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On: 29 November 2014, At: 00:41

Publisher: Routledge

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer

House, 37-41 Mortimer Street, London W1T 3JH, UK



Aging & Mental Health

Publication details, including instructions for authors and subscription information: http://www.tandfonline.com/loi/camh20

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Warren J. Donnellan^a, Kate M. Bennett^a & Laura K. Soulsby^a

^a Department of Psychological Sciences, University of Liverpool, Liverpool, UK Published online: 20 Nov 2014.

To cite this article: Warren J. Donnellan, Kate M. Bennett & Laura K. Soulsby (2014): What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study, Aging & Mental Health, DOI: 10.1080/13607863.2014.977771

To link to this article: http://dx.doi.org/10.1080/13607863.2014.977771

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What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study

Warren J. Donnellan*, Kate M. Bennett and Laura K. Soulsby

Department of Psychological Sciences, University of Liverpool, Liverpool, UK (Received 12 June 2014; accepted 13 October 2014)

Objectives: Much is known about the factors making caring for a spouse with dementia burdensome. However, relatively little is known about factors that help some spouses become resilient. We define resilience as 'the process of negotiating, managing and adapting to significant sources of stress or trauma'. We aimed to assess whether spousal dementia carers can achieve resilience and to highlight which assets and resources they draw on to facilitate or hinder resilience, using an ecological framework.

Method:Twenty in-depth qualitative interviews with spousal carers from two carer support groups and a care home in North West England.

Results: Eight participants were resilient and 12 were not. A resilient carer was characterised as someone who stays positive and actively maintained their relationship and loved one's former self. Resilient carers were knowledgeable and well supported by family but especially friends, with whom they shared this knowledge. They were more actively engaged with services such as respite care.

Conclusion: There is a need to move towards more ecological models of resilience. We propose that access to assets and resources is not always sufficient to facilitate resilience. Implications of these findings are discussed.

Keywords: resilience; dementia; spousal care; ecological framework

Introduction

Caring for a person with dementia is stressful (Lévesque, Ducharme, & Lachance, 1999). This burden often falls on family carers. 27% of primary carers in the UK are spouses (Alzheimer's Society, 2012). Pinquart and Sörensen (2003), in an extensive review, noted that most studies centred on burden. However, burden is not the full story. Whilst stress, at least initially, is common to adversity, carers are not homogeneous (Bonanno, 2004). Some spouses might find caring entirely burdensome whilst others might find it life-enhancing; these carers are resilient (Windle & Bennett, 2011).

Resilience is often examined from a psychological perspective, emphasising psychological and trait resilience (Windle, Woods, & Markland, 2010). Recently, work has emphasised the link between psychological resilience and community and social resilience (Wiles, Wild, Kerse, & Allen, 2012). This is important since individuals may fail to become resilient if the community does not facilitate opportunities to adapt (Ungar, 2011). Despite this resilience is often narrowly defined and not well operationalised (Gaugler, Kane, & Newcomer, 2007; O'Rourke et al., 2010). In light of these limitations, Windle (2011) defined resilience thus 'The process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation or "bouncing back" in the face of adversity' (Windle, 2011, p. 163). Bennett (2010) operationalised resilience using the following criteria: participants view their current life positively; actively participate in life; return to or maintain a life that has meaning or satisfaction; be coping and not be distressed. There is still a need for an integrated, fully operationalised definition, which may be used to determine resilience in carers. Here, we draw upon both accounts to develop the following criteria for resilience. There must be a significant challenge, in this case caregiving; there must be no obvious sign of (di)stress; maintenance of a life of meaning and satisfaction (a sign of bouncing back); active participation in life (a sign of managing) and current life must be seen as positive (a sign of adaptation). Our conceptualisation addresses whether resilience can be achieved in our participants, and allows identification and characterisation of facilitating/hindering factors.

