis of these broadly-defined constructions was informed by what Edwards (1997) refers to as the ‘could-have-been-otherwise’ quality of talk; every detail of what is said is treated as potentially significant because it was said in that way and at that particular time. When it appeared that an utterance had a particular function – such as constructing identity in a certain manner – there followed an exploration of *why* the transcript was being read in such a way, and how this could be supported by what was in the text. Analytic points are illustrated by direct quotations.

Results and analysis

In this section, we examine the ways in which participants oriented to identity issues in their responses to the question "in what ways has your illness affected you as a person?" Preliminary analyses showed that some respondents constructed themselves as having changed their outlook as a result of their stroke. In several email accounts, these

changes were described as positive. These are examined in more detail in Section 1 where we also address the issue of what is achieved through these communications. In section 2, we examine extracts from the focus group discussions which display a rather different pattern.

Section 1: Email Communication

In the following extract, Ana describes the effect of having had a stroke as profound and she warrants this claim by producing examples of what has changed.

Extract 1 DSIPCp12 Ana

- 1 Having had a stroke has affected me profoundly:
- 2
- 3 My value systems have altered i.e. there are different
- 4 priorities I consider important. I place less importance on
- 5 ideas of 'morality', 'goodness', etc and more on the basic
- 6 principle that people are more important than ideas.

In particular, Ana claims that her “value systems have altered” (line 3), and that she now considers “different priorities” important. Her use of the terms “value systems”, “priorities” and “basic principle” indicate the non-superficial nature of the change that stroke has brought about in her. She also contrasts her current and former values. Specifically, she contrasts “ideas”, to which she now attaches less importance, with “people” to whom she now attaches more importance. One interesting feature of this characterisation is that she works up a listing of examples of these ideas on which she places less importance: “ ‘morality’ ”, “ ‘goodness’, etc”. These are aspects of human

experience that are normatively regarded as positive. But this listing is developed in a particular way. It is identified as a set of “ideas”, and the two specific examples that are offered are typographically represented through the use of inverted commas. This conveys to the reader that ‘morality’ and ‘goodness’ are functioning as labels for these ideas, rather than the qualities themselves. The implication here is not that Anna places less importance on whether people are moral or good but rather that she places less importance on abstract ideas of morality and goodness. She contrasts “ideas” with “the basic principle” that “people are more important than ideas”, which constructs her as someone who cares more about others than about abstract notions. Moreover, the level of the importance which people hold for Ana is emphasised by the positive nature of the abstract ideas she chooses to list.

Slightly later in her email, Ana indicates other ways in which she has changed.

Extract 2 DSIPCp13 Ana

19 I am probably less tolerant of some behaviours e.g.
20 rudeness and other sorts of bad manners, dishonesty, etc,
21 and more tolerant of others e.g. eccentricity.
22
23 My moods can be changeable and I can be irritable, this
24 is noticeable not because it's necessarily abnormal, but
25 because I was so calm and placid before.

Here, Ana produces a description of herself that might lead to the inference that stroke has had a negative effect on her. She describes herself as “less tolerant”. However, this

self-ascription is mitigated in several ways. First, her expression of lack of tolerance is preceded by “probably less” which suggests room for doubt. Second, her lack of tolerance is described in relation to specific behaviours rather than being, say, a general trait or one directed towards particular people. This specificity is reinforced by her claim that there are other behaviours of which she is more tolerant, such as eccentricity. Third, examples of behaviour of which she is less tolerant include “rudeness and other sorts of bad manners, dishonesty” (line 20). A common-sense inference is that being less tolerant of such behaviours is not necessarily a negative aspect of the self; a reasonable person might be expected not to tolerate bad behaviours.

In lines 23 to 25, Ana offers a third example of change: “my moods can be changeable and I can be irritable.” But, as in her second example of change, this is moderated. By claiming that she “can” be irritable, Ana emphasizes the transitory nature of her emotional states. At line 24, she makes relevant the question of whether her irritability is normal or not by suggesting, albeit in a qualified sense, that it is noticeable but not abnormal, and she accounts for this by providing a description of herself before her stroke as “so calm and placid.” This establishes a version of herself with which her (sometimes) irritable self is contrasted, and accounts for the significance of being more irritable.

