

There's no apprenticeship for Alzheimer's: the caring relationship when an older person experiencing dementia falls

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ABSTRACT

Older people experiencing dementia are twice as likely to fall with consequences of serious injury, reduction in everyday activity, admission to long-term care and mortality. Carers of people with dementia are themselves at greater risk of physical and mental ill health, which increases as the dementia progresses. Unsurprisingly, carer burden also increases when a care-recipient falls. The aim of this study was to explore the experiences of falling of community-living older people with dementia and their carers. A qualitative approach was taken using interpretative phenomenological analysis. Nine older people with predominantly Alzheimer's disease and their ten carers were recruited from a large mental health National Health Service trust and participated in one-to-one and joint in-depth interviews. Three dyads participated in repeat interviews. Three focus groups were also carried out, with nine older people experiencing memory problems and 12 carers from a local Alzheimer's Society branch. The antecedents, falls events and consequences of falls were discussed. This paper reports specifically on the impact of falls on the caring relationship. Three themes emerged: 'learning as you go', 'we're always together', 'nobody was interested'. The findings demonstrate how falling accentuates the impact of dementia on the dyad. Spouse-carers' discussion of their own falls emphasise the need for joint assessment of health and wellbeing to reduce carer burden and preserve the couplehood of the dyad.

KEY WORDS—falls, dementia, carers, personhood, couplehood, interpretative phenomenological analysis.

Introduction

Falls by older people are of great concern for health and social care providers, with falls being the fifth leading cause of death in older people (Rubenstein 2006). The risk of falling increases as people age with an

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estimated 25 per cent of the population falling by 70 years of age and 50 per cent by 80 years (Logan *et al.* 2010). The projected rise in the average age of the population in the United Kingdom (UK), and globally, indicates that the incidence of falling amongst older people will be of increasing concern (Martin 2009). Also of concern is a projected increase of the current global population with dementia from 24.3 million to 81.1 million, with a rise from a current figure of 700,000 to 1.4 million in the UK within the next 30 years (Department of Health 2009; Ferri *et al.* 2005). Older people experiencing dementia are twice as likely to fall as cognitively normal older people, with a 70–80 per cent incidence rate annually (Shaw 2007). The incidence of falls is also said to vary according to the type of dementia experienced, with Allan *et al.* (2009) identifying that people with Alzheimer's disease are twice as likely to fall as their cognitively normal counterparts.

There is increasing evidence for the effectiveness of multi-factorial falls risk assessment and tailored intervention for cognitively normal older people living in the community, but there is insufficient evidence for these interventions (or any other) with older people with cognitive impairment and dementia (American Geriatric Society and British Geriatric Society 2010). Apart from a few studies such as those by Shaw *et al.* (2003), Jensen *et al.* (2003), Allan *et al.* (2009) and Faes *et al.* (2010), older people experiencing dementia have been commonly excluded from falls research. The need for appropriate falls management is heightened when one considers that the consequences of falls such as serious injury (*e.g.* hip fracture), lying on the floor for a long period, decline in everyday activity, admission to long-term care and mortality are more likely for older people with dementia and cognitive impairment (Fleming and Brayne 2008; Kallin *et al.* 2005; Oude Voshaar *et al.* 2006).

The psychological impact of falling, such as loss of self-efficacy and autonomy as well as fear of further falls are acknowledged in cognitively normal older people (Lord *et al.* 2007). Anxiety and fear of further falls manifest in carers of older people; sometimes resulting in protective or coercive behaviour towards the care-recipient (Horton and Arber 2004). Carers of older people are often seen as the gatekeepers for successful provision of services and interventions following a fall of the care-recipient (Horton and Arber 2004; Mackintosh, Fryer and Sutherland 2007). Buri and Dawson (2000) also identified that carers of older people with dementia accept or reject falls advice given by professionals based on their own experience, values and coping strategies. Even though carers' decisions to reduce the activity of the care-recipient are motivated to prevent further falls and subsequent injury, these actions are potentially de-skilling for the care-recipient (Horton and Arber 2004). Carer burden and carer strain are correlated with the incidence of falls and hip fracture in older people

(Kuzuya *et al.* 2006; Saltz *et al.* 1999). Subjective and objective carer burden, carer strain, reduced health and wellbeing, as well as restricted activity and participation for the carer are also said to increase as the severity of the dementia develops in the older person (Baker and Robertson 2008; Vikström *et al.* 2008).

Recent research has moved toward a more compassionate model of dementia care, spearheaded by Kitwood (1997), where the preservation of the personhood, quality of life and wellbeing of the person is paramount and the impact of dementia on the carer and whole family is acknowledged (Nolan *et al.* 2002). Indeed recent research has advocated a ‘couplehood’ approach where the dyad or whole family are considered (Hellström, Nolan and Lundh 2005; Keady and Nolan 2003). In the UK, carers of people with dementia are often older and frail themselves (Department of Health 2009) and so the recent National Dementia Care strategy objectives in the UK are that health and social care services meet the needs of both older people with dementia and their carers (Department of Health 2009), but it is not clear if this involves meeting the individual or joint needs of the dyad. Involving older people and carers in falls research and service development is said to be crucial to facilitate implementation and acceptance of recommendations and findings (Department of Health 2001; Ross *et al.* 2005). Therefore involving older people experiencing dementia and their carers in research into their falls experiences provides the opportunity for health and social care professionals to better understand their complex needs and circumstances. Moreover, the ways in which a fall may influence relationships between people with dementia and their carers has been largely neglected in previous research. It is this issue that forms the focus of the study reported here.

