

## Exploring caregiving experiences: caregiver coping and making sense of illness<sup>1</sup>

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**Objectives:** The current research explores how family caregivers (1) make sense of caregiving and (2) cope with their circumstance.

**Method:** We analysed semistructured interviews of 13 caregivers of people with either stroke ( $n = 5$ ) or dementia ( $n = 8$ ) and used photographs that caregivers took exemplifying their caregiving experiences to elicit their description of how they made sense of caregiving. This enabled greater insight into caregivers' perspective of caregiving complementing our use of Interpretative Phenomenological Analysis (IPA) to analyse verbatim transcripts.

**Results:** Emerging themes included (1) *making sense of illness* including the implications of receiving a diagnosis, caregiving motivations and receiving support, and (2) *coping with caregiving*, with variance in coping depending on, in part, individual differences in sense making. Caregivers adopted active and information seeking techniques to deal with current problems and to increase their sense of control, but avoidant techniques when considering future logistics of caregiving and when feeling helpless due to the burden they faced. At times caregivers looked on the bright side and made downward comparisons.

**Conclusion:** The combination of elicitation techniques and analysis using IPA established patterns across caregivers and individual differences between caregivers in the meaning they assigned to their caregiving experience. Differences in sense making were based on the context of the caregiving stressor, which in turn influenced the variability in caregiver's coping techniques adopted. The analysis detailed within this article provides evidence that information and service provision must be tailored to individual caregiver experiences.

**Keywords:** ageing; Alzheimer's disease; dementia; stroke; caregiving

### Introduction

Two million people in the United Kingdom become informal caregivers every year (Carers UK, 2010). Adult onset brain disorders, such as stroke or Alzheimer's disease (AD), affect a large proportion of the ageing population with family caregivers most likely to provide support for those affected. In the United Kingdom, there are 150,000 newly diagnosed stroke victims each year (The Stroke Association, 2011), while 200,000 people are diagnosed with a form of dementia in the United Kingdom each year (Banjeree et al., 2013). Although the characteristics of stroke and dementia are different (i.e., acute versus progressive onsets), both impede sufferers' cognitive, physical and behavioural functioning. Many caregivers self-report depleted physical and mental health as a consequence of caregiving for adults with such conditions (Draper & Brocklehurst, 2007; Pinquart & Sorensen, 2003; Samuelsson, Annerstedt, Elmstahl, Samuelsson, & Grafstrom, 2001; Sanders, Ott, Kelber, & Noonan, 2008; Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlan, 2003).

Theoretical perspectives suggest that not all family caregivers experience caregiving in the same way (Stanton, Revenson, & Tennen, 2007). The transactional stress model proposes that some individuals experience stress in a positive light and gain strength from challenges (*eustress*),

while others perceive more negative consequences of stress (*distress*) (Lazarus & Folkman, 1984). In conjunction with the evolution of positive coping theory, researchers propose that caregivers are able to experience both positive and negative emotions simultaneously (Kramer, 1997a, 1997b; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Pinquart & Sorensen, 2004; Rapp & Chao, 2000). Caregivers' reappraisal of negative consequences into more positive consequences and their attentiveness to positive experiences help them endure their role (Folkman, 1997; Folkman & Tedlie-Moskowitz, 2000b).

Quantitative methodology – largely adopted among caregiving research – fails to consider the quality and significance of individual differences in stress perceptions, coping and outcomes of caregiving experiences. We use Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) as a qualitative analysis method. By very definition, IPA enables interpretation of the phenomenon of individual caregiving. IPA facilitates a deeper understanding of experiences and how individuals make sense of their circumstance. Its idiographic nature produces in-depth material open to both within and between subject comparisons.

We also use photograph elicitation based on photovoice (Wang & Burris, 1994, 1997; Wang, Yi, Tao, & Carovano,

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1998). Participants' photographs of their experiences act as elicitation aids when discussing their circumstances. In accordance with a major premise of IPA, the presence of photographs allows individuals to become more reflective and cognizant of their feelings and the meaning they attach to experiences (Wang & Burris, 1997). The freedom of choice given to participants concerning which image to capture and which photograph to discuss in the interview instils a sense of confidence, mastery and permits the caregiver to become the expert of their experience (Wang & Burris, 1997, p. 372). These benefits have the potential to encourage participant disclosure and positive rapports between the interviewer and interviewee.