In extracts 1 and 2, then, Ana produces three examples of ways she has changed. These include her value systems, tolerance of behaviours, and moods. It is noticeable that none of these refer to physical functioning, and that they are all presented in modified ways that imply that change is positive, balanced or moderate. Further moderating devices are used to achieve a similar effect in extract 3 below.

Extract 3 DSIPCp12 Frederick

4 It has taken a big part away from me in terms of self realisation
5 (i.e. I won't be able to do what I wanted to achieve before and
6 I'm not even able to see myself the way I was before). This is
7 not self generated, but a reflection of how society looks at
8 disabled people. I don't fit the profile of any other group in the
9 hierarchy in our macho society. Personally I find that I have
10 more time to reflect on life and spiritual values have overtaken
11 material ones.

In contrast to Ana's account above, Frederick characterises the effect of stroke in terms of loss: "it has taken a big part away from me in terms of self realisation" (line 4). He also specifies two ways in which self realisation has been prevented. At line 5, he describes not being able to achieve what he wanted "before" (presumably prior to having a stroke). He also writes "I'm not even able to see myself the way I was before" (line 6). These descriptions are precisely the kinds of account that would be expected from the literature, which claims that chronic illness produces a loss of self. However, what is interesting here is the nature of the explanation he goes on to provide for this state of affairs. At lines 6 to 8, he claims that this is not "self generated" but "a reflection of how society looks at disabled people." In other words, he claims that self realisation is thwarted not because of some deficiency or fault of his own, but because of others' perceptions of disabled people in general, and society's pre-occupation with machismo. Moreover, he implies that he is ascribed membership (by others) of the category 'disabled' because he does not fit any other profile. It is by default, then, rather than due to Frederick's physical functioning or abilities. This depiction of society helps

to establish that the problematic nature of this stroke experience is grounded in external factors, rather than in personal responsibility.

Frederick then produces an account of his personal views of how stroke has affected him. Specifically, he describes two changes: having more time to reflect on life, and “spiritual values” having become more important, in that they have “overtaken” material values. This description is worked up as a factual account by describing it as a “find” that he has made. It is also noteworthy that, at line 9, Frederick stresses the relevance of this outcome to himself by emphasising that it is something he has “personally” found, thereby implicitly contrasting it with the perceptions of himself which are not “self generated” but which are merely reflections of how society sees disabled people.

In the final extract we examine, Barry claims explicitly that stroke has changed him “for the better” and he produces a list of ways in which he has changed.

Extract 4 DSIPCp12 Barry

1 I think my haemorrhage has changed me for the better.

2

3 After the actual seriousness of my illness had sunk in, I

4 decided not to take things for granted again. My friends, family

5 all rallied round to help me recover, so I am forever in their

6 debt.

7

8 I learned that you can't let little things in life get you down, and

9 that every day is a new experience. My mother gets upset if the
10 car breaks down for example, and she has to walk to work.
11 Whereas I would look at it as "thank goodness the car broke
12 down at home, and not out in a lonely place late at night". I
13 know that's a weird example, but I look at the best in each
14 situation. I take each day at a time, I don't get stressed out as
15 much. I always try and smile, no matter how hopeless the
16 situation. I think "if I didn't laugh about it and smile and be
17 kind to others - I'd go mad!" It's certainly better than feeling
18 sorry for myself and shut myself away, a sad fact that a lot of
19 stroke sufferers do.

First, at lines 3 and 4, Barry describes himself as not taking "things for granted again." He warrants this by claiming "my friends, family all rallied round to help me recover" and his consequent reaction "so I am forever in their debt". The implication is that in the past he might have taken others' support for granted, whereas he will never do so again. Insofar as taking others for granted is not generally regarded as a positive way of relating to others, it can be inferred that Barry's new attitude is a change for the better. Barry's more positive relations with others are further emphasised towards the end of his account where he describes himself as being "kind to others" (line 17).