Methods

This study explored the experiences of falling by older people with dementia and their carers and this paper will particularly focus on the aspect of the caring relationship in relation to falls. A qualitative methodology was chosen as it is commonly used to explore the insider’s view and/or subjective experience in the real world (Morrow 2007). A phenomenological approach known as interpretative phenomenological analysis (IPA) was taken. Phenomenology is considered a useful approach to explore systematically the experiences of individuals through their personal accounts (Wilding and Whiteford 2005). IPA is not only influenced by phenomenological philosophy, but also hermeneutics and idiography. Therefore IPA studies not only focus on the meaning making of personal experiences by

participants but acknowledge that the researcher interprets (or makes sense of) the participant's sense-making of their experience, which IPA researchers describe as a double hermeneutic (Smith, Flowers and Larkin 2009). IPA is attractive to health and social care professionals as it allows a deeper exploration and understanding of the perspectives of individuals with a health condition whilst complementing bio-psycho-social theories of health and functioning (Biggerstaff and Thompson 2008; Clarke 2009; Reid, Flowers and Larkin 2005). It is useful because it seeks a nuanced account of the lifeworld, paying attention to both explicit content and implied meanings, through for example, analysis of linguistic features such as metaphor (Smith, Flowers and Larkin 2009). This makes the approach very appropriate for exploring experiences that are possibly taken for granted and difficult to articulate, as was expected in the present study. IPA has been successfully used in research investigating the experiences of people with a recent diagnosis of dementia and carers (Clare 2003; Robinson, Clare and Evans 2005; Quinn *et al.* 2008). The emphasis of IPA, on attempting to uncover or illuminate the unique and shared subjective experiences of individuals experiencing a phenomenon such as falls, dementia or caring, is therefore highly appropriate to this research study.

Design

Both interviews and focus groups were used in this research to gather data. Different sets of participants took part in each method.

Participants

Interviews. People aged 65 and over with predominantly Alzheimer's disease who were service users of a large London mental health National Health Service (NHS) trust community health-care team and who had reported a recent fall or 'near fall' were identified by their community health-care team and approached to take part in interviews. Other inclusion criteria were that participants were living at home, being cared for by a spouse, partner, family member or friend. People were excluded if they lacked capacity to give consent, had moderate/severe behavioural or communication problems, or were not aware of their diagnosis of dementia. Nine people with mild, moderate, moderate/severe dementia were recruited along with their permanent carer (spouse/partner, child, sibling or friend) using purposive sampling. The participants for the interviews were six women and three men experiencing dementia with two wife-carers, four husband-carers, two daughter-carers and two son-carers. All of these participants were white European and either working or middle class.

In-depth interviews were carried out separately and then jointly with both members of the dyads where possible. The opportunity to hear the individual and joint stories of the dyads allowed for differing perspectives of the same experience to be articulated and no one perspective was privileged over another. All interview participants were invited to be interviewed again to explore their experiences in greater depth, with two dyads being interviewed once more and one dyad interviewed a third time. All participants were interviewed in their own homes as it was considered that this would provide the most supportive and enabling environment for them.

Focus groups. Three focus groups involving 21 members of a support group for people with memory problems and their carers (six men and three women with memory problems, eight women and four male carers) were also carried out at a London branch of the Alzheimer's Society. All participants were white European and the people with memory problems were aged over 65. Focus groups were considered as the most appropriate choice of data collection with these participants as they were an already established group, meeting regularly for both social and educational events. Focus groups are often carried out to encourage group discussion, debate or modification of ideas and opinions of a topic. However, they are also considered a valuable means of accessing individual members' personal ideas and understandings of an experience through the interaction with other group members (Kreuger and Casey 2004; Wilkinson 2004).

Whereas the interview participants (*see Table 1* for demographic information) were aware of their diagnosis of dementia, the focus group participants (*see Table 2*) were only aware of memory problems and were either unaware of, or had not received, a formal diagnosis of dementia at that time. Participant information was therefore altered to reflect the needs and awareness of the different participant groups. Whereas it was possible to gather some understanding of the severity of the dementia of the people participating in interviews it was not possible (and also deemed inappropriate) to ask this of focus group participants.

The term 'care-recipient' will be used from here on to represent the person experiencing dementia or memory problems so that these participants can be differentiated from those participants who were carers.

Procedure

The interviews and focus groups involved participants identifying a previously significant fall of the care-recipient and discussing this in terms of possible antecedents, experience of the fall itself and perceptions of

TABLE 1. *Demographic information for the interview participants*

Person experiencing dementia	Severity of dementia (MMSE score) ¹	Age	Ethnicity	Carer	Relationship of carer	Age of carer	Ethnicity of carer
George	Mild (28)	84	White/UK	Vicki	Daughter	Middle-aged	White/UK
Tony	Mild (28)	76	White/UK	Susan	Spouse	Retired	White/UK
Wendy	Moderate (?)	84	White/UK	Bernard	Spouse	80+	White/Swiss
Vera	Moderate/severe (14)	87	White/UK	Paul	Son	Newly retired	White/UK
Rita	Moderate/severe (12)	84	White/UK	Neil	Son	Middle-aged	White/UK
Sheila	Mild/moderate (23)	82	White/UK	Patrick	Spouse	82+	White/UK
Bob	Moderate/severe (14)	87	White/Irish	Norma	Spouse	80+	White/Irish
Eileen	Mild/moderate (23)	79	White/UK	Karl	Spouse	85	White/Polish
Bridget	Mild/moderate (23)	83	White/Irish	Harry and Alison	Spouse and daughter	80+	White/Irish and White/UK

Note: 1. Severity of dementia of Alzheimer's type determined by Mini Mental State Examination (MMSE) (Folstein, Folstein and McHugh 1975), where mild = 24–30, mild/moderate = 20–23, moderate = 15–19, moderate/severe = 10–14, severe = < 10.