The literature supports these criteria. Carers with higher perceived control, who favour challenge over stability present with fewer depressive symptoms at follow-up (O'Rourke et al., 2010). Gaugler et al. (2007) found that high levels of resilience in dementia carers led to significantly less instances of institutionalisation at three-year follow-up. They characterised these resilient carers as more accepting of support. However, the type of support is important; support may be detrimental if it creates feelings of over-dependence (Ingersoll-Dayton, Morgan, & Antonucci, 1997) or if it is not empathic (Haley, Levine, Brown, & Bartolucci, 1987). Carers may prefer and compare themselves with those in a similar situation

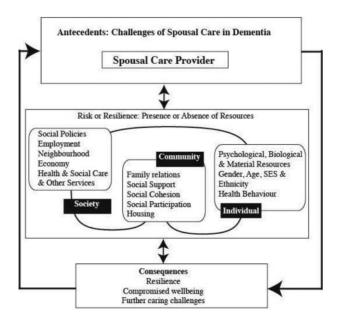


Figure 1. The resilience framework applied to carers (Windle & Bennett, 2011).

(Farran, Loukissa, Perraud, & Paun, 2004). Formal support and service provision are important. Support services designed to provide practical support to encourage carers to remain socially active and maintain healthy living are valued by those carers with access to them (Seddon et al., 2009). Resilience, therefore, can be fostered within the individual, their immediate surroundings and wider social environment.

Windle and Bennett's (2011) theoretical model of resilience for carers (see Figure 1) posits that each carer draws on individual assets. They emphasise that carers do not exist in isolation but interact with their environment by drawing on community and societal resources. Carers use these assets and resources to facilitate or hinder resilience. The absence of assets and resources may lead to compromised well-being or further caring challenges. No qualitative work has been conducted examining factors associated with resilient carers, nor has there been any work conducted to examine whether qualitative themes can be mapped on to the framework.

We use a qualitative approach to examine spousal dementia carers' capacity to be resilient. Our participants are classified as either resilient or not using the criteria above. We highlight the facilitating and hindering factors that participants draw on to achieve resilience, and whether they map on to the resilience framework (Windle & Bennett, 2011). The primary research question asks, Can spousal dementia carers achieve resilience? The first objective addresses which assets and resources the carers draw on that facilitate or hinder resilience. The second addresses, How do these assets and resources map on to the framework?

Method

Participants

We recruited from two dementia support groups and a care home in North West England. The first author made contact with each organisation by phone, before being invited to give a brief talk about the research. Although 35 carers volunteered, this paper focuses on the 20 participants who provide spousal care. This exceeds the minimum theme saturation threshold of 12 interviews; the point at which no new information or themes are observed in qualitative data (Guest, Bunce, & Johnson, 2006). There were 13 women and seven men. Each had been caring for their spouse for between 2 and 10 years (mean = 5.62 ± 2.73) and had been married for between 28 and 61 years (mean = 50.35 \pm 7.36). Age ranged from 62 to 86 (mean = 75.95 ± 7.47) (see Table 1). Most participants lived with and cared for their spouse at home although two were already widowed (Mrs L., Mr Gr.) and another had admitted her husband into nursing home care (Mrs G.). Care recipients had different levels of impairment, and care durations did not always correspond with the time of diagnosis. For example, Mrs F. had provided eight years of care to her husband, but he only had a formal diagnosis of dementia for three years. The socioeconomic status of the participants was broadly representative of similar demographics in the British population (ONS, 2001).

The interview

Semi-structured interviews were conducted and recorded during monthly carer meetings. Private interviews, lasting between 25 and 60 minutes, were conducted by the first author and by two assistants, Lauren Walsh and Naomi Hayes. The interview began with factual questions (section A): age, marriage, care duration and employment. We used an open chronological and retrospective approach to allow feelings and events to be traced to specific stages of care. Section B asked about life before the presentation of cognitive impairment. Participants described a typical day spent alone and with their spouse, relationship quality, division of responsibility and type and amount of support given and received. Participants were asked about the period surrounding diagnosis or first suspicions of impairment (C) and their initial emotional and behavioural reactions to the news. The final section (D) concerned the present, repeating section B's questions in light of current circumstances. Concluding questions prompted participants to consider which of their own personal characteristics may have helped them as a carer. They were given the opportunity to provide advice and recommendations for formal practice and legislation. The study received ethical approval from the University of Liverpool Research Governance Committee, and all identifying features have been anonymised.