Photovoice was initially developed to address problems within society at both community and policy level (Wang & Burris, 1997). Previous research used photograph elicitation to document quality of life of hospital patients (Radley & Taylor, 2003), breast cancer survivors (Lopez, Eng, Randall-David, & Robinson, 2005) and homeless women (Bukowski & Buetow, 2011). Photographs alone are unlikely to reveal the full extent of meaning; however, participants' narratives of photographs facilitate greater depth of insight into an individual's experience (Radley & Taylor, 2003). In previous research techniques used to analyse participants' photovoice, narratives include thematic analysis (Radley & Taylor, 2003), content analysis (Bukowski & Buetow, 2011) and grounded theory (Lopez et al., 2005). Aubeeluck and Buchanan (2006) used content analysis to evaluate the written narratives of photograph choices by Huntington's disease family caregivers. Although the results were novel, the quantitative nature of content analysis failed to captivate a profound understanding of the meaning caregivers assign to their experiences.

To our knowledge, photographs have not been used as elicitation for interviews, which are analysed using IPA. Consequently, we present findings based on caregivers' in-depth accounts of their experiences and the meanings they assign to them aided with the use of photograph elicitation and analysed using IPA. The first theme called 'making sense of illness' details how caregivers sampled within this research article made sense of their role and their recipient's illness. The second theme labelled 'coping with caregiving' delineates caregivers' ability to deal with caregiving demands. Two remaining themes, which focus on negative and positive caregiving outcomes, are presented elsewhere (Williams, Morrison, & Robinson, 2013).

The authors' existing understanding of caregiving stress remains within the socio-cognitive domain where stress and illness appraisal influence coping and stress outcomes. Thus socio-cognitive terminology is applied when assigning labels to themes.

## Method

### Participants

Family caregivers ( $n = 78$ ) completing time one of a longitudinal survey (Williams, Morrison, & Robinson, 2011)

were asked to record their contact details if they wished to participate in future caregiving research. Fourteen participants who met the criteria of adult caregivers providing care for persons identified as having a primary diagnosis of either stroke or dementia gave their consent but data from 13 caregivers are included here because of the subsequent non-availability of one potential participant.

Participants were family members ( $n = 12$ ) including wives ( $n = 5$ ), daughters ( $n = 7$ ) and a friend ( $n = 1$ ), providing care for persons having a primary diagnosis of either stroke ( $n = 5$ ) or dementia (including AD;  $n = 8$ ). Information about patient diagnosis was provided by the caregiver rather than from a clinician; therefore, while the recipient may have had co-morbidities, caregivers were asked to provide the primary illness their recipient had been diagnosed with. There was one male caregiver. Eight caregivers lived with their recipient and five caregivers lived separately. Caregiving duration ranged from 6 months to 10 years with the majority of participants caregiving full time. Caregivers' age ranged from 33 to 73 years and recipients' age ranged from 54 to 95 years.

### Design

We adopted a cross-sectional qualitative design conducting semi-structured interviews and using photograph elicitation.

### Procedure

#### Photograph elicitation

A month before being interviewed, consenting caregivers were sent standard disposable cameras and asked to take a minimum of three photographs depicting significant caregiving experiences. Caregivers were instructed to write details of the image on a description sheet, which they could refer to during the interview. Caregivers were given approximately two weeks to take photographs but in difficult circumstances a longer length of time was allowed. Caregivers were contacted after one week to provide guidance on the procedure if required. Once the cameras were returned, photographs were developed and a date for the interview was arranged. The photographs were not used as data for analysis within our article *per se*, but as stimuli for the interview discussion.