TABLE 2. *Focus group participants*

Focus group	Person experiencing memory problems	Carer
1	David, Andrew, Edward and Bill	Diana, Kathryn and Christine
2	Eamonn, Verity and Bill	Marion, Maggie, Derek and Sally
3	Sarah and Rena	Peter, Joe, Deidre, Joyce and Geoff

short-/long-term consequences. Consequences for the relationship are specifically explored in this paper. Interviews lasted approximately 30 minutes each, with a total of 90 minutes of interview for most dyads. The concurrent focus groups were 45–60 minutes long. Interviews and focus groups were carried out by the first author with assistance from a clinical practice colleague; they were audio-recorded and transcribed verbatim. Focus group transcripts were parsed so that the narratives of individual participants could be identified. All names have been replaced with pseudonyms to preserve confidentiality.

Sample sizes of four to ten for interviews are of common acceptance in IPA (Smith, Flowers and Larkin 2009) with the method of data analysis varying slightly where larger numbers are involved. Although not a prescriptive process, data were analysed as recommended by Smith, Flowers and Larkin (2009) and described by Alexander and Clare (2004). The aim is for ‘thick’ interpretation of participants’ accounts so that both the unique and the shared perspective is communicated, an aim which Osborne and Smith (2008) consider of particular relevance where the topic under scrutiny is under-researched, multifaceted and contextual. As it was important to consider the experiences of both members of the dyad, it was decided that the transcripts for each dyad were to be considered as one data item. Where repeat interviews had been carried out, these transcripts were also considered as part of this data item for the dyad. Clustering of emerging themes for the first and then subsequent transcripts was carried out until all transcripts had been analysed. Patterns and connections of clustered themes were then looked at for the whole data set. Recurring and diverging themes were identified and re-clustered to devise major themes.

Procedures were put in place to ensure the quality of the research as this is much debated, especially in hermeneutic phenomenological research where the study focuses on the researcher’s interpretations of the subjective experiences of individual participants (Smith, Flowers and Larkin 2009). However, an independent scrutiny was carried out by the second author (an experienced IPA researcher) of the analysis and interpretation. Data have been stored and analysis recorded in such a way that an audit trail through the process is possible.

Ethical considerations

The study was scrutinised and agreed by the local research ethics committees from the authors' university, the NHS trust involved and their Research and Development committee before commencing recruitment and data collection. Giving informed consent to participate in the research was of obvious concern and a procedure for the interviews, similar to that described by Dewing (2007), took place. Consent to participate in the interviews was requested in three stages. The community mental health care team key workers identified potential participants for interviews, who met the study criteria and who they considered had the capacity to give consent. The key worker approached potential participants to ask if they would be interested in participating and give permission for their details to be passed to the researcher. Participants were then contacted by the researcher, when information about the study was briefly given, to gain confirmation of their interest and to arrange the interview. At the beginning of the interview, information about the research was repeated to both members of the dyad (verbally and in writing) and consent was given separately by each participant. Consent was obtained to access the case notes of the care-recipient for date of diagnosis, severity of dementia (often as a Mini Mental State Examination (MMSE) score) and also age. Personal details of the carer were not requested.

Focus group participants were recruited through a different route, namely an Alzheimer's Society local branch meeting. They were given information about the research and asked if they would be willing to participate. Those who were interested signed a written consent form prior to the focus group taking place. As already discussed, focus group participants were not asked about the severity of memory loss, nor were they asked for their age. However, the Alzheimer's Society branch manager was aware that inclusion criteria for the study specified that people experiencing memory problems would be aged 65 and over.

Findings

Several recurring themes emerged as a result of the data analysis. Three themes that relate to the caring relationship and falls are presented here. It is worth considering that these findings do not focus exclusively on the falls experiences. It was difficult to consider these experiences in isolation from the dynamics of the dyadic relationship of the care-recipient and their carers. The falls experience both permeates, and is permeated by, this relationship. The three themes are: 'we're always together', 'learning as you go along' and 'nobody was interested'. Whereas the first theme considers the

TABLE 3. *Prevalence of themes for participants*

Older person with dementia	Carer	Relationship	Themes ¹		
			We're always together	Learning as you go along	Nobody was interested
George	Vicki	Daughter	*	*	*
Tony	Susan	Spouse	*	*	*
Wendy	Bernard	Spouse	*	*	*
Vera	Paul	Son	*	*	
Rita	Neil	Son		*	
Sheila	Patrick	Spouse	*	*	*
Bob	Norma	Spouse	*	*	
Eileen	Karl	Spouse	*	*	*
Bridget	Harry and Alison	Spouse and daughter	*	*	*
Focus group 1: David, Andrew, Edward and Bill	Diana, Kathryn and Christine	Spouses	*		*
Focus group 2: Eamonn, Verity and Bill	Marion, Maggie, Derek and Sally	Spouses and daughter (Maggie)		*	*
Focus group 3: Sarah and Rena	Peter, Joe, Deidre, Joyce and Geoff	Spouses		*	*