Method of analysis

We used a three-stage hybrid method in our analysis (see Bennett, 2010). We used a grounded theory approach (Bennett & Vidal-Hall, 2000; Charmaz, 1995) as an exploratory method to read and code the interviews. We adopted this method without a-priori assumptions about the data. However, the remaining analysis then departed from the principles of classical grounded theory to identify resilience and identify which factors were associated

Table 1. Demographic details and resilience classification of carers.

Carers $(N = 20)$	Age (years)	Marriage duration (years)	Care duration (years)	Resilient/Not resilient
Mrs W.	62	28	3	Not resilient
Mrs C.	68	48	9	Resilient
Mrs Wi.	69	51	4	Not resilient
Mrs F.	71	51	3	Not resilient
Mrs L.*	73	53	10	Resilient
Mr G.	81	52	5	Resilient
Mrs G.**	82	49	5	Not resilient
Mrs Go.	69	40	5	Resilient
Mrs O.	77	59	2	Not resilient
Mrs S.	86	61	6	Not resilient
Mr Go.	74	52	10	Resilient
Mr Wh.	71	50	10	Resilient
Mr H.	81	53	5	Not resilient
Mrs P.	75	49	4	Not resilient
Mr N.	71	41	7	Resilient
Mr Gr.*	88	56	9	Not resilient
Mrs H.	89	58	7	Not resilient
Mrs La.	83	55	2.5	Not resilient
Mr Ha.	80	52	3	Resilient
Mrs Cl.	69	49	3	Not resilient

^{*}Widowed. **Institutionalised.

with resilience in the ecological framework (Windle & Bennett, 2011).

- (1) The first author read through each interview to gain a contextualised understanding of each participant's experience. Interviews were then coded line-by-line and focused codes were developed, before identifying themes based on all interviews. The approach was reflexive so that each emergent theme led to re-coding. All interviews were then coded blind by the second author. A consensus was reached between the two coders. Some prominent themes to emerge at this stage were resilience, staying positive, knowledge and expertise on dementia and shared experience.
- (2) Next, we re-read the interviews to identify participants as resilient or not. Each author classified each participant independently, using the same method as above. We used the criteria outlined earlier:
 - a. There must be a significant challenge: caregiving.
 - b. No sign of (di)stress.
 - c. Maintaining a life of meaning and satisfaction (a sign of bouncing back).
 - d. Actively participating in life (a sign of managing).
 - e. Current life seen as positive (a sign of adaptation).
- (3) Finally, we re-examined the codes from stage one in order to identify the factors that facilitate or hinder the capacity for resilience as identified at stage two. We specifically addressed two research objectives: we identified which individual,

community and societal resources participants drew on to facilitate or hinder resilience, and whether they mapped onto the resilience framework. By classifying our participants first, using an independent set of criteria (Bennett, 2010), we avoided circularity in the findings.

Analysis

Classification

Our primary research question was: Can spousal carers achieve resilience? We identify eight participants as resilient. Thus, some spousal dementia carers can achieve resilience. The following will determine the multidimensional nature of resilience; e.g. some resilient participants draw on factors that hinder resilience and some non-resilient participants draw on factors that facilitate resilience. Resilient participants are younger (mean = 73 years \pm 4.81) than non-resilient participants (mean = 78 years \pm 8.58). Resilient participants have been caregiving for longer (mean = 7 years \pm 2.77) than non-resilient participants (mean = 4 years \pm 2.06). Men were more likely to be resilient (5/8), women less so (10/12) (see Table 1). The following illustrate resilient and non-resilient participants:

Mrs C. is classified as resilient because she shows no obvious signs of distress. She has adapted to becoming a dementia carer and views her current life positively as she adopts a positive outlook from the point of diagnosis and continues to instil this in her husband:

It changed and yet I tried to be positive and say all they've done is give it a name. You're still the same person you were yesterday. (Mrs C., P7, L7) She ensures that both her and her husband maintain a life that has meaning and satisfaction by continuing to travel on holiday and engage with the local community. She has bounced back from the initial challenge of becoming a carer:

We've been very lucky. We travelled before he got Alzheimer's and we continued to travel with Alzheimer's up until 2-years ago when it got too difficult. We realised all the things we wanted to do in retirement so we didn't let it stop us. (Mrs C., P3, L7)

Mrs C. actively participates in life, managing charity work and attending support groups:

I've got to go out every day. He's at an allotment this morning ran by [charity]. That's a charity I've accessed an awful lot, they've been invaluable. (Mrs C., P17, L13)

Conversely, Mrs W. is not resilient because she is distressed; she is not positive about her current life and seems resigned to her circumstances:

This is my retirement in other words. Not what I planned of course but there you go. (Mrs W., P2, L12)

Mrs W. has not managed to bounce back as she focuses mainly on those things that have become lost or changed irreparably, rather than maintaining existing competencies:

It's not husband-wife anymore it's carer-caree...It's like looking after a child. (Mrs W., P17, L1)

Although Mrs W. participates in a carer support group, she does not welcome social support from her family and does not fully participate in life:

I do have a problem with family support because we don't get many phone calls from his lot. We don't encourage them to come up to be honest because he doesn't like visitors, well it's not that he doesn't like people, he loves people. (Mrs W., P8, L18)

Mapping resilience factors on to the resilience framework

Our research objectives addressed; (1) which resources carers draw on that facilitate or hinder resilience, and (2) how these map on to the resilience framework. Although the process of analysis happened sequentially (see Method), we integrate them in our presentation.

Individual level of the resilience framework

Psychological assets

The first theme is maintaining continuity. Whereas all participants emphasise the decline in function of the care recipient, some participants maintain and encourage aspects of their spouse's former self. Mrs Wi. actively encourages aspects of her husband's former lifestyle:

He used to go out every Monday and every Friday playing snooker and that hasn't stopped. He goes on his own because I've told them right from the beginning about [husband] having Alzheimer's. (Mrs Wi., P13, L14; not resilient)

The maintenance of self-identity and existing competencies re-emphasises the fact that resilience may not just concern adjustment and change, but concerns the management of stress and maintenance of normal functioning. Carers do not flourish or become 'super functioning'; they maintain previous functioning by actively emphasising features of their previous life. Another theme is the ability to stay positive:

I'm positive. I laugh and I sing and she laughs and I act soft in the house. I've even said to one of the neighbours about my singing and she says [Mr Go.] it's a good job we've got a detached house. I sing at the top of my voice. (Mr Go., P17, L17; resilient)

Humour is important in facilitating resilience and is mutually enriching for carer and care recipient alike. Participants frequently use downward comparison when referring to others:

I was getting a little bit depressed and then I have a talk to myself and I think there's millions of people like these and in one respect he's been lucky if he's going to have it that he got it when he was eighty and not fifty. (Mrs S., P17, L8; not resilient)

This facilitates resilience by diverting attention from the challenge of caregiving and providing meaning so that, given the wider context, carers appreciate their own circumstances which become normalised. In contrast, some participants have a more negative outlook which hinders resilience. These participants are less resilient:

If there is a problem that's weighing you down a bit you just work at it, don't you? That's your life. You've had the best and now you've got to put up with the worst. (Mr Gr., P15, L22; not resilient)

The most resilient participants do not simply stay positive; they use caregiving as an opportunity to acquire expertise on dementia. Whilst the ability to acquire knowledge is an individual asset, the carer interacts with the community and uses societal resources:

I went on the internet, got up what medication he should be on... and I was like a dog with a bone. We just became proactive. Within a couple of weeks I went to the Alzheimer's [support centre] and I just sort of took on board everything but, it's 9 years later and you're still learning all the time. (Mrs C., P11, L8; resilient)

Psychological assets seem to be dominant in our sample. But these interact with community and societal resources, as Mrs C. highlights. One might suggest that attempts made to promote resilience should start with individual psychological assets, as it is Mrs C's drive to acquire knowledge that leads her to interact with wider services.