Second, Barry claims "I learned that you can't let little things in life get you down" (line 8), and in lines 13-14 he further stresses his optimistic attitude towards potentially stressful situations ("I look at the best in each situation"). This contrast is developed by means of a hypothetical case that Barry explicitly identifies as an example. At lines 9 to

13, Barry provides an account of the difference between the way his mother would respond (by getting upset at the inconvenience) and the way he would respond to a problematic event (a car breaking down). In this account, Barry characterises himself as someone who would identify the positive features of the situation through contrast with what could have been otherwise (e.g. the car breaking down at home rather than in a lonely place, before work rather than late at night). The vividness of this example is emphasised by Barry's use of a reported speech marks, which implies that he is reporting actual thoughts. Thus, he presents his hypothetical response to the problematic event as though it had occurred. At lines 12 and 13, Barry orients to his own example of the car breaking down as though it is in some way problematic – “I know that's a weird example.” Barry can thus be heard as acknowledging that this may be open to challenge. Immediately afterwards, though, he introduces a gloss in highly positive terms, “I look at the best in each situation” (lines 13 and 14) by means of the disjunction “but”. In doing so, Barry orients to his own example as potentially problematic, and at the same time establishes that it is merely an example of his own positive outlook.

Third, at lines 14 to 17, Barry provides a list of other ways in which he looks “at the best” : taking each day as it comes, not getting so stressed, trying to smile whatever the circumstances, and not feeling sorry for himself.

In this account, the positively evaluated nature of Barry's current state is portrayed as an outcome of Barry's own efforts. This is accomplished by a switch from the passive voice (“has changed me”, “had sunk in” in lines 1 and 3) to a series of first person singular active voicings. For example, at lines 3 and 4, not taking things for granted any

more is described as an outcome of his own decision (“I decided ...”), while at line 8 his positive attitude towards potentially stressful situations is described as something he has learned. At lines 11 and 13 (“I would look at”; “I look at”), he uses the active voice to suggest that he would view a problematic event more positively than his mother.

This same device appears at a number of other points in lines 14 to 17. Especially noteworthy is his description of his own cognitive state of thinking at lines 16 and 17 (“I think “If I didn’t laugh about it and smile and be kind to others – I’d go mad!””).

This reported speech formulation is designed to function as a report on an interior monologue, thereby emphasising that his positive outlook is a consequence of conscious and deliberate thought processes.

In a number of ways, Barry implies that his current situation is one that some people would find hard to deal with. For example, he describes himself as “trying to smile” which makes available the inference that his situation is one in which smiling may be difficult. This is given further emphasis by his acknowledgment that at least some situations he finds himself in might be classified as “hopeless”. The seriousness of his situation is further identified through his use at lines 16 and 17 of an ‘if ... then’ construction (Potter, 1996). If it were not for his laughter, smiles and kindness, the situation would be one that might affect his mental health. Barry’s own case is then contrasted with that of members of the category “stroke sufferers” who are depicted as not coping as well with these difficulties. Instead, this category of people is associated with the “sad fact” of feeling sorry for themselves and shutting themselves away. In this respect, it is interesting to note that Barry avoids attributing to himself the categorisation “stroke sufferer” opting instead for the slightly unusual phrasing of “my haemorrhage” and “my illness”

Summary

In accounting for change, the account-giver is faced with certain interactionally sensitive issues. On the one hand, participants can be expected to display some sensitivity to the issue of having acquired a ‘damaged’ identity or sense of self as a result of their illness. In all three cases above, Ana, Frederick and Barry attend to issues of accountability. On the one hand, they display sensitivity about a potentially ‘damaged’ sense of self by highlighting positive features of their experiences. On the other hand, participants are also likely to attend to the interactional context in which these accounts are developed – one in which they are being asked to provide accounts of their own illness. Here, then, respondents present less positive elements of their experience as stroke sufferers but they do so in such a way as to minimise their negativity or to play down any personal responsibility for those negative outcomes. Thus Ana works up her own irritability as noticeable only in contrast to her former self. Frederick describes his inability to achieve his desires as located externally, in societal views, rather than as deriving from himself. In contrast, Barry reports the more positive aspects of his experience largely in terms of his own efforts and responsibility.

