Co-construction of chronic illness narratives by older stroke survivors and their spouses

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Abstract
Illness narratives have mainly focused on individual patients’ accounts, and particularly those of people experiencing the onset of chronic illness in mid-life. However, a growing number of older people are spending their later life with their partner, with both experiencing complex morbidities. We examine the shared creation of meanings among older stroke survivors and their spouses and the implications for individual and couple identity. Joint biographical narrative interviews were held with 13 stroke survivors aged 75–85 and their spouses. The analysis examined both narrative content and narrative style. Three main types of co-presentation of identity were identified. The ‘united couple’ described couples who pulled together and emphasised their accommodation of the stroke and normality as a couple, despite often considerable disability, and was strongly underpinned by collaborative interaction in interviews. Caring relationships were distinguished as ‘positive’, involving self-reliant couples who took pride in how they managed and ‘frustrated’ in couples who emphasised the difficulties of caring and hardships experienced and were characterised by a conflictual style of narrative. We argue that joint interviews provide new forms of data that extend notions of how illness is lived and demonstrates how the marital relationship can mediate the experience of chronic illness and disability and its impact on identity.

Keywords: stroke, older age, chronic illness, narrative, joint interviews
Co-construction of chronic illness narratives by older stroke survivors and their spouses

Introduction

It is now well recognised that chronic illness can lead to a fundamental rethinking of a person’s identity and biography, can affect relationships and material and practical affairs and may lead to the need to restructure future goals and priorities (Bury 1982). The conceptual strategies that people employ in the aftermath of biographical discontinuity to create a sense of coherence, stability and order were described by Williams (1984) as narrative reconstruction, which involves narrativising chronic illness within the framework of one’s own life history. As he explained, by assigning meaning to events that have disrupted and changed the course of one’s life by linking up and interpreting different aspects of biography, one may ‘realign the present and past and self with society’ to achieve a redefined self (Williams 1984: 197).

The early focus on adults experiencing the onset of chronic illness in midlife has since been broadened to locate and understand the influence of a diverse range of contextual factors on biographical disruption, and to understand more fully the process of self reconstruction. Studies have shown the significance of an individual’s whole biography for the meanings they assign to chronic illness and processes of narrative reconstruction. This is illustrated by Kaufman (1988), Pound et al. (1998) and Sanders et al. (2002), among others, who demonstrate how individuals with various chronic conditions differ in their prior experience of crises and struggles associated with their age and socio-economic background, which in turn shapes the meanings of new bodily disruptions.

Support provided by social networks is also identified as a contextual factor and resource that is often critical to the ways in which illness is lived and negotiated in people’s lives. For example, Corbin and Strauss (1987) described spouses as playing an important role in the process of reconstructing the identity of people with various chronic illnesses, including stroke, with this often involving denying or minimising their failed everyday performances, for example relating to personal care. However, most studies that consider the experience of chronic illness for other members of the patients’ social network have focused on the demands of providing ongoing care to a person who is chronically ill (for example, Clarke and Smith, 1999, Sholte op Reimer et al 1998), or how the experience of the chronic illness of a family member affects the lifecourse of those around them (e.g. Öhman & Söderberg...
2004). These studies have all tended to rely on the individual interview, which as Lawton (2003 p.35) notes in the context of qualitative work, may lead to particular types of narratives that tend to give less emphasis to the ‘mundane’, daily aspects of ‘coping with’ the diseased body, despite the physical aspects of living forming the prime focus of the experience of chronic illness. Lawton (2003 p.35) therefore called for a shift from the dominance of the single research interview and ‘opening the door to a broader range of methods and methodologies to give access to a more broad-ranging and comprehensive picture of individual illness.’

We argue that the meanings and disruption consequent on chronic illness need to be considered together for both the patient and their spouse, rather than only for each party individually. An important way forward is therefore to conduct joint interviews with the chronically ill person and their partner, and to focus not only on what is said in terms of the content of talk but also to analyse the style of the narrative, in terms of how people talk about and present events. A few studies have employed joint interviews in examining experiences and responses to chronic illness but have mainly only presented the content of joint accounts. These include a study of male coronary patients and their wives aged 30-70 years, which described how the marital relationship influenced men’s styles of adjustment (Radley, 1989), a study exploring couples’ reactions to one partners’ diagnosis of dementia (Robinson et al. 2005) and a study of adjustment to prostate cancer among couples aged 50-64 years compared to older couples (Harden et al. 2006). The largely descriptive accounts of findings led Robinson et al. (2005) to suggest that further research should focus on couples’ conversational interaction to gain a better understanding of the ways in which couples engage in the construction of joint chronic illness narratives.