Note: 1. Asterisks indicate which themes are found in each dyad or group account.

couple's experiences and maintenance of their relationship in response to falls, the remaining themes relate more to the carers' experiences and perhaps demonstrate the tensions that existed for carers to maintain the caring relationship, and to deal with changes that occurred as a result of falls. All the themes occur in the majority of the data set from both interviews and focus groups. Table 3 identifies the themes and their prevalence across the data set.

We're always together

This theme presented itself in different ways, but demonstrates the close relationship between the dyads, although this closeness carried various meanings. Sheila (care-recipient) who made the statement 'we're always together' considered that she did not worry about falling over outside, or the consequences of a fall, as she rarely went out without her care-giving husband. Sheila expressed great satisfaction and happiness about being together as a couple, going to the shops and sharing the enjoyment of the

social interaction with others. The togetherness of the relationship, and reliance on her husband not only to protect her from harm and to provide enjoyable activity was also illustrated by Sheila immediately referring the interviewer to Patrick, her husband, for memory of facts or incidence of falls, rather than attempting to remember this herself. The reliance upon the carer to remember the facts of their falls was also expressed by Bob, George and Bridget (care-recipients). George's rationale for doing this was his concern to 'get the facts right'.

In other circumstances, in joint interviews and focus groups, the couples had a joint memory of a fall with the carer facilitating the care-recipient's recollection of their fall, by either confirming their recall or by prompting and telling the story of the fall together.

Bernard (husband-carer): ...The serious one was when we were expecting Pauline and you decided to clean the wall in the kitchen.
 Wendy (care-recipient): Oh yes, I remember it happening
 Bernard: and you fell off the stool
 Wendy: it's my sense of balance. I don't think I've got a good sense of balance.

The telling of a joint story was not exclusive to spouse couples. For example, Vicki (daughter-carer) and George (care-recipient) also talked about a fall which Vicki had not observed. Vicki hypothesised that her father, George, fell because he could not decide between the need for the toilet or a drink. In another instance Vicki prompted George's memory of events of a recent fall:

Vicki (daughter-carer): You said that you saw the flowers in Prince John's Park.
 George (care-recipient): Oh yes, well I did.
 Vicki: Because you told me how nice the flowers were.
 George: Yes, they all were very good.
 Vicki: And I know that he hadn't been down there recently to that...
 George: ...It's quite a little walk, you know.

In other instances, the sharing of experience extended to the care-recipient's rehabilitation, for example, where carers said 'we go to physiotherapy'. Patrick's involvement in Sheila's home exercise programme was apparent:

...And he has given us special exercises on the bed where she'll put her legs that way, brings them together. And then we put a roll of kitchen towel under her legs and lift her legs up and down... (Patrick, husband-carer)

In Vicki and George's narrative the closeness of the relationship between father and daughter is evident, and in Patrick's narrative the intimacy of the relationship of husband and wife are fore-grounded rather than the relationship of carer and care-recipient.

Sheila's narrative also showed her feelings for Patrick. She relied on Patrick, her husband, not only for memories of facts and the successful carrying out of everyday activity, but also for emotional support:

...No I didn't feel embarrassed – because Patrick being with me. If I'd have been on my own I would have been ... But seeing he was there, you know. I suppose he was there before I fell. (Sheila, care-recipient)

In some instances the obvious affection and the acknowledged reliance of the older person on their carer was marred by the impact of the dementia on the relationship. Vera's and Paul's conversation provides an example of this:

Vera (care-recipient): ... I don't know what I would do if I didn't have him.

Paul (son-carer): Can't even remember my name.

Vera: Pardon?

Paul: You can't even remember my name.

Vera: No, I can't. I can't talk to you half the time can I?

Paul: Well I think you've done alright.

In IPA, dissonant experiences are valued as well as shared accounts. For Paul (carer) and Vera (care-recipient), the 'being together' in sharing of the falls experiences was limited. Paul (carer) expressed feelings of guilt that he rarely witnessed his mother falling – but that he deduced that this had happened by finding her on the floor or through an awareness of her being more subdued and uncommunicative. Vera (care-recipient) could not recall falling but was aware that she probably had fallen because she had 'aches and pains' and felt 'stupid'. Because of Vera's limited awareness, Paul tended to make unilateral decisions for changes to Vera's home such as removing furniture and rugs, or restricted her activity by no longer taking her for a walk outside. This was based on his supposition of how or why Vera fell, according to where he found her.

Being together for Neil and his mother Rita occurred after Rita had a series of falls and subsequent hospital admission:

Neil (son-carer): They said to me then that she can't be left alone any more ... Because I used to come and go. I had a girlfriend I was seeing you know ... and uh ... well I came back you know and I'm living with her permanently now you know. Well I can't see her go in a home ... So ever since I've been a 24-hour carer.

Interviewer: ... so if your mum wants to get up in the middle of the night do you ...