#### Interview procedure

We received the appropriate ethical approval from the University's School of Psychology ethical and research governance committee. Participants' written informed consent forms were obtained before commencing the interview. Caregivers picked out three to five photographs they wished to discuss during the interview. For one participant who had trouble gaining recipient consent and for another two participants where photographs failed to develop, a small number of photographs were available; in one case, no photographs were developed. In cases where there were fewer photographs than required,

caregivers were asked to contemplate caregiving experiences they most wanted to discuss. The interview question order was not predetermined and depended on the degree of participant disclosure (see the Appendix for the schedule). Interviews were audio-taped, and to prevent the possibility of losing data if this equipment failed they were also video-taped. Exceptions included one caregiver who did not feel comfortable being video-taped and another who had insufficient space to fit the video-recording equipment in their living room. Interview length ranged from 35 to 100 minutes ( $M = 55$ ).

### Analysis

Interviews were transcribed verbatim. The researcher (K.L. Williams) followed analytical steps recommended by Smith et al. (2009) concerning larger sample sizes (i.e., greater than  $n = 8$ ). As a result, analysis took place at group level, whereby recurrent themes, i.e., themes present in 50% or more of the transcripts were included into the analysis. Themes that were interrelated were integrated to form major themes. Themes and subthemes were compared with original transcripts during the analysis and the write-up process to ensure validity. The whole process was reviewed by the lead supervisor (V. Morrison) as an audit of quality, validity and transparency as recommended by Smith et al. (2009, p. 184).

### Results

Within this section, we provide a brief description of the typical photographs caregivers chose to discuss during their interviews followed by the results from analysing caregiving interviews using IPA. The first theme from this analysis is (1) *making sense of illness* followed by (2) *coping with caregiving*.

#### Photograph choice

Some photographs contained recipients to represent caregiver burden, love and reasons for caregiving or to signify recipient's deterioration. Caregivers often chose photographs of objects, which symbolised the strains they were experiencing at the time of the interview and their inability to escape from caregiving, including for example, toilets to show how many times a day they had to clean their bathroom. Photographs of objects showing caregivers' ability to escape from caregiving, such as cars, pets, gardens or walking boots, were often popular choices (see Figure 1 for some examples of the photographs taken).

#### Making sense of illness

##### *Understanding the diagnosis*

For caregivers of people with dementia receiving a diagnosis brought about a sense of confirmation and relief. Caregivers expected to receive some form of support: 'I knew there was something wrong with him and just to

have been told that there is something wrong with him, and you're going to get loads of help, er, it was brilliant' (Aged 65, caregiving for her husband, diagnosed with AD).

A diagnosis does not inevitably resolve confusion. One caregiver, whose husband was diagnosed with fronto-temporal dementia (FTD), was uncertain daily of how he would react 'It's knowing how he's feeling... and whether that might change... I can't work out when I leave the house, even if I leave him happy, whether he's gonna be happy the whole time' (Aged 33, caregiving for her husband, diagnosed with FTD).

Many caregivers were reluctant to accept that the recipients' symptoms were caused by their illness. Caregivers would blame symptoms on conditions such as arthritis, the natural ageing process, or aspects of the recipient's pre-morbid personality 'some of his traits I've found it hard to wonder, like, is that his personality or is that his illness' (Aged 33, caregiving for her husband, diagnosed with FTD).

Perhaps there is a reluctance to attribute recipients' symptoms to a specific illness, because particularly for caregivers of stroke victims, the illness onset is a shock, 'No not what I expected caregiving to be and it's not the way I expected to end my life' (Aged 73, caregiving for her husband, a stroke patient). The caregiver whose husband was diagnosed with FTD was quite young and reported the unexpectedness of the disease onset 'I couldn't possibly of thought that this would happen, obviously with it being an older person's disease normally' (Aged 33, caregiving for her husband, diagnosed with FTD).

#### *Making sense of motivation to care*

Some caregivers believed their pre-morbid caregiver-recipient relationship defined willingness and ability to care. One participant caregiving for her mother diagnosed with AD reported a good pre-morbid relationship and her love and desire to provide the best possible care was so strong that she was content with relinquishing her job to do so, 'I didn't hesitate finishing work to look after her. It's something that I want to do and I'm quite happy doing it' (Aged 48, caregiving for her mother, diagnosed with AD).

A number of caregivers confessed that their caregiving motivations were less selfless. The gradual loss to other aspects of their life through providing care meant that caregivers were dependent on their role, providing purpose in life, 'That's why I'm, er, wanting him [her husband] alive for – me – really aren't I?... to have somebody to go and see'. (Aged 65, caregiving for her husband, diagnosed with AD).