Gerhardt (1991) emphasised the importance of focusing on the process of meaning construction in joint interviews with couples to gain insight into their joint interpretations of the ‘marital reality’ and shared social world. Her analysis of a single case study involved a joint interview with a married couple prior to the husband’s coronary artery bypass surgery, which depicted the couple as striving together to present a ‘unified front’, creating an image of their relationship as competent and ‘normal’, despite experiencing chronic illness and financial hardship. Moreover through their narrative about the low rate of sickness benefit, they presented themselves as an honest working couple abandoned by an uncaring welfare state, thus legitimating their claim as a respectable family. A subsequent joint interview study by Manzo and colleagues (1995) involved male stroke survivors and their wives, and ‘control’ interviews with men who had various other chronic conditions (e.g. arthritis) and
their wives. In contrast to Gerhardt’s (1991) finding of a ‘unified front’, the authors found that stroke survivors lacked agency in the narratives as their wives tended to dominate, for example, by answering questions directed at their husbands and engaging in ‘competitive’ storytelling, supplementing, correcting and contradicting their husbands’ stories. However, the authors did not elaborate on this or on any other differences between the two groups.

As the compression of morbidity has not accompanied increasing life expectancy in later life in many countries across the globe (European Health Expectancy Monitoring Unit, 2009), more older spouses will be living with long-term conditions as well as caring for a partner who also has complex morbidities (Pickard et al, 2001). Stroke is the single biggest cause of severe disability in the UK and is a common condition of older age; each year 110,000 people in England and Wales have a first ever stroke, with 81% of strokes occurring in those aged 64 years and over (Carroll et al. 2001). The study is based on interviews with stroke survivors aged 75-85 years and their spouses, and thus focuses on a section of the older population that come within the policy category of ‘frail older people’ with physical and social care needs that can compromise independence and quality of life (Department of Health, 2001). This paper builds on prior studies of couples’ co-construction and presentation of joint biographical narratives and aims to explore how older couples used narratives to make sense of stroke and how stroke impacted on their relationship and identities, contributing towards an understanding of how older couples assign meaning to stroke through narratives (Williams, 1984).

**Methods**

**Data Collection**

Participants were recruited from the South London Stroke Register (SLSR), an ongoing population-based register recording first ever stroke in people of all age groups in south London (Wolfe et al, 2011). At the time of recruitment to the interview study approximately 1,800 living individuals were registered, 21% (378) of whom were aged 75 years and over.

Eligibility criteria employed to identify potential respondents were: community-dwelling stroke survivors aged 75-85, at least one year post-stroke to ensure adequate time for participants to have adjusted to changed circumstances after an initial period of physical recovery (Mayo et al. 1993), an Abbreviated Mental Test score of seven or above to exclude those with severe cognitive impairment or memory problems; and the absence of severe aphasia
(communication impairment), recorded on the SLSR, although those with mild aphasia that may involve slurring or difficulty finding the correct word were included. In January 2009-June 2010, 252 patients fulfilling these criteria were identified.

All stroke survivors on the SLSR give written consent to being contacted about participating in research and a random sample of just over one-quarter (69) was sent an information sheet with an invitation to participate in an interview about the experience of their stroke together with their spouse or informal carer, if they wished. A follow-up telephone call was made to those who did not return a reply slip. The majority contacted by phone were happy to participate but found it difficult to return the reply slip due to physical impairment. Thirty-six individuals were not contactable, reflecting the attrition in longitudinal studies, especially among older respondents with poor health (Chatfield et al. 2005).

Only seven stroke survivors declined to participate, mainly due to ill health, with 26 consenting to participate either alone or with their spouse. This paper reports on a subset of 13 joint interviews conducted with stroke survivors and their spouses as part of a wider study that also included stroke survivors interviewed alone. Permission was requested from both stroke survivors and spouses to participate in a joint interview and ethical approval was given by Bromley NHS Research Ethics committee.