Neil: I'm there, I'm on call. I'm there. Yeah she's only got to call out.

Neil's use of surveillance in his concern for his mother Rita (care-recipient) to prevent her from falling was also apparent in other relationships. Harry (carer) voiced how he tried to ensure his wife Bridget remained with him at all times when they went shopping to prevent her from falling and possibly

from getting lost. Harry himself had health problems and poor mobility and used a mobility scooter when they went out together:

A lot of women are like this, I see them here. The wives walk 10 yards behind the husbands ... Well time and time I said ... And I said 'hold the back of the scooter when you're coming out with me ... so ... Of course the fact that she's behind me, [but] I look – she's missing... (Harry, husband-carer)

Harry's narrative portrayed his anxiety about the consequences of Bridget not doing as instructed by not staying together. Bridget's sense of agency and autonomy was also indicated in the interview. Although Bridget had mild dementia at the time of the interview she did not go out alone, but expressed enjoyment of times of solitude in their home and in recollections of the past. However in this narrative, Bridget's time alone resulted in her falling on the pavement, unable to get up and being found by a passer-by. Harry's desire to keep Bridget together with him did not always prevent her from falling. Bridget and Harry's daughter, Alison, recounted how she had taken her mother, Bridget, shopping:

...the pavements were really bad, and that's obviously how she fell. I mean she was actually holding my arm, but she still went just down like a sack of potatoes. (Alison, daughter-carer)

Different aspects of 'being together' have been portrayed here. For some the intimacy and closeness in the relationship are apparent even in joint participation in post-falls exercises or in sharing a supportive facilitation of memories during the interview. In other instances the 'being together' involved bodily surveillance by the carer and some discord between the couple, with the carer placing restrictions on the person with dementia to prevent falls from happening again.

Learning as you go along

This theme relates to how carer participants considered how they learned to deal with the impact of falls, how they tried to prevent them re-occurring, as well as their struggles to maintain the status quo. The theme is taken from an extract of Neil's interview (carer) and he, like many other participants, expressed how he learned to care through trial and error. Carers recounted how they learnt to physically look after the care-recipient who had had a traumatic injury after a fall, such as fractures, lacerations or painful bruising. Other carers found themselves providing assistance with everyday activity because of the care-recipient's loss of confidence. In some instances, carers described deciding that they needed to take more responsibility and control following a fall. The care-recipients' accounts revealed an increasing reliance on the carers to prevent falls, with a handing over of responsibility to remind

them of potential hazards or protect them from harm. Carers talked about changing their own behaviours but sometimes the change in behaviour was described as more of a challenge, or as perhaps requiring too much of a mental load:

... And sometimes it's not that you haven't got the will; it's sometimes that you're not concentrating on what you're going to do, perhaps you know that you don't take in all the circumstances, but yes it has changed my behaviour. I have tried to be more solicitous when we're near kerbs. . . (Susan, wife-carer)

Carers voiced their concerns in different ways, especially about possible injury to the care-recipient as a result of the fall. Peter, a carer in one of the focus groups, talked about his distress after finding his wife Sarah (care-recipient) following one particular fall:

I heard a noise coming from my wife's room, a groaning sound, so I went in there and she was laying on the floor at the foot of the bed, face down, and I sort of moved her slightly to make sure she was still breathing and so as not to do further injury I phoned the ambulance service . . . And anyway they tested her and released her that same day. And I've come to the conclusion that the accident was caused by the bedcovers draping on to the floor by several feet. There was about a foot sort of laying on the floor. So she got her feet and went out that side of the bed, entangled her feet in the bedcovers, and fell. Though the moral of that is of course always tuck your bedcovers under the mattress to avoid that. (Peter, husband-carer)

It seemed that many carers, like Peter, learned what to do by trial and error, responding to upsetting or serious fall experiences. Carers described many strategies to prevent further falls, including advocating for more investigations for the care-recipients from their general practitioner (GP), using surveillance or control by locking doors, or by trying to eradicate home hazards such as rugs, stools or gas ovens. The dilemma of 24-hour monitoring to prevent falls from happening again was recounted by others:

... of course I have to watch him; sometimes he forgets where he's going. He doesn't know where the toilet is and I have to go and show him where it is. Well, he's better in the morning because he has the tablets you see. (Norma, wife-carer)

Maggie (daughter-carer) also advocated a monitoring approach in caring for her mother saying:

You have to be there for them as they don't know what the consequences could be. . .

Not all monitoring was intended to prevent falls. Norma locked the house doors to prevent Bob (care-recipient) from going out; not just to stop him from getting lost, but also to prevent him from knocking on their neighbours' doors. Such bodily surveillance and control could be said to prevent Bob from carrying out socially stigmatising behaviour.

Other carers found supervising and monitoring difficult to adjust to. Vicki perceived her father George (care-recipient) to have lost his confidence and independence overnight after a fall. George had been independent and actively contributing to family life. However, immediately after his fall he became very dependent upon Vicki and her husband for everyday tasks such as knowing what to wear and how he should dress. His sudden dependency and inability to make decisions changed their relationship dramatically, and also that with his grandchildren and his role within the family.