Material resources

Most participants report having sufficient finances but having access to disposable income facilitates resilience by leading to a better quality of life for the carer and care recipient alike. We have already shown how Mrs C.'s financial capacity allowed her to continue travelling. For other participants, access to disposable income is not always useful and sometimes hinders resilience, as Mr Ha. explains:

We're spending no money. We have a system at the bank where it clears it down to £2000 for the rest of the month and the rest it clears away. I could well afford to buy anything I just can't think what to buy. (Mr Ha., P8, L12; resilient)

Specifically, access to material resources may not necessarily equip someone to be resilient. Although Mrs La. claims to have had a very good life, going on cruises and on 'wonderful dancing holidays' (P2, L16) with her husband prior to his dementia, she now feels differently:

I feel I'm a prisoner. It's a prison sentence for me and for him because you've lost the freedom we had before. (Mrs La., P8, L35; not resilient)

Community level

Family relations

Although most participants value the support they receive from family, many prefer family to be 'hands off' rather than over-involved, and to provide practical rather than emotional support. This theme is a characteristic of even the most resilient of participants, as Mrs C. describes when referring to her two adult daughters:

We said you've got your own children now all in school, your husbands with jobs. We will get help from other people. We will find help as and when we need it. (Mrs C., P13, L5; resilient)

Other participants hold strong views on the role of family support. Although Mr Ha. acknowledges that his daughter has been present and sympathetic, he goes on to say:

Our daughter has been coming over Sunday afternoon regularly lately. I don't really want her to, it's my place. (Mr Ha, P7, L36; resilient)

Although resilient, Mr Ha. is dismissive of support whereas Mrs C. appreciates the importance of support. Carers may prefer to control the amount of family support they receive to maintain independence and avoid feelings of dependency.

Social support

Friends, and particularly friends in similar circumstances, are a great source of support. Social support facilitates resilience most when participants are able to demonstrate and share their expertise and insight with others. This is illustrated by two interviews with participants who are

friends through a support group; Mrs C. advises Mrs Wi. with regards to a specific problem:

Her husband got a strop on this morning because he kept asking her the time and she was saying 5 to 10 5 to 10 and she said it's because you're deaf. She said he got so angry and stormed upstairs and I said oh, cause we don't mind telling each other stuff, two things there, I said one; you're pointing out another failing which makes him feel bad, and the other thing is; you need to look at does he know what five to ten means. (Mrs C., P22, L21; resilient)

When I got in [Mrs C.] said well he might not be recognising what 5 to 10 is...you see you learn something every day and you think you're down but knowing that somebody else has got another look on it. (Mrs Wi., P22, L17; not resilient)

This specialised and confident application of knowledge highlights dementia carers as experts on the condition as well as their care duties. The receipt of advice can be as important as the provision of advice. Resilience might predispose individuals to take control of the role, garner information and become experts; this knowledge can then be passed on to others in the same situation. Sharing advice demonstrates carers are embedded in a wider social arena.

This type of stable and supportive friendship is less common in the non-resilient:

People drop out, you know, friends. They don't fall out with you but you can tell they're not in. There's nothing for them anymore. You've got no conversation and they've got their own lives and their own friends and that's a bit hard. So you are a bit isolated. (Mrs H., P4, L20; not resilient)

This category represents an interaction between each level of the resilience framework. Mrs C. and Mrs Wi. met in the support group, a societal resource, before sharing individual resources on a community-level.

Social participation and cohesion

Many participants emphasise the social groups they are part of, and the function they serve. Participating in social groups facilitates resilience:

I'm in an international Christian group which is good because not only do you have spiritual direction but you have the group supporting you. And whatever you say is confidential. (Mrs La., P7, L19; not resilient)

Some of the more well-supported participants emphasise the value and function of the dementia support groups, in particular. The friends made here are a more highly regarded source of social support by all who have them, as Mrs Go. explains:

Coming here has helped me because the people that come here are in the same position as I am. They've been in it longer than me some of them so I can use their experience and I can relate to what they're saying. (Mrs Go., P22, L4; resilient)

For some non-resilient participants, attending groups is the only form of social support they have access to:

I don't think there is anybody apart from going the coffee mornings... my daughter is distressed so I couldn't really put it on her. (Mrs Cl., P9, L24; not resilient)

Dementia support groups facilitate resilience by providing a forum to acquire and share information by using the expertise of other carers. Support group friendships provide a source of practical and emotional reassurance.