Section 2: Focus group interactions

In this section, we turn to interactions that arose during focus group discussions in which the participants were co-present. In the following extracts, the participants included both stroke sufferers and some of their carers. The names of carers are represented in italic font, and the interviewer’s name is underlined. Two features distinguish these interactions from the email communications analysed above. The first

is that focus group discussion allows for the sequential unfolding of accounts across conversational turns. So focus group discussion makes sufferers' accounts immediately available for challenge by carers in a conversational next turn. This differs from the email context described in section 1, where claims that are made are practically unavailable for immediate challenge. In the extracts that follow it can be seen that sufferers' claims are open to question within the focus group format. The second feature of everyday conversations that arises in these discussions is that the interactional setting allows carers to initiate accounts. And, as is the case in everyday conversation, sufferers can be seen to orient to these carers' accounts in their subsequent contributions.

In the following extract, a stroke sufferer, Eric, produces an account of how he changed as a result of stroke that is then challenged by one of the carers present, Alison.

Extract 5 FGDS2

- 584 Eric: but I would have taken the view .hh before the stroke that
585 I could have run this hospital you know .h I could have
586 been the .h the (1.0) manager of the place you know but
587 eh .hh now I just [blows out 'pwrr'] couldn't care less
588 Jennifer: mhmm
589 Alison: [that's not true that's not true to say you couldn't care
590 less
591 Euan: [I could still I could still do I could still but I keep falling
592 asleep [[laughs
593 Eric: [[laughs

- 594 *Alison:* because you could care less and that's what's bugs you=
595 *Eric:* that's the frustration yeah

Earlier in the discussion, Alison and Lorna (respectively, carers of Eric and Euan) had been talking about what Eric was like before and after his stroke in terms of his belief in himself as strong and invincible.

At the start of this extract, Eric describes how he has changed, and in lines 584-587, he uses a contrast formulation to construct the extent to which he has changed as a result of his stroke. He claims that, whereas before his stroke he would have taken the view that he could have run the hospital (in which the focus group was held), now he couldn't care less. With this claim, he constructs the change as one of motivation rather than, say, inability. At lines 591-592, Euan adopts an affiliative stance, affirming that he could still perform roles of this sort. He incorporates into his turn a reference to his present incapacities by referring to his tendency to fall asleep. However, both he and Eric orient to this as a non-serious or humorous claim. So both Eric's and Euan's claims are carefully designed to deal with the delicate interactional problem of accounting for the changes stroke has brought about, while lessening the negative impact on identity associated with loss of ability.

In her next turn, Alison directly challenges Eric's description of his current self as lacking motivation, through the repeated phrase "that's not true that's not true." She claims, by contrast, that he does care and she produces evidence of the extent to which he cares through her reference to this as something that "bugs" Eric. The implication is that it is not motivation but ability that prevents Eric from achieving what he would

have before the stroke. At line 595, Eric appears to accept this alternative account by stating that his current state of affairs is associated with frustration. That is, Eric's response to Alison's challenge is not to defend his earlier claim, but rather to agree with her. Thus, he seems to contradict what he has just said. This apparent contradiction can be explained if we consider the *actions* that are being performed in each turn. When Alison challenges Eric's claim, she ignores any inference that Eric might still be capable of running the hospital, and orients instead to the potentially damaging implication that he lacks motivation. Thus, for Eric to agree with her construction at this point is for him to maintain a positive identity.

The 'conversational' setting of focus group discussion, then, affords carers the opportunity of challenging sufferers' accounts. However, it also provides them with interactional slots where they can develop their own accounts. This is demonstrated in the following extract, which arises following a discussion about how tired the stroke sufferers become as a result of their illness.