Susan had conflicting feelings about the changes that were occurring in her relationship with Tony (care-recipient) and she seemed undecided in what she needed to learn in this relatively new role from wife to carer:

It has just made me realise that I've got to keep an eye on him. I haven't got to the point where I don't feel he can go out on his own, because I don't think that would be right ... There's no way I am going to sort of mother him or smother him so he doesn't do anything. I mean I do a lot for him... (Susan, wife-carer)

Dealing with the impact of falls, trying to prevent them from happening again and coping with everyday life provided unwanted challenges for many carers. Patrick (carer) found himself increasingly caring physically for his wife, as Sheila's mobility declined after fractures to both her humerus and femur following two successive falls:

... walking and toileting is the bane of my life. I go to bed some days and I think to myself 'when is it going to end, do we see any end to it?' I mean when you think about the Alzheimer's to start with you think 'oh that's a piece of cake'. But it's the things that come along ... The consequential things that come along ... That you don't know about do you? ... Like bringing up kids, you don't get an apprenticeship. (Patrick, husband-carer)

Patrick's sense of hopelessness and isolation demonstrates the struggle that carers were undergoing on a daily basis, learning by often negative experiences in how to care for the care-recipient. These struggles related not only to the progression of the dementia but also in dealing with the consequences of falls. It would also seem that many carers, like Patrick, were increasingly attending to the body rather than the person they were caring for, either because of the care-recipient's physical injury or loss of confidence as a consequence of the falling. The monitoring and restriction of activity to prevent falls and subsequent injury is likely to have led to a loss of autonomy for the care-recipient, a change in the relationship between the dyad and also a subsequent change in role for the carers (and potential loss of identity) from wife, husband, son or daughter. In some accounts, these changes were represented as occurring suddenly, and in other accounts, quite insidiously.

Nobody was interested

Whereas the two preceding themes have considered the dyadic relationship between the care-recipient and their carer, and how they as couples or families responded to the falls experiences, this theme reveals the feelings of isolation, vulnerability, sense of responsibility and impact on the health and wellbeing of the carer, particularly associated with a fall by the carer or the care recipient.

The quote ‘nobody was interested’ is taken from Patrick’s (carer) narrative as he talked in one instance of feeling at the point of collapse. He later related how his own fall at home had resulted in admission to hospital with consequential surgical intervention. Sheila, his wife (and care-recipient) was cared for by their son and family until Patrick was discharged from hospital. Waking up during his first night home, he found his wife Sheila huddled on the floor and he recounted how he struggled to get her back into bed, even though he had been advised not to do anything too strenuous following his surgery. This feeling of coping alone and putting one’s own health second was echoed by another husband-carer, Harry, who had also been advised not to do any heavy lifting because of his own health condition. Even so, he recounted struggling to get Bridget, his wife and care-recipient, up from the floor after she fell during the night. The challenge of trying to deal with their own health issues whilst caring for their spouse after a fall and dealing with the expectations of health-care professionals that they should be able to cope is illustrated in another instance by Patrick (carer):

At no time was I as a carer addressed. They [acute care services] don’t care that I’ve got prostate cancer, which I have, or whether I’m asthmatic or whether I’m now half blind, they couldn’t care less about that. . .

Similar concerns were voiced by other carers. They described feeling that their GP and acute care services were unsupportive and had little understanding of their situation or had poor attitudes to people with dementia:

His doctor won’t suggest anything, because he thinks once you’ve got dementia you shouldn’t be alive, practically. He was busy telling my father when he was first diagnosed – ‘well you’re wasting your time taking these tablets’ . . . (Vicki, daughter-carer)

Karl’s desire to maintain his wife Eileen’s opportunities to go shopping (a favourite activity) and to run necessary errands made going out to the local shops a challenge. Karl (carer) recounted how Eileen (care-recipient) had fallen over crossing a road, also pulling him to the ground. As a result of Eileen’s deteriorating mobility, increase in falls and Karl’s own declining health and abilities, Karl described going to the GP for help. However, he

was dismayed that the GP refused to sign an application for a disabled parking permit. Karl felt he had little option but to buy a wheelchair for Eileen:

- Karl (carer): I mentioned to the doctor that I was going to buy one. He said don't buy one because she will, she will, uh. . .
- Eileen (care-recipient): . . .recover
- Karl: . . .it would be no good for her. Where if I didn't then it would be. . .
- Eileen: . . .stuck in the house all the time.

This lack of understanding of the couple's difficulties left Karl feeling powerless and unsupported in trying to maintain his wife's main social interaction and enjoyment whilst preventing falls and struggling to manage the daily routine. In this narrative one can also wonder what Karl *did not say*. A supposition of what was unsaid was perhaps the GP's concern for potential deterioration in Eileen's mobility if she used a wheelchair, versus Karl's concern about a potential reduction in their quality of life, Eileen's mental state and his ability to cope if they were both limited to the house. However, this can only be surmised.

Karl's (and others') resolution to avoid falls and their consequences was often framed as an attempt to prevent admission of the care-recipient to residential care. Even though Karl felt his own health and wellbeing being was at risk, he had a greater fear of long-term care for Eileen (care-recipient), as a result of witnessing the distress and deterioration of a family friend whilst in a nursing home.