Interviews were carried out by ER, a young researcher, and took place in participants’ homes. Interviews lasted between one and two hours. They were based on Rosenthal’s (2004) biographical-narrative method that focuses on both narrative content and structure. They began with an open question asking the participants to tell the story of their stroke, with the aim of eliciting a detailed narrative indicating how couples made sense of the stroke, what meanings they attached to it, how they presented themselves as a couple and how they attempted to locate the stroke in their overall biography. The main narrative was uninterrupted but was followed by internal narrative questions that elicited more detail regarding themes already discussed, based on brief notes taken during the main narration. In the final part of the interview, external narrative questions were asked concerning topics of interest not previously discussed, such as the spouses’ health.

Analysis
Interviews were transcribed verbatim and pseudonyms assigned. The analysis was adapted from Rosenthal's (2004) biographical case reconstruction method and involves two levels. First, data were analysed with a focus on the content of the narrative through exploring the events couples talked about, referred to as the ‘life history’ and involved constructing a timeline to set out the temporal sequence of events before and after the stroke. Secondly, the analysis explored how participants selected the topics discussed during the narrative, how they interpreted the stroke and why they narrated their story in a particular way. This involved a detailed reading and coding of data according to Rosenthal’s (2004) ‘textual sorts’:

1. **Argumentation**, reasoning and theorising of general ideas; e.g. a participant discussing why it is more appropriate for their spouse to care for them rather than a paid carer.
2. **Description**, a sequence of text providing description; e.g. description of routines in relation to caring for a spouse.
3. **Narration**, linked sequences of past events related to each other through temporal and/or causal links; e.g discussion of the history of their ill health.

A further coding scheme was employed to analyse couples’ co-presentation in terms of the structure of narratives and interaction that was informed by Veroff et al’s (1993) scheme for the analysis of joint interviews. This involved coding each shift in speaker as one of six types of interaction; the first three types were categorised as collaborative styles of narratives and the last three as (explicit or implicit) conflictual styles:

1. **Collaboration**: extending the idea of the spouse, questioning for information, answering questions that further the story or continuing a storyline that the spouse had previously begun.
2. **Confirmation**: a statement of agreement e.g. ‘um-hmm’.
3. **Confirmation-collaboration**: an interruption that affirms the previous statement of the spouse and adds new material.
4. **Conflict**: disagreeing or interrupting the spouse with a negative response.
5. **Non-response**: explicitly avoiding responding to the spouse’s previous comment.
6. **Continuation**: continuing the narrative without reflecting on the spouse’s previous comment.
The approach to coding was agreed in discussion by all authors. Initial coding was carried out by the first author (ER) which was checked and verified by the other authors (MM, KL), with any discrepancies discussed in detail and consensus reached.

**Characteristics of participants**

Nearly all of the 13 couples participating had lived in the same property (mainly flats on council estates) for the majority of their married lives. Most had previously held skilled manual or semi-skilled occupations, with just two couples (Helen and John, Hilary and Adam) previously engaged in professional occupations (table 1). None of the couples lived with other relatives, although eleven couples had adult children. Six of the stroke survivors were female, with stroke survivors aged 75-85 years and their spouses aged 59-85.

Insert table 1 around here

Five of the stroke survivors were wheelchair users, three of whom rarely left their home. Three had mild aphasia; Tom and Sarah had slightly slurred speech and Tony had difficulty finding the correct words. All stroke survivors had multiple chronic conditions. Although the spouses were generally in better health, with all but one able to walk unaided, eight had at least one chronic condition. Only two stroke survivors (Sarah and Helen) received assistance with personal care from paid carers.

The findings section first discusses the couples’ styles of narrative and then describes the different forms of co-presentation of identity that we refer to as ‘united couple’, and ‘positive’ and ‘frustrated’ carers.

**Findings**

**Styles of narrative**

Couples frequently began their narrative with a focus on the stroke event and then discussed in more detail living and coping with stroke in the present and near future. The interactional dynamics between the couples frequently shifted throughout the interview, with spouses often taking it in turns to narrate, sometimes talking between themselves while trying to negotiate their narrative, and at other times one spouse would take a more dominant role than the other.
Couples’ narrative style emerged as either predominately conflictual or collaborative based on the frequency of Veroff’s codes applied to each shift in speaker. The speech of the collaborative couples mainly built on each other’s narratives, with a high degree of ‘confirmation’ and ‘confirmation-collaboration’ codes and very little conflictual interaction. The couples with a mainly conflictual style of interaction also engaged in some collaborative interaction but also often disagreed or interrupted the spouse with a negative response and frequently continued talking without taking into account what their spouse had said previously (identified as continuation), indicating an implicit conflictual style. ‘Non-response’ codes did not occur frequently. Hearing problems, common in older age, appeared to contribute to most of the non-response rather than this being intentional.