Extract 6 FGDS2

636 *Lorna:* but you've (1.0) dropped lots of things that you used to
637 do as well
638 *Euan:* mhmm
639 *Lorna:* you would do it I think if you were asked (1.0) like (1.0)
640 do that extra wee bit of (1.0) tidying up in the garden that
641 you might have done voluntarily before (2.0) You j- the
642 whether that's energy or just (2.0) whatever you just don't
643 do it now

644 Sharon: mm
645 Eric: I think it's a bit of both really
646 Lorna: yeah
647 Eric: I think it's (1.0) energy
648 Alison: I mean Eric will say I'll ask him the the the same thing
649 yeah "I'll do that for you" [but it doesnae happen
650 Euan: [I always get ideas of things I
651 want to be doing but (2.0) never get them done
652 Eric: energy and motivation [yeah
653 Lorna: [mhmm
654 Alison: yeah I've wondered about that as well whether that's (1.0)
655 the stroke or whether it's just that they have well (1.0) it
656 doesnae [doesn't] (1.0) I cannae [can't] be bothered you
657 know whether it's (1.0) being lazy or whether it's (1.0) the
658 stroke

In this extract, Lorna describes Euan as no longer carrying out tasks he voluntarily performed before his stroke. However, she indicates in her next turn that Euan is capable of performing these tasks in that he would carry them out if asked. At lines 642-643 she then offers up two candidate explanations for this state of affairs: "energy" or "you just don't do it now". The first explanation draws upon the common sense idea that ill people might not have the same energy levels as healthy people. This provides an explanation for Euan not performing tasks he formerly carried out. However, Lorna then offers a second potential explanation, "just not doing" something. Presented in contrast to lacking energy, this may implicate laziness, lack of motivation or apathy and

indeed, there is evidence later in the extract that this is how it is taken (“energy and motivation”, line 652; and a result of stroke or “being lazy”, line 657). Moreover, not doing something because of a lack of motivation or laziness is problematic in contrast to not doing it because of a lack of energy (resulting from) the stroke. It is also worth noting that whereas Lorna’s reference is to Euan specifically, Alison claims that Eric displays similar behaviour (thereby implying that this may be a feature of stroke sufferers in general). She also upgrades Lorna’s complaint about having to ask Euan to do tasks, claiming that Eric will agree to do something but “it doesnae happen.”

In the conversational turns between Lorna and Alison’s accounts, Euan and Eric address the relevance to them of these potential explanations. At line 645, Eric does agreement with Lorna’s assessment in attributing not doing tasks to both “energy and motivation” in saying “I think it’s a bit of both really” (645). At line 651, Eric seems to orient to Alison’s prior turn as indicating that his reference to “energy” is insufficient as an explanation by amending his claim to include both energy and motivation.

In the following extract, which immediately follows on from the previous extract, Eric can be seen to address Alison’s implicit criticism that he is lazy by providing an extended description of how illness affects people in a way that could be interpreted as laziness.

Extract 7 FGDS1

659 Jennifer: mhmm

660 *Alison*: [it's sometimes like that

661 Eric: [it's very easy (1.0) eh I can understand how people who

662 have got eh .hh hip problems or whatever back problems
663 whatever .hh they just sit because it's it's very easy just
664 to sit there and just say .hh "ah it's too much effort" .h
665 you know

Eric's turn begins “it's very easy” (line 661), then, rather than saying immediately what it is that is very easy, he inserts a claim - that he understands how other people “just sit” because it is too much effort to do otherwise. This claim provides an indirect means of countering Alison's challenge. It does this in three ways. First, by claiming to understand these other people, we might infer that his problem is similar to theirs; that is, difficulties with mobility. Second, Eric's understanding can be contrasted with Alison's failure to work out what is going on. Third, he provides a warrant for the behaviour of these other people. That is, they may “just sit”, but they are identified as having good reason to be immobile - hip and back problems. The indirect nature of Eric's response to Alison's challenge is what renders it rhetorically powerful. He does not provide a straightforward account that would give an indication of how much of his inability might or might not be attributable to stroke, and instead makes a claim that would be hard for Alison to counter. His “understanding” is an internal event, therefore difficult to refute. He refers to a hypothetical group of people, and therefore his attitude towards them could not easily be challenged on the basis of actual behaviour. Furthermore, the attributes of the group to which he refers provide a reasonable warrant for their behaviour.