Caregivers reported providing support because they felt bound to their role, they had promised to provide care or there was lack of alternative support. Lack of choice and feeling dissatisfied with life left one caregiver resenting her position, 'There's times I look at him and I feel extremely sorry for myself and I think my life's ended really... I don't feel fulfilled and rewarding... I



Figure 1. Examples of photographs taken by caregivers.

feel resentful'. (Aged 62, caregiving for her husband, a stroke patient).

There was a sense of obligation to provide care. One caregiver's mother behaved in an aggressive and unappreciative manner. This led her to resent providing any support other than the bare essentials: 'I, I'll try to be good to my mother but I will not try to please her beyond a certain point' (Aged 47, caregiving for her mother, diagnosed with dementia).

Conscience and moral reasoning might have prevented caregivers who felt tied and resentful from desiring

a permanent end to caregiving (i.e., their recipient's end of life or entry into a care home).

I look and think, is he breathing, and then I see he is, and then I feel relief.. .You feel like relief that he is breathing then another feeling, it's another day. . . I feel guilty for thinking, you know, this is the end. (Aged 62, caregiving for her husband, a stroke patient)

Another caregiver voiced concerns and guilt for her mother's safety, 'I'd be devastated if anything happened

to her' (Aged 57, caregiving for her mother, a stroke patient).

In terms of the future, caregivers expected more demands. They perceived caregiving would become more difficult requiring more time and energy, causing them to further neglect their own needs and family. They were uncertain of their recipient's deterioration trajectory and what effect this would have, i.e., how, where and when. One caregiver had many unanswered questions: 'I still got those same questions in my head, like how long will it be till blah happens? ... I still don't know really, what, how it affects the mortality side of life' (Aged 33, caregiving for her husband, diagnosed with FTD).

Caregiver health status influenced perceived ability to continue caregiving into the future. As long as they were physically able, caregivers would continue caregiving but worried about managing increased physical demands if their recipient deteriorated, 'unless I can improve my health. ... I need a hip operation so that will probably happen one day. But I need to lose weight really for my sake and his [recipient's]' (Aged 33, caregiving for her husband, diagnosed with FTD).

#### *Reflecting on received support*

Some caregivers felt able to continue as long as they received support from family. One caregiver felt her husband's ability to bring humour into a situation alleviated tension caused by the extent of her mother's (recipient) decline and the consequential demands this elicited, 'He's [husband] my, my star, because he will, he'll support her, he'll help her in the wheel chair, he'll help her get in and out the car, he'll joke with her, he'll make. I can't do that' (Aged 58, caregiving for her mother, diagnosed with AD).

Caregivers desired their recipient to express some form of support, gratitude or contribution to reassure them that their role was worthwhile. Caregivers felt more motivated if the support they provided was in some way reciprocated or acknowledged highlighting that caregivers require their needs also to be fulfilled. This brings into sharp focus the challenge of maintaining motivation when providing care to a recipient whose behavioural and verbal reciprocation is limited or even impossible 'he [caregiver's husband/recipient] does encourage me to, to, to do some, some of my own things you know' (This participant did not provide details of her age, caregiving for her husband, a stroke patient).

Where step-families were involved, the situation became complex. One caregiver imagined a hierarchy of idealised support based on her beliefs of family duty. Although in desperate need of support, she forfeited help from her own family because she felt embarrassed that her husband's children were not willing to offer support, 'I don't see my kids anymore because I won't have them come here to look after things for him, for my husband because I feel his kids must come and look after him' (Aged 73, caregiving for her husband, a stroke patient).

Caregivers were generally dissatisfied with the support received from formal services and reported feeling

neglected. Many caregivers provided continual care to their recipient almost single-handedly. Although they developed expert knowledge and skills, many struggled to receive acknowledgement by formal services:

I've mentioned it [her mother's swollen leg] to the nurses several times, I've said 'look this legs getting worse what can we do?' 'Oh there's not a lot we can do about that' [Nurse replies]. Nobody seems to care about it you know and I'm worried sick. (Aged 57, caregiving for her mother, a stroke patient)

One participant described the shock and initial demand of becoming a caregiver, 'You're just left at the deep end' and 'you're just left swimming basically' (Aged 62, caregiving for her husband, a stroke patient). The word *left* in these phrases is a likely metaphor highlighting she felt abandoned by support services. The support she received while her husband was in hospital was no longer available to her after discharge, yet this was when she needed it most.