These collaborative and conflictual styles of narrative underpinned three types of co-presentation identified in relation to the content of the narratives. These different forms of co-presentation are described below.

Co-presentation of identity

‘United couple’

Presentation as a ‘united couple’ was evident in aspects of most couples’ narratives but emerged very clearly in six (Jack/Penny, Molly/David, Helen/John, Patrick/Betty, Gretel/Vas, Tom/Nora). Despite the stroke often initially causing great disruption to their lives, these couples presented themselves as morally competent, self-sufficient couples who had jointly adapted to varying levels of disability as a result of the stroke. Their narratives showed that together they were currently managing life with stroke as well as other illnesses and hardships, and often minimised the impact of the stroke. Their narrative style was largely collaborative, characterised by the frequent use of ‘we’ and by confirming and collaborating talk through repetition and overlapping to finish each other’s sentences in ways that emphasised their partnership. One example is Molly and David. After Molly’s stroke David had to help her with aspects of personal care such as getting dressed and he took on more of the household chores, despite his own heart condition and problems with his eyesight. However they presented themselves as a ‘normal’ couple who engaged in activities as other retired couples did. As David observed, ‘There a lot a people ‘alf our age who’re worse off than us, ain’t they, you know what I mean’, while Molly supported this adding that they were soon to go on a short holiday. To continue the storyline each built on what the other had said, as illustrated by the following extract that focuses on David’s past experience with the anticoagulant drug warfarin, a drug they both take.
Molly: We both go to the (warfarin) clinic together.
David: The only trouble is it don’t ‘alf alter your blood you know, that warfarin.... I ‘ad a lump come up didn’t I, ah you wanna hear another problem?
M: He had a lump in his jaw.... Never stopped bleeding.
D: ... And eventually they can’t stop the bleeding so I get them tablets, I got huh some acid tablets, they didn’t stop it so James er from the er what was it?
M: From the warfarin clinic.
D: From the warfarin, he phoned up some professor geezer and he said er double it up but then we had another plan what we should have done in the first place, keep chewing on lumps of cloth, trying of course to stop the bleeding. I was waking up in the morning and my tongue was like that.
M: Yeah it was horrible, wasn’t it?
D: Cough, oh my god, frighten you. I think we managed to sort it out ourself Molly didn’t we (laughs).
(Molly, aged 76, stroke survivor and David, aged 81)

In some cases ‘united couples’ described their relationship as strengthened through the shared experience of stroke. For example, Gretal, a stroke survivor, described how she could only go out of their high rise flat if her husband (Vas) was with her due to her risk of falling. Rather than talking about being dependent on her husband she presented the two of them as ‘a team’ who were dependent on each other, demonstrating a sense of agency and autonomy as a couple. Throughout their narrative they engaged together in a confirming and collaborating form of interaction, agreeing with one another and building on each other’s narrative:

Gretel: We have always been a loving and caring couple, I can say that without hesitation but obviously our relationship has changed because chores in the house I would do without thinking about it. I am restricted doing so...
Vas: Now I’ve got to do it (laughs).
G: You don’t have to, but you do it (laughs). So our relationship has deepened. No?
V: Oh absolutely.
G: We are more, as I said before we have always been close, very close and we are well known among friends and family, they say with a couple like you, one doesn’t fight very often... it was destiny that I came from Germany and Vas came from Cyprus, we met and lived happily, happily ever after... Both of us we are a team. We’ve always been but since I had the stroke-
V: We’ve always been, now it’s more, because she needs me. We are more close than ever.