In future even I think if we need home help then I don't want her [Eileen] to go to an old people home, you know. I never . . . I kept some cuttings from newspapers and I have a friend in one of these homes and when we used to go to visit her she was always knocked over . . . not because she was beaten, but fell down. (Karl, husband-carer)

Where support had been given by services, carers sometimes described negative experiences. Neil (son-carer) voiced his concerns about respite care:

. . .she [Rita] went in for a couple of weeks at XXXX and she had a fall, she come home one day and she was . . . well she came out . . . As I collected her from the vehicle and she couldn't hardly walk. She couldn't hardly stand, I should say . . . I said - 'You weren't like this when you were here'. I don't know, I weren't there I'm not criticising, but she went downhill. . .

As a result of the fall during respite care and her consequent lack in mobility, Neil felt that he could no longer trust others with the responsibility of his mother, Rita. He considered refusing respite care for his mother, but also voiced the dilemma that he needed relief from caring.

In other narratives, carers' own vulnerability to falls emerged. Carers related how they themselves had been pulled to the ground by their spouse as they fell. Carers also described their own falls, attributing these to getting older, feeling unsteady, being busy or distracted. In one focus group, wife-carers Christine, Diana and Kathryn talked about how they had fallen whilst out without their husbands, with Christine suggesting that her pre-occupation about her husband, amongst other demands, led to her fall.

It could be suggested that the mental load and feelings of responsibility for the care-recipient, even when they were not physically present, made these carers themselves more vulnerable to falls, with consequential feelings of frailty.

Where support was given or requested from service providers, carers often felt let down, ignored or left with a sense of mistrust, thus increasing their potential sense of isolation. The impact of falls and their prevention on the health and wellbeing of the carer and also the interdependence of the health and wellbeing of both members of the dyad did not seem to be fully understood or acknowledged by those around them. This seems particularly pertinent for Karl, Harry and Patrick; all older spouse-carers with their own health conditions and activity limitations. Indeed one could also argue that the carers themselves (*e.g.* Neil and Christine) either ignored or placed their own health and wellbeing needs second to those they were caring for.

Discussion

The findings presented here have demonstrated the complexity of the caring relationship for these dyads. The experiences of falling were recounted as turning points in relationships, causing greater physical and emotional reliance on the carer by the care-recipient. Although cognitive impairment and dementia are considered as high risk factors for falls (American Geriatric Society and British Geriatric Society 2009), these findings also indicate that falling has a detrimental effect on the health, wellbeing and personhood of these participants, which Kitwood (1997) suggests influences the manifestation of dementia. In this study, the care-recipients experienced loss of self-efficacy and confidence following their fall and in turn a loss of autonomy. In one instance the relinquishing of independence was through the volition of the care-recipient (George to daughter Vicki), but in other instances independence in everyday activity and participation was lost as a result of physical trauma or curtailment by the carer through fear of further falls. All of these issues are likely to contribute to reduction in health, wellbeing and personhood. These findings resonate with studies of cognitively normal older people where a sense of self and

identity, quality of life, lifestyle and health status were all affected by falls (Kingston 2000; Roe *et al.* 2009). Even though much of the responsibility for the management of falls seemed to be shouldered by the carers in this study to maintain the care-recipients' quality of life, it could be said that the carers' reaction to the fall and their attempt to manage the consequences through bodily surveillance and curtailment in activity also impacted upon the self and identity (personhood) of the care-recipient (a process also noted by Horton and Arber 2004).

The impact of falls on the carers' health, wellbeing and personhood is also present in the findings. Most of the carers were dealing with the consequences of the care-recipients' falls by providing help with self-care tasks, indoor and outdoor mobility. Skaff and Pearlin (1992) suggest that carers are more vulnerable to their own loss of self and identity when immersed in self-care tasks of the care-recipient rather than engaging in treasured occupations and social contacts. It is also worth noting that some of the older spouse-carers discussed their own health conditions and mobility problems, with one carer identifying that the fear of his wife entering residential care meant that he would continue to care for her even at the expense of his own health. These findings, when combined with evidence from Ross *et al.* (2008) where older spouse-carers tend to spend more time on caring than other groups and are seen to have a heavier burden of care, indicate that the health and wellbeing of these older spouse-carers are at risk. Younger carers did not seem to experience the same negative aspects of caring, apart from one son-carer who was solely providing 24-hour care for his mother. This may have been because the person they cared for had less severe dementia at the time of data collection, or had more family and social support or sharing of care.

Interestingly, spouse-carers also discussed their own falls with various negative consequences, ranging from hospital admission to feelings of being old and vulnerable. One carer's attribution of their own fall to always thinking of the care-recipient highlights the psychological impact of caring on health and wellbeing, whether the care-recipient is physically present or not. The impact of carer burden or lack of support on the mental and physical health of carers is well recognised (Alzheimer's Society 2011; Farran *et al.* 2008) but the association between carer health, wellbeing and falls has not been fully considered. Role engulfment as a result of a necessary commitment to the self-care needs of the care-recipient following their falls, and also the loss of self-esteem and efficacy as a result of their own falls, all indicate a potential loss of self or personhood of the carers in this study (Skaff and Pearlin 1992).

