Family close but friends closer: exploring social support and resilience in older spousal dementia carers.

Warren J. Donnellan[a*], Kate M. Bennett[b] & Laura. K. Soulsby[c]

[a] e: wjd@liv.ac.uk tel: +44(0)151 795 0647

[b] e: kmb@liv.ac.uk tel: +44(0)151 794 1410

[c] e: L.K.Soulsby@liv.ac.uk tel: +44(0)151 794 1409

[abc] Department of Psychological Sciences

University of Liverpool

Eleanor Rathbone Building

Bedford Street South

Liverpool, L69 7ZA

UK.

Running header: Family close but friends closer

*Corresponding author

Abstract

Objectives: Spousal dementia carers have unique support needs; they are likely to disengage from their existing social networks as they need to devote more time to caring as the disease progresses. Previously we showed that support resources can facilitate resilience in carers, but the relationship is complex and varies by relationship type. The current paper aims to explore social support as a key component of resilience to identify the availability, function and perceived functional aspects of support provided to older spousal dementia carers. Method: We conducted 23 in-depth qualitative interviews with spousal carers from two carer support groups and a care home in North West England. Results: Family and friends served a wide range of functions but were equally available to resilient and non-resilient participants. Family support was perceived as unhelpful if it created feelings of over-dependence. Participants were less likely to resist involvement of grandchildren due to their relatively narrow and low-level support functions. Friend support was perceived as most helpful when it derived from those in similar circumstances. Neighbours played a functionally unique role of crisis management. These perceptions may moderate the effect of support on resilience. Conclusion: Family and friend support is not always sufficient to facilitate resilience. Support functions facilitate resilience only if they are perceived to match need. Implications of these findings are discussed.

Key words

Spousal care; dementia; social network; social support; resilience.

Introduction

Dementia carers have unique support needs (Roth, Mittelman, Clay, Madan, & Haley, 2005): they are likely to suffer declines in the availability of people to provide informal support over time (Clay, Roth, Wadley, & Haley, 2008), and disengage from their existing social networks as they devote more time to caring as the disease progresses (Hough, Magnan, Templin, & Gadelrab, 2005; Han et al