(Gretel, aged 78, stroke survivor and Vas, aged 80)

It is important to acknowledge that there were variations among co-presentations as a ‘united couple’. Tony and Cathy’s narrative differed markedly in structure to the others as, although Tony had made a good physical recovery from his stroke, hisaphasia meant he spoke in a slow, stilted manner and had some difficulty finding the correct word. As the narrative progressed Cathy began to take a more dominant role by prompting, correcting or answering for Tony and finishing his sentences. Tony would also ask Cathy for confirmation or support to continue the storyline, shown here in the context of his recounting the history of his stroke:

Tony: I, we was on the boat, hh and um, no I had heart attack on the boat and I got to New York and they took me off the boat into the hospital and they fitted me with a pacemaker and it’s, how many days after?
Cathy: It was about four days after you had a pacemaker put in, he had the first stroke....
T: Affart from the s, speech, um, that’s all the result of the stroke, uh I don’t
C: Yeah I mean obviously you’re not as agile now as what you was before.
T: Huh now and again I get, um, leg, leg, left leg seelsa bit funny at times but ur I get about on that.
C: Not your left leg, your right leg.
T: Uh Right leg.
C: Because it was all down the right side.
T: Right leg.
C: where it was affected, yeah, yeah.
T: Sometimes it feels a bit funny but apart from that. A, a all er the troubles that I uh had is the breathing problems.
C: He has, he’s made a fantastic recovery. You know, as I say, no one thought he was going to come through it, even the doctors was so surprised.

(Tony, stroke survivor, aged 75 and Cathy, aged 74)

Together the couple sought to minimise the impact of Tony’saphasia by using humour, enabling them to display an image of a ‘normal’ united couple. For example Cathy joked about her own hearing problems saying, ‘he can’t get his words out and I can’t hear, we’re a pair well matched!’
Although Cathy assumed a dominant role in the narrative she appeared to use this to construct a socially acceptable presentation as a ‘united couple’, with Tony actively collaborating and inviting Cathy to take this role through his requests for confirmation from her at different points throughout the narrative. This could therefore be regarded as forming ‘scene support’ rather than Shakespeare’s notion of ‘scene stealing’ by a dominant individual in the dyad (Shakespeare, 1993). This narrative form did not occur in the co-constructed narratives of the other two participants with aphasia, possibly because they did not experience problems with word-finding as Tony did, as well as reflecting differences in individual personality.

**Carer relationships: ‘Positive’ and ‘Frustrated’ carers**

All couples brought up caring for their spouse following stroke as an unprompted part of their narrative. However in some narratives the notion of a spouse as carer was an image that dominated the couples’ co-presentation. This is illustrated by Jack and Penny who together engaged in a confirming-collaborative narrative to present themselves as a self-reliant couple, with Penny willingly caring for Jack who had very limited mobility and required the use of a walking frame and wheelchair. Together they presented Penny as a ‘positive’ carer with Jack describing how well he was looked after and Penny emphasising that it would be difficult to seek assistance from a paid carer due to Jack’s stubbornness, implying that she was the best person to care for him. This was supported by Jack who emphasised Penny’s ‘natural’ role as his carer:

Jack: Penny’s be, been brilliant... In hospital I didn’t like them cleaning me and washing me... If the wife’s doing it, I mean, we’ve been together alotta of years and it seems more of a natural thing. But to have a stranger doing it, it’s, to me that weren’t on... The thing is I’ve always been a very, very stubborn person.
Penny: Oh yes, very stubborn..... Well I know basically how, what he likes, what he don’t like, you know, and I’m here all the time.
J: She knows how moany I can be.
P: Oh yes, I don’t think a carer could take it, you know. They’d be running away (laughs).
J: She lays the law down...but really when I sort of think about it, I, she’s right.

(Jack, stroke survivor, aged 79, and Penny, aged 59)
Whereas this extract accords with the notion of females as ‘natural’ carers, it was not only wives who were presented as ‘positive’ carers, as illustrated by Grace and Simon’s narrative:

Grace: Not one of my children would ever do me, open their hearts to me as how Simon... He wash, he cook, he iron, he clean, he do everything believe me... He’s not well as well so I don’t want to see him lay down ‘cause if he lay down I will suffer.
Simon: ... I’m not too well really...I’ve got this prostate (problem)...life have to continue. G:... He have to do everything, he have to put my clothes on for me. So it is really bad. Really, he, he wash me. So I am really bad. I’m not hiding it and I can’t, God give me him for a reason.
(Grace, stroke survivor, aged 78 and Simon, aged 75)

Other spouses similarly talked about their caring responsibilities with a sense of pride. For example, Betty related that her GP told her that by ‘nursing’ her husband ‘in the right and proper way’ when he had pneumonia recently she had ‘saved the hospital hundreds of pounds.’ Similarly Judy described herself as a ‘good nurse’ and reported that while visiting Richard in hospital after his stroke a nurse told her that she admired the way Judy cared for her husband. However whereas Judy described her ‘positive' caring role, this was accompanied by aspects of the dutiful but ‘frustrated’ carer that also characterised the account given by Rita. Judy and Rita were both very keen to tell their own story of their husband’s stroke in terms of the disruption it meant for their own lives due to the high level of care their husbands required as a result of a lack of mobility due to the stroke and also both husbands’ severely limited eyesight that had led them to be registered as blind (table 1).