What the preceding extracts have demonstrated, then, is that when sufferers produce accounts, carers may challenge those accounts. Carers may also introduce their own

accounts to which sufferers, in turn, must orient in their subsequent contributions.

Because of this, sufferers display an ongoing sensitivity to the interactional consequences that arise out of the different participatory roles which they and their carers inhabit during these discussions.

Extract 8 FGDS1

- 853 Jennifer: can anybody say in what in (1.0) what wa:ys would you
854 say that having had a stroke has affected you as a
855 person?
856 (3.0)
- 857 Yvonne: impatient (1.0) e:h
- 858 Jennifer: what make it has made you impatient
- 859 Yvonne: mhmm
- 860 Jennifer: yeah?
- 861 Yvonne: [very quietly] aye
862 (3.0)
- 863 Norman: yeah it's [unclear]
- 864 Ian: it's maybe
- 865 Norman: one of the things that trauma and shock bring on
- 866 Ian: yeah maybe you should ask the carers rather than the .h
867 the sufferers of that [laughs]
- 868 Yvonne: that's right

There are several features of Yvonne's response to this question which are worth noting.

First, there is a lengthy pause of three seconds after the initial question which indicates

that the issue of post-stroke change is a difficult one for the focus group members (participants were generally fluent speakers; analysis of the full transcript shows very few pauses of this length). Jefferson (1989) suggests that a silence of this length may indicate that what has been said is problematic, or that providing a response is problematic. Second, when Yvonne does reply, she provides a relatively minimal response, “impatient” which is not directly attributed to, say, her own behaviour or feelings. Thus, the interviewer produces a question seeking clarification, “it has made you impatient” which in turn indicates that she interprets this as a reference to a psychological state or trait. The focus group moderator’s questions at lines 858 and 860 therefore open up a slot for Yvonne to expand on this change but Yvonne again produces a minimal turn, with her second reply being voiced in quiet tones. So although Yvonne provides conversationally appropriate responses, in that she provides answers to the moderator’s questions, she avoids producing further description of the relationship between her stroke and impatience. This is left to the other participants.

After a further lengthy pause, Norman produces an agreement at line 863. In the subsequent turns, Norman, Ian and Yvonne then jointly work up an explanatory account that offers justification for stroke sufferers being impatient while, at the same time, attending to the interactional sensitivity of this admission within the particular context. One feature of this account is that Norman provides an impersonal explanation, saying that impatience is “brought on” by “trauma” and “shock”. The use of these terms helps to establish the sufferer’s impatience as a rational response to a serious personal event. So although impatience is a negative feature of someone’s psychological state, the stroke sufferer’s personal responsibility for being impatient is minimised. It is noteworthy that Norman frames impatience as only “one of the things” that may result

from the trauma and shock of stroke. This might make a listing of further negative aspects appropriate as a continuation of his turn. However, at this point Ian says “maybe you should ask the carers rather than the .h sufferers”, thereby indicating that carers are in a better position to assess the consequences of stroke than sufferers are. At the same time, Ian displays that his comment is intended to be humorous, indexing it with laughter at line 867. This switch to a more humorous tone works to indicate that the potential difficulties associated with stroke sufferers becoming impatient may not be as serious as could otherwise be imagined. At the same time he offers the conversational floor to the carers who are present. This explicit reference to carers allows Ian to acknowledge that the issue of sufferers being impatient is one that is relevant to their carers.