The findings also demonstrate the readjustments made to the relationships of the dyads in response to falls alongside the difficulties faced because

of dementia. Re-orientation of relationships, change in roles and challenges to couplehood by extrinsic circumstances are all demonstrated (Hellström, Nolan and Lundh 2005). Surveillance and monitoring of the care-recipient by carers occurred not only to minimise the physical risk and consequences of falling, but also to prevent them from getting lost when out in the community. One could suggest that the carer was not only attempting to avoid the consequential injury, and its accompanying emotional and psychological distress, but also to avoid the stigmatising societal response to 'wandering' individuals. Bartlett and O'Connor (2010) and Brijnath and Manderson (2008) suggest that bodily surveillance of the care-recipient by carers resonates with Foucauldian theories of power tensions between the carer, the care-recipient and society. In most circumstances these care-recipients complied and accepted the control of others, but in other instances the carers' power and control were challenged by the care-recipients either leaving the house and knocking indiscriminately on neighbours' doors or walking alone at their own pace. Such power struggles could be said to impact on both the relationship between the dyad and also the personhood of the care-recipient (Bartlett and O'Connor 2010; Kitwood 1997). The activity of caring for the care-recipient also impacted upon the roles and identities of study participants. Most carers endeavoured to maintain their previous relationship within the dyad, whilst also struggling to fulfil their role of carer; often learning by negative experience. Whereas daughter-carers described taking a more facilitative approach to their parents with mild dementia, the two son-carers revealed a monitoring and controlling approach to prevent falls and keep their mothers safe, creating a reversal in the parent-child relationship; similarly to the study by Horton and Arber (2004). In these instances the mothers had moderate/severe dementia at the time of the interviews and perhaps were less aware of potential risks or their own needs.

Even though the differences in the caring experience in relation to the severity of the dementia cannot be deduced from the available data, it is interesting to note that carers, whose care-recipient had mild dementia at the time of the interview, described trying to adjust to their new role of carer. It could be argued that their own sense of self and identity were being threatened and the role of carer enforced by both the fall and the progression of the dementia symptoms (Karner and Bobbitt-Zeher 2005). O'Shaughnessy, Lee and Lintern (2010) suggest that carers' own needs and identity become overwhelmed by having to take sole responsibility in the relationship and 'working alone' (Keady and Nolan 2003). It is potentially in Patrick's story of his unmet needs as a carer that we can perhaps see this transformation of identity and the 'working alone' in the spousal relationship. However, this was not a constant element in all the

relationships. In many instances, there was evidence of working together, and intimacy, for example where the couple shared the experience and enjoyment of social activity and post-fall exercises.

The delight in doing things together was voiced by many of the care-recipients with even the carrying out of everyday activities together being of psychological importance. The joint telling of experiences in this study are also examples of the dyads working together to support the competencies of the care-recipient (Perry and O'Connor 2002). Hellström, Nolan and Lundh (2007: 395) describe older dyads as making the best of 'life's little pleasures' to maintain past relationships and ensure mutual enjoyment. Going out, especially to the shops, seemed to be of particular importance to the spousal dyads; indeed this was possibly the only joint social interaction with others that the couples had. Not only is it considered that joint activity encourages reciprocity and interdependence in dyads, which Vikström *et al.* (2008) suggest sustains the care-recipient's personhood, but enables the carer to also maintain their sense of identity as spouse, son or daughter (Perry and O'Connor 2002). However, threats to personhood of the dyad, especially (but not exclusively) for older spouse-carers, were also articulated where service providers ignored or did not comprehend the needs of both individuals to manage and prevent falls and maintain valued activities.

In terms of critical evaluation, in line with other IPA studies, this study does not profess to make generalisations to larger populations. However, the themes revealed in this study not only resonate and support other research, but also present new findings. The study has not only used individual and joint interviews, but also focus groups with older people experiencing memory problems and dementia, and carers. The use of joint interviews allowed for the co-construction of experiences, and provided opportunity for the sharing of accounts by the dyads; sometimes for the first time since falling. The use of focus groups in IPA is currently debated as there is a concern that there is more limited opportunity to gather idiographic data from group interviews with less sharing of personal experiences and more socially desirable responses (Smith, Flowers and Larkin 2009). However the use of a naturally occurring and already established group as participants in this study facilitated the sharing of personal experiences, as suggested by Tomkins and Eatough (2010). Their involvement as 'equals' in the focus groups meant that carers talked about their own falls as well as those of the care recipient. This resulted in the authors revisiting the interview data to explore the dynamic of the carer's health in the dyadic relationship. As the impact of falling on the carers' health, wellbeing and personhood was not fully appreciated at the beginning of this study, certain demographic data such as age of carer, ethnicity and socio-economic group were not collected. The age of the carers (and all focus group participants) can only be surmised

by the researcher's observations at interview and also in relation to the age of the care-recipient. Therefore the relationship between some of these factors and the qualitative accounts cannot be fully explored.

Overall there are many similarities with the findings of this study to both the literature on falls in cognitively normal older people and also to the dementia literature. However, this is one of few studies that have considered the impact of falls on people experiencing dementia, their carers and most especially, the couples' relationships. Falling seems to often precipitate and threaten the personhood of the care-recipient, impacting on the dyadic relationship and potentially the personhood of the carer and their capacity to care. Whereas the progression of dementia already threatens the personhood or couplehood of the dyad, it can be seen here that a fall can often accelerate or accentuate this threat, with the carer working alone (often by trial and error) to control or prevent falls of the care-recipient (and their own), rather than working together to preserve couplehood (Hellström, Nolan and Lundh 2005). These findings reinforce current policies that the needs of both people with dementia and their carers should be recognised and supported to maintain their health, wellbeing and personhood, both as individuals and more importantly as couples to address the challenges of falls and dementia.

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