#### *Making sense of illness summary*

A diagnosis confirming caregivers' suspicions of their recipient's illness elicited relief. When the diagnosis, illness onset or deterioration was out of line with expectations, a sense of helplessness could be witnessed. Premorbid caregiver-recipient relationships contributed to willingness and perceived ability to care. Some caregivers felt bound to their duties out of obligation. Many felt that as long as they were physically able to deal with caregiving demands, they would continue. Some caregivers appreciated support, others felt neglected, and for some a frustration arose from not having a voice, in spite of feeling like the expert.

#### *Coping with caregiving*

There was a tendency for caregivers to look on the bright side when they felt unable to change the negative impact of their recipient's illness. Although saddened by her husband's loss of physical strength, one caregiver considered herself lucky because he had retained his personality. Optimism permeated throughout this participant's caregiving career and was a strategy she adopted in life, in general, 'He's [husband/recipient] still got the same sense of humour and things like that. ... from that point of view I'm very lucky' (This participant did not provide details of her age, caregiving for her husband, a stroke patient).

Caregivers made downward comparisons with other caregivers they believed were in a worse situation. Considering their own situation as more fortunate and their own coping resources as more efficient seemed to enhance well-being and also an appraisal that their coping efforts were successful:

I bet there's lots of carers who never find out about half of that because they don't have the same, their brain doesn't



work in the same whatever... they just don't go out thinking about chasing whatever, and all those things do contribute to managing reasonably well. (Aged 47, caregiving for her mother, diagnosed with dementia)

Humour was adopted by caregivers when they felt helpless. One caregiver recalled an incident in church where her husband lost his set of teeth, distracting the priest's sermon. Seeing the funny side helped her to accept and adapt to his deterioration:

The poor, err, chaplain, he couldn't do his service because he [husband / recipient] took them [false teeth] in and out, in and out, all the whole time (laughs)... He [chaplain] got mesmerised by them... He [chaplain] just went blank in the sermon (laughs). (Aged 65, caregiving for her husband, diagnosed with AD)

Acceptance was adopted when caregivers realised they could not do anything to improve the situation but wanted to move on rather than dwell on losses. For many caregivers of people with dementia an increased sense of illness identity, through receiving a diagnosis, facilitated their ability to come to terms with the illness and find solutions to difficulties they were experiencing, 'So having the diagnosis sort of was like a confirmation and although tinged with, with sadness it was like a right this is what this now means, get on with it, you know' (Aged 33, caregiving for her husband, diagnosed with FTD).

In situations where the recipient's losses were irreversible, acceptance encouraged caregivers to adopt innovative coping techniques, such as changing their own behaviour to improve a situation rather than trying to change their recipient's conduct, 'No I just have to modify my behaviour to account for whatever crops up in life' (Aged 33, caregiving for her husband, diagnosed with FTD).

Caregivers seemed to gain comfort from normalising problems associated with their recipient's illness as being universal to other caregivers. This reassured participants that they were not in isolation and reduced the sense of threat caregiving imposed, 'he [her husband] was fairly aggressive in the beginning which I believe is quite normal' (Aged 62, caregiving for her husband, a stroke patient).

Caregivers used planning, organising and seeking information to increase their sense of control over circumstances they felt powerless to change, 'then I come up with a plan and I think "right ok next time"'. When caregivers felt overwhelmed with multiple demands, prioritising and planning ahead gave them a sense of control and more spare time: 'If he forgets to wash his hair, doesn't really matter' (Aged 33, caregiving for her husband, diagnosed with FTD).