Summary

In focus group discussions, then, the role of carer provides these participants with the rights and entitlements to criticise sufferers’ accounts and to put forward their own alternative, potentially negative accounts as reformulations of or as counter-arguments to the sufferers’ accounts. In this way, sufferers’ evaluations of the life consequences of experiencing stroke are open to immediate challenge by those carers whose lives have also been seriously affected. In addition, carers are able to initiate their own descriptive accounts that highlight negative aspects of the stroke sufferer that have arisen as a result of experiencing a stroke.

In producing their own accounts, stroke sufferers display sensitivity to this interactional issue. In particular, it is noteworthy that the accounts of focus group participants differ from those of email participants in that they did not provide explicitly positive

evaluations of the impact which stroke has had on their lives. Both email and, focus group participants oriented to stroke as a serious life event. And in describing the effects of stroke, they work to minimise potential negative inferences about themselves arising out of their experience of stroke. However, unlike the email participants, the focus group stroke sufferers displayed sensitivity to the issue of how their mitigation of the negative aspects of stroke would be received and dealt with by those carers who were co-present. So, although there are similarities between the sufferer's accounts produced in the email context and in the focus-group context, there are also important differences.

Discussion

The approach taken in this study is that accounts describing illness might fruitfully be examined for their rhetorical function. At the beginning of this paper, we noted that stroke sufferers' accounts of their experience of illness were likely to represent both positive and negative aspects of stroke. The extracts examined here show that participants sometimes display sensitivity to the issue of having acquired a 'damaged' identity as a result of their illness. However, they do so in a way that allows them to emphasise positive aspects of their experience that have in some way improved their lives. At the same time, participants can be seen to attend to the issue of whether the accounts they develop are persuasive or believable. Their accounts are designed so that they are not heard as inappropriately positive about their experiences of suffering from a traumatic illness. Among the email participants, the more negative elements of their experience as stroke sufferers are reproduced in accounts so as to minimise any personal responsibility for those negative outcomes. More positive aspects of this experience, by contrast, are depicted largely in terms of the participants' own efforts and responsibility.

The focus group participants also oriented to stroke as a serious life event. But like the email participants, focus group sufferers described their experiences in a way that minimised the potentially negative inferences that others might make about them as stroke sufferers.

However although there are similarities between the sufferer's accounts produced in the email context and in the focus-group context, there are also important differences.

Focus group stroke sufferers, unlike email participants, did not produce highly positive evaluations of their experience. Moreover, they displayed sensitivity to the way that carers would respond to mitigation of the negative aspects of stroke. It seems that in part this difference arises out of the difference in interactional contexts. In focus group discussions, carers were able to criticise sufferers' accounts and were also able to generate their own, potentially negative accounts. In their contributions to the discussion, sufferers oriented to these actual or potential criticisms in the way that they designed their claims. This provides an important demonstration of the context-dependent nature of identity-constructions, and of the ways in which carers play a role in maintaining damaged identities.

In this research, participants who had suffered stroke did not talk or write about a disrupted self, as discussed by Ellis-Hill, Payne & Ward (2000). They did, however, work to construct a positive identity. That they did this allows us to infer that there is indeed some stigma surrounding stroke. Our findings also elaborate previous research that indicates the importance of identity to stroke sufferers (Clarke & Black, 2003; Shadden, 2005; Shadden & Agan, 2004), and in particular how it can be influenced in interactions with others.

White & Johnstone (2000) suggest that stroke sufferers can be held accountable for their recovery. We have shown how participants in focus groups, whose carers were co-present, showed particular sensitivity to the identity implications of their talk. Stroke rehabilitation is characterised by its focus on regaining physical function – an emphasis that has been criticised because it fails to take enough account of the interests and experiences of the sufferer (Kirkevold, 2002). This study suggests that people who have suffered stroke do orient to the difficulty in maintaining a positive sense of self, particularly in the presence of their carers. It also demonstrates the value of a qualitative approach to studying the experience of living with a stroke, and in particular the usefulness of discourse analytic methods.

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