Social resources

Health and social care

Participants make use of different health and social care services, including day and respite care, home help and support groups. Resilient participants are more likely to acknowledge their own limitations and know when to take a break. Eight out of 20 participants in our sample refer to some form of respite care and 4 participants use it. Those who use respite are classified as more resilient than those who do not, so it represents an important facilitator of resilience:

I'm getting respite on a weekend. I really do know the meaning of recharging my batteries now. I feel more, you know, on the Monday morning right let's get on with the day. (Mrs C., P13, L22; resilient)

Some participants like the idea of respite care but do not know that it is available to them:

If carers could get respite care on a regular basis that'd be a most wonderful thing because it would give them the strength to go on, wouldn't it? Rejuvenate them. (Mrs La., P11, L19; not resilient)

Reducing or temporarily removing the burden caused by the care recipient provides an opportunity to 'recharge' some of the individual assets of resilience. Although respite care facilitates resilience for both carer and care recipient, not all participants draw upon it. Our non-resilient participants are least likely to use this service; either they are unaware of the service; do not know how to acquire it; or feel that they are not ready for it.

Other services

Some participants take part in unique innovative services which facilitate resilience:

We helped make a DVD for [local health service]. They interviewed the two of us together... His theme song for that is always look on the bright side of life [laughs]; the Monty Python one. (Mrs C., P9, L17; resilient)

Mrs Wi. spoke of a pilot scheme that she is part of at the local memory clinic: I do voluntary work as well...I'm a carer talking to the carers...they ask the questions and I say and that's where I learnt about that...I know it sounds daft but it is a break away, it's different, and yet you're helping others. (Mrs Wi., P18, L21; not resilient)

These services are different from the latter health and social care services, in that the participants seem more engaged with them. Carers may be more likely to use societal resources if they can provide social support to others in the same situation. Services which encourage independence and 'giving back' rather than dependence may be preferred. This represents an interaction between societal resources and community resources.

Discussion

We asked whether spousal dementia carers could achieve resilience. We demonstrate that some can achieve resilience, although the picture is more complex. Our research objectives were to identify the assets and resources carers draw on that facilitate or hinder resilience, and to address how these might map on to the resilience framework (Windle & Bennett, 2011). We identified several factors that facilitate or hinder resilience in spousal dementia carers and found that these map on to the levels of the framework.

Facilitating factors emerged primarily at an individual level, and included psychological assets which were frequently associated with resilient participants. Maintaining continuity showed that resilience is about bouncing back to previous functioning rather than flourishing beyond previous functioning (Smith et al., 2008; Windle & Bennett, 2011); it could be those carers who need to adapt least who are most resilient. Staying positive has several beneficial functions: positive cognitions buffer against sources of burden (Zauszniewski, Bekhet, & Suresky, 2009); enjoyment in the role reduces burden and depression (Pinquart & Sörensen, 2003); and sharing a joke can maintain companionship (Murray, Schneider, Banerjee, & Mann, 1999), reciprocity (Voelkl, 1998) and the care recipient's sense of identity (Hellström, Nolan, & Lundh, 2005). Downward comparison with those that are 'worse off' may be an important way of increasing self-efficacy and the carer's confidence in how well they are doing (Farran et al., 2004). The acquisition of knowledge supports existing dimensions of resilience, such as favouring challenge and garnering control (O'Rourke et al., 2010). Facilitating factors emerged at a community level, including friendships with common experience and social participation. Friends provided mutual experience and shared understanding for dementia carers, and good quality social relationships were reinforced through shared experience (Farran et al., 2004).