A few caregivers reported adopting avoidant coping behaviours particularly when feeling helpless at improving their recipient's or their own quality of life or when they lacked control over their recipient's deterioration. For caregivers who considered their pre-morbid

caregiver-recipient relationships to be poor, avoidance tactics were appraised as adaptive when feeling overwhelmed with responsibility:

If I'd had a hard day with her or something like, or something had gone on, the next day I almost just wanted to hibernate and not be part of the world... I do what I have to do in a way and, and I try and avoid too much of the emotional side of it. I just find that too hard to cope with. (Aged 68, caregiving for her mother, diagnosed with AD)

Caregivers did not want to face the loss of their recipient's dignity, but still wanted to protect themselves or their recipient from embarrassment and humiliation. These caregivers would either camouflage their recipient when out in public so that no one could recognise them, or they stopped attending public places and events:

I don't want to be seen to be struggling with my husband. I don't want my husband to be seen to be being so incapacitated publically. It's one thing in the family or with close friends but it's quite another publically with people that you don't know. (Aged 73, caregiving for her husband, a stroke patient)

One caregiver, who adopted planning as a general proactive coping strategy, in some situations found that she did not want to do so. This caregiver was concerned her husband would become lost or lose his house keys if he went out but as she had no control over this she would avoid thinking about it 'he didn't have his keys and so he could get lost and as much as that seems every day, I think oh that's not gonna happen or that's not gonna happen' (Aged 33, caregiving for her husband, diagnosed with FTD). This highlights her desire to avoid reality to protect her own emotions and is in accordance with findings from proactive coping research where individuals avoid thinking about possible negative events before they occur as a coping strategy and instead focus on the positives of their circumstances or of stressors they are able to overcome (Greenglass & Fiksenbaum, 2009).

Caregivers would try and take control of unavoidable and overwhelming caregiving demands by mentally or physically removing themselves from that burden. By imagining or planning what they would do when they had time-off, caregivers were able to escape the reality of their situation:

...brilliant to think well you know in three weeks time I'm going to be able to, you know, do such a thing. So now I book things... Go and see my friends or go to [place named]... see my daughter.... (This participant did not provide details of her age, caregiving for her husband, diagnosed with stroke)

### *Coping summary*

Acceptance allowed caregivers to take proactive approaches in dealing with their caregiving demands. Avoidance was a popular technique when the caregiver

felt less in control of their circumstance. Caregivers reported using specific coping techniques across different contexts; however, most did not rely solely on these preferred techniques and were able to alter their coping response according to the context. The possible range of coping strategies a caregiver uses reflects the dynamic and contextual nature of appraisals and coping. Individual differences in coping are dependent on variability in sense making.

## Discussion

Caregivers' reports of uncertainty about the illness trajectory and their future role inspired active information seeking and avoidance coping. This raises the enquiry of whether 'knowledge is power' (Hill, Higgins, Dempster, & McCarthy, 2009) or 'ignorance is bliss'. In their IPA study, Hill et al. (2009) found the search for knowledge facilitated a sense of mastery in circumstances where fathers had little control over their child's leukaemia. Within our research, particularly for caregivers with no prior experience or knowledge of the condition, the sudden onset and in some cases novelty and unpredictable nature of stroke meant caregivers faced an uncertain role and a heightened sense of threat or loss. When confronted with an uncertain illness trajectory, a number of caregivers sought knowledge as a way of re-gaining control. For caregivers of people with dementia, knowledge of the recipient's diagnosis provided relief and control because it confirmed long-term suspicions thus reducing uncertainty.

Hunt and Smith (2004) found uncertainty as a recurrent theme throughout the initial stages of caregiving for stroke victims. Similar to that reported here, caregivers attributed the shock they experienced to the unexpected nature of stroke onset and their lack of understanding of how their recipient would deteriorate. They were uncertain of their future caregiving role and ability to cope with expected heightened demands. While all caregivers within Hunt and Smith's (2004) study desired knowledge as a way of overcoming uncertainties, some caregivers within the current study refrained from seeking information as an avoidant way of coping. Ignorance was bliss. Uncertainty proved favourable when considering future implications. When it is perceived nothing can be done to alter fate, avoidance or emotion-based coping is commonly used (Carver, Scheier, & Weintraub, 1989; Schroevers, Kraaij, & Garnefski, 2007; Tennen, Affleck, Armeli, & Carney, 2000). In a previous IPA study, dementia family caregivers avoided dealing with the future to avoid the anxiety that accompanied being faced with a deteriorating illness (Quinn, Clare, Pearce, & van Dijkhuizen, 2008). Conforming to the transactional stress model, (Lazarus, 1999; Lazarus & Folkman, 1984) caregivers purposefully manipulated their levels of knowledge to avoid facing stressful circumstances likely to evoke negative emotions. Similar avoidant coping behaviours have been found when researching the impact of chronic conditions on patients, family and caregivers who have a strong understanding of the illness and rate