This is illustrated by the following extract in which Judy engaged in a conflictual style of narrative, interrupting her husband and seeking to present herself as the dominant narrator who will tell the ‘correct’ version of the story:

Judy: He used to go down to the pub every day, you know, to have a couple of pints and he just come barging in one day and through the door and he said, ‘I can’t walk’. And he just got near the chair and I had to grab ‘im, he just fell to the floor nearly, and I just got him in a chair. So I called our doctor and she came out. She was a French doctor at the time, and er she said, ‘Oh, you’ve had a slight stroke Mr Finch and she’-
Richard: She sat there, says, ‘you’re having a stroke’
J: Yeah, yes, well we know that Richard. I’m just giving her [the researcher], I’m telling her exactly what happened. (Addressing the researcher) Sorry, I’m not being rude to him, but he does this every time.
Similarly Rita who presented herself as a dutiful but ‘frustrated’ carer took a dominant role in her narrative with Ted:

Rita: I’ve had ‘eart attack myself, well I’ve had three stents put in as well you see so, obviously I can’t, when he falls I can’t pick him up. And I’ve also got arthritis all over me back and I just can’t whatsaname so I can’t cope with him....I have to cut his food up for ‘im and ‘cause, you know, he can’t cut his food up properly and he can’t see what’s on the plate and that goes everywhere... He can’t see the steps when he goes out like, you know. When he goes out he’s got his stick, his white stick and that but but I was out one afternoon, he’d gone across the shops on his own, you see so he can’t be trusted.

Ted: I’ve gone across to the shop on the crossing.

R: That doesn’t make any difference, whether you’re on the crossing or not because you can’t see... I tell him he’s not to answer the door when I’m not here. So but I think on the whole his life has completely changed...

A further variant of the carer relationship was provided by Sarah and Nelson. This narrative focused on Sarah’s role in caring for Nelson ‘day and night’ during their 60 years of marriage in view of his depression and mental health problems, and Nelson’s inability to act as a carer for Sarah who was left severely disabled and housebound after her stroke. The couple talked about Nelson’s severe depression happening as a direct result of Sarah’s stroke and how he spent eight months in a mental health unit from the week she was discharged from the stroke unit, meaning they were living apart during that time. Although Sarah had slurred speech she took the dominant role, talking about how she coped with disability and how she relied on paid carers and her children. Their narrative differed from those of Ted/Rita and Richard/Judy as the conflictual interaction was less explicit with minimal response from Nelson.

Underlying tension and conflict between Ted/Rita, Richard/Judy and Sarah/Nelson emerged in the structure of their narratives, largely dominated by themes of illness, profound disability and the need for a high level of care. Various health problems experienced by both the stroke survivor and their spouse appeared to be making their lives very difficult. The couples’ conflictual narratives therefore appeared to be at least partly driven by the practical realities and hardships they were experiencing in coping with stroke and other ill health at
the time of the interview and may have been influenced by the relative recency of the stroke, with interviews at 1-3 years post stroke.

Discussion

This study has extended notions of how illness is ‘lived’ in terms of older couples’ interpersonal relationships and daily lives and identified three main types of co-presentation of identity from joint interview data. ‘United couple’ displayed couples as pulling together to cope with the stroke and other disabilities, strongly underpinned by the couple’s collaborative interaction. ‘Positive’ carer presentations were similarly underpinned by a collaborative style of narrative as part of a display of self-reliance as a couple, with both a ‘united couple’ and ‘positive’ carer characterised by a stoic attitude. Although many of these stroke survivors were physically dependent on their spouse, thus lacking personal autonomy, their co-presentation demonstrated a sense of agency and autonomy as a couple. In contrast, the ‘frustrated’ carer was mainly underpinned by conflictual interaction that may reflect both the prior marital relationship and the practical realities and hardships experienced by older spousal carers in coping both with their own health and their spouse's disability.