Hindering factors emerged at individual and community levels of the ecological framework. Individual factors such as a negative outlook, and focusing on aspects that have become lost or irreparably changed, are frequently associated with non-resilient participants. At a community level, perceived or actual loss of friends hindered

resilience, and increased feelings such as isolation. This supports Gaugler et al. (2007), who characterised highly resilient dementia carers as more accepting of informal support. Some factors are only facilitating up until a point, after which they may become hindering. Our data give examples of this from individual, community and societal levels; at an individual level, a sense of freedom and access to disposable income may be limited by the demands of dementia. This finding is unexpected and would not be predicted by the resilience framework, which might have predicted that a lack of material resources was instead a hindering factor. The fact that our participants did not raise lack of money as a negative issue is not to say that it is not a valid factor. No empirical research has looked directly at the role of material resources in facilitating resilience. At a community level, family support that is perceived as over-intensive may create feelings of dependence. This is unexpected given that carers often prefer social relationships based on shared experience, and family members are likely to share more experience than friends (Farran et al., 2004). Pinquart and Sörensen (2000) suggest that this may be because family are structurally determined and associated with negative social exchange surrounding the sick relative, whereas friends are selected and associated with the 'good old times'. At a societal level, respite care is valuable but some participants feel that they are not ready for it or are unaware of its availability. Thus, access to resources is not always sufficient; carers must wish to use them. This supports Bennett's (2010) view that the time has to be right to achieve resilience.

This study contributes much that is new. First, by focusing on spousal care, we provide a novel perspective through which we examine resilience. Qualitative interviews examine the individual experience of dementia care; however, we were also able to identify a number of community and societal resources. Unexpectedly, few societal resources emerged from our analysis. The resilience framework suggests that social policy, employment, neighbourhood and economy issues might emerge more but they did not. This may be due to the nature of our interview; we asked questions that focused on psychological and interpersonal aspects of the caregiving experience, encouraging participants to talk about their affective and behavioural reactions. Wild, Wiles, and Allen (2011) found that social resources emerged prominently when participants were asked about community, household and neighbourhood issues. Despite this, we uncovered some important societal factors which seem to facilitate resilience in our participants. By operationalising resilience, we were able to identify who is resilient and who is not, which may aid the promotion of resilience through formal and informal intervention. A limitation of this study is that the majority of the sample was recruited from dementia support groups, which may represent a resilient subgroup of participants such that the findings cannot be generalised to other non-resilient carers. However, 6 out of 20 participants were recruited from outside support groups and not all those participants recruited from support groups are resilient. Furthermore, it is difficult to recruit

those carers who are not known to services and so emphasis should be placed on extending our findings to them. Another limitation is that the notion of drawing on assets and resources, and the classification system used, may be too simplistic. We showed that some factors are only facilitating up until a point, after which they may hinder. We found that some resilient participants draw on factors that hinder resilience and some non-resilient participants draw on factors that facilitate resilience, suggesting that resilience is multidimensional. Further discussion of these issues goes beyond the scope of this paper. Our study emphasises the need to integrate resilience within an ecological framework (Windle & Bennett, 2011), using different methods of research and analysis.

In conclusion, a resilient carer is someone who stays positive in the face of care demands and actively maintains and preserves their relationship and loved one's former self. Resilient carers have access to and use services such as respite care and may actively engage with innovative schemes that aim to 'give back' to others in similar situations. Resilient carers are knowledgeable and well supported by family but especially friends, with whom they share this knowledge. Support group friends share emotional and practical advice and reassurance that may help the carer manage their role better. In doing so, carers may be more encouraged to pursue the positive aspects of caring which buffer the effect of burden on resilience. Resilient carers can be encouraged to share their knowledge and expertise with those who are not resilient. The ideal forum for this is the support group setting; a societal resource, within which individual assets and community level resources can be facilitated. Formal services could step in to help potentially at risk individuals, such as those who are not resilient and/or those without knowledgeable peers. Our findings emerge on individual, community and societal levels, which suggest that resilience is a multidimensional construct and supports the continued need to examine resilience from an ecological perspective.

Acknowledgements

Special thanks are due to the men and women who shared their stories in this study. We thank Lauren Walsh and Naomi Hayes for their kind data contributions.

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