of deterioration (Carlisle, John, Fife-Schaw, & Lloyd, 2005; Hagger & Orbell, 2003; Leventhal, Leventhal, & Cameron, 2001; Moss-Morris et al., 2002; Roberts & Connell, 2000; Roesch & Weiner, 2001; Smith, Haynes, Lazarus, & Pope, 1993; Weinman, Petrie, Sharpe, & Walker, 2000).

Caregivers within our study were motivated to care when the support they were providing was in some way appreciated or reciprocated by their recipient. Research has found that if a recipient's speech and cognitive abilities are maintained, family caregivers experience less strain (Draper & Brocklehurst, 2007; Forsberg-Warley, Moller, & Bloomstrand, 2001). It is possible that within our study, maintained communication improved relationship quality and caregivers' ability to perceive the positives of their role because recipients were able to voice appreciation.

Motivation to care was conditional upon caregiver's self-efficacy and physical ability. A previous study of 57 family caregivers of AD patients found caregivers with greater self-efficacy perceived their role more optimistically than caregivers with lower self-efficacy (Semiatin & O'Connor, 2012).

Caregivers within our study would often describe the lack of choice over providing care due to moral reasoning, conscience or guilt. Consistent with previous research, anticipation of feeling guilty if their recipient came to harm, prevented caregivers from sending their relative into formal care provision (Hunt & Smith, 2004; Samuelsson et al., 2001; Sanders et al., 2008). Previous research sampling informal caregivers to older adults reported that factors which encourage caregivers to provide care but which the caregiver has a lack of control over, such as cultural expectations (e.g., Parveen, Morrison, & Robinson, 2011) or guilt (Schulz et al., 2012) can reduce caregiver psychological and mental well-being.

Looking on the bright side and using humour were popular strategies adopted by caregivers within our research. These techniques encouraged caregiving motivation. Early research neglected the concept of positive coping. When faced with irreversible adversity, caregivers adopt a meaning-focused approach to endure their stressor (Folkman, 1997, 2010; Folkman & Tedlie-Moskowitz, 2000a).

Caregiver reports of coping could have been influenced by the level of burden they were experiencing. In previous research, caregivers who reported experiencing high levels of burden reported adopting passive coping techniques such as avoidance, while caregivers who adopted more active coping such as problem solving reported being less burdened by caregiving (Bruvik, Ulstein, Ranhoff, & Engedal, 2013). Bruvik et al. (2013) found that recipients diagnosed with dementia who exhibited more behavioural disturbances contributed to greater perceived caregiver burden than caregivers whose recipients diagnosed with dementia displayed more cognitive decline. This suggests dementias, where there is greater behavioural decline, increase caregiver reports of burden; and therefore, avoidance coping than caregivers to recipients with more cognitive declining symptoms of dementia

or recipients diagnosed with physical illness (Etters, Goodall, & Harrison, 2008; Pinquart & Sorensen, 2004).

Our findings support social cognitive theory. Caregivers used a variety of coping techniques depending on appraisals of the circumstance. Meaning making and in some cases active avoidance assisted caregivers to notice the positive elements of their role, and gain a sense of control, hope, mastery and self-esteem. This implies that perceiving benefits is an adaptive and conscious effort based on the dynamic nature of making sense of threat, coping and reappraisal.

### **Strengths and limitations**

The fact that family caregivers were considered the expert of their experience potentially encouraged greater honesty during disclosure in addition to developing a greater positive rapport between the interviewer and interviewee. This latter point is particularly advantageous for IPA where a double hermeneutic involves the researcher interpreting the participant's interpretation; and therefore, requires openness and honesty on the participant's behalf (Smith et al., 2009).