Narratives are likely to vary according to age, gender and class, reflecting couples’ particular life experiences and circumstances. In terms of gender, husbands and wives appeared to engage equally in the construction of the narratives, with both using similar collaborative or conflictual forms of interaction. This supports the findings of Seale et al. (2008) that ‘traditional’ gender differences in terms of linguistic style and topic content as described by Coates (2004) are reduced in joint interviews. However during the three mainly conflictual narratives the wives tended to dominate, reflecting Seale et al.’s (2008) findings that women’s perspectives are more prominent in joint interviews as they speak significantly more and more often than men. However our interviews, as with Seale et al.’s (2008) study, focused on health related matters for which women are commonly regarded to be the most appropriate reporters. In contrast to these wives’ dominant narrative role, West and Zimmerman (1998) showed how men use interruption as a way to dominate naturally occurring conversational interaction with women (including conversations between couples), and drew parallels with their earlier findings based on parents’ domination of conversations with their children.

The dominance shown by women in our study’s mainly conflictual narratives may have reflected the general nature of these couples’ marital relationships in which the wives took a
dominant role in conversational interaction with their husbands. However their relationships may have changed over time and been shaped by the men’s ill health and high level of physical dependency, with the nature of the marital relationship known to be influenced by illness and disability (Walker and Luszcz, 2009). This is suggested by the way in which both Judy’s and Rita’s accounts tended to portray themselves as ‘frustrated’ carers coping with a high burden of care and to infantilise their husbands who were both registered as blind.

By applying a novel method to analyse joint biographical narrative interviews our research has enabled an in-depth understanding of older couples’ relationships and how they adjusted and accommodated to the considerable impacts on their lives of stroke and other chronic illness and disabilities. For example, it was notable that stroke survivors were often able to demonstrate agency through drawing on their autonomy as a couple, despite being physically dependent on their spouse. We also highlight the complexities of spousal caring amongst older people, especially as they are more likely to rely on a spouse for social, emotional and physical support as more couples survive into old age (Pickard et al, 2001) and wider social support networks shrink. The findings have implications in terms of addressing the needs of older spousal caregivers, particularly in relation to the three couples presenting mainly conflictual narratives. These ‘frustrated’ carers appeared to be struggling to cope with the impact of their partner’s stroke and other chronic illness, as well as their own ill health, pointing to a need for practical and emotional support. As Dean and Thomas (1996) noted, stereotypical views of old age tend to homogenise older people and thus their role as informal carers, whereas our data demonstrates that older spousal carers are a diverse group within themselves, with differing levels of need; indeed many of our participants would be unlikely to regard themselves as ‘carers’. This heterogeneity among older couples needs to be reflected within the context of providing health and social care to an ageing population.

Our analytic approach was based on the premise that couples were participating in a social performance during the interviews and the narrative data were therefore analysed as shared meanings created through social interaction, or social constructions. The narrative analysis method was systematic and practical to ensure transparency, rigour and validity (Atkinson 1997). Although Rosenthal’s (2004) biographical narrative interview method aims to provide participants with as much freedom as possible to structure their own narratives, the questions asked, how they were asked and which spouse they were directed to inevitably had some influence on the construction of narratives. The significant age difference between participants and the younger researcher may have also influenced couples’ co-
presentations. As Rozario and Derienzis (2009: 551) suggest, the much younger researcher may have ‘served as an external reminder of their age, and their representations of themselves might be seen as reactions to this reminder.’

Joint interview data are constructed by both participants in a continual process of negotiation and can therefore be viewed as a ‘particular form of “institutional talk”’ (Seale et al., 2008: 126). Jointly interviewing those who are chronically ill and their spouse may make participants feel more comfortable; additionally it may be more acceptable for the chronically ill participant to take rests during the interview (Morris 2001), while for aphasic participants, having a spouse to support their narrative construction may make participation easier. Much previous work based on joint interviews with couples would have benefited from moving beyond a purely thematic approach with minimal interpretation of the co-construction of narratives, while further studies are required to examine variations in the content and style of interaction that may occur at different stages of managing the demands of chronic illness and disability and for different age, socio-economic and cultural groups.

Acknowledgements

We are grateful to Charles Wolfe for access to the South London Stroke Register and to register staff for their assistance.
We would also like to thank all the couples who participated in this study.
References


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