It is unlikely that such findings would have been achieved through quantitative survey-based research. Previous qualitative researchers have praised the benefits of metaphorical expression proposing it can elucidate complex cognitions and emotions, and can formulate the basis of interventions (Carpenter, 2008; Hunter, Lusardi, Zucker, Jacelon, & Chandler, 2002) such as in this study where we see metaphorical expression pronouncing a sense of isolation.

Our cross-sectional data inevitably limits reflections to past caregiving situations and given that dominant theories suggest making sense of stress and illness is a dynamic process, future IPA studies should adopt a longitudinal approach as Smith et al. (2009) suggest. This is ongoing with the current study. The majority of the current sample was female (12 of 13), all were Caucasian, and the majority was retired. The demographic composition of our sample, therefore, possibly introduces bias into our findings. Women are more likely to report greater stress, distress and depression in general and within chronic illness settings (Stanton et al., 2007), which is pertinent, given that society expects more physical and personal care tasks from women because they are perceived as more caring in nature than men (Lawrence, Goodnow, Woods, & Karantzas, 2002).

With regards to ethnicity, Parveen et al. (2011) found that while White British caregivers use both avoidance coping and positive reframing, British South Asian groups relied on more religious coping strategies, strategies which do not emerge in the current sample. Parveen et al. (2011) also report that while all of the British South Asian participants expressed willingness to provide care, two of the White British caregivers reported being unwilling to provide care. Further caregiving ethnic variation research suggests South Asian caregivers are more distressed by caregiving, adopt more behavioural disengagement and religious coping in addition to exhibiting more familism

than White British caregivers (Parveen, Morrison, & Robinson, 2013b). Additionally, these coping techniques are mediated between familism and caregiver gains and depression (Parveen, Morrison, & Robinson, 2013a).

In terms of possible influences of caregiver social economic status on caregiver experience, the evidence is mixed; some studies have found unemployed or low income caregivers reporting greater distress and burden (Kim, Baker, Spillers, & Wellisch, 2006) and greater social isolation amongst caregivers who have given up work to provide care (Lee, 1999); however, others suggest that employment adds a further demand on caregivers which can increase the sense of burden (Lee & Gramotnev, 2007).

However, there is no doubt that purposive recruitment of a more mixed caregiver sample could better address the possibilities of gendered, cultural and socioeconomic variations in such caregiving expectations (Parveen et al., 2011, Parveen et al., 2013b).

### **Implications**

The findings from the current research suggest that, in spite of witnessing caregiver policy and service improvements in recent years, caregivers are still reporting feeling neglected, unheard and confused. The use of data collection, elicitation and analysis techniques in our research that significantly draws on individual caregiving experiences adds further evidence to support this. Our findings suggest that caregivers and recipients require greater community-level support. Practitioners and formal services should seek caregivers' experiences and knowledge as a foundation for offering a caregiver-centred approach. Providing support and information tailored to individual caregiver's needs, as outlined many times previously (Brereton, 1997; Burton & Gibbon, 2005; Neufeld & Harrison, 2003), should remain high on the health and social care agenda.

### **Conclusion**

There are no parsimonious explanations concerning how caregivers make sense of their circumstance, what motivates someone to care and how they cope with the role. We were able to understand how the caregivers sampled within our research made sense of their experiences. We established patterns among caregivers while still considering idiosyncrasies and nuances, a major premise of the analytical approach adopted (IPA). Caregivers, understanding of their role, their proactive approach to problem solving in addition to avoidance coping were dynamic, tailored to individual circumstances and stressors.

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## Appendix. The cross-sectional interview schedule

Caregivers pick a minimum of three photographs that mean the most to them. If there are no photographs available, ask caregivers to think of and disclose three to five scenarios to discuss.

### Photo choice/image choice

What is it?

Why did you take/why did you imagine it? Prompt what was happening at the time you chose to take it/of the situation?

Why did you choose to discuss it in this interview?

How does it make you feel?

Any thoughts on why you feel this feeling?

How does this have an effect on any aspect of your life?

How does this affect the care you provide?

What are your thoughts on how this will affect you in the future?

How do you deal with it?

What do you think can be done about it in the future?

What do you think you can do about it in the future?

### Example of a typical prompt

That is interesting could you tell me a little more about that?

De-briefing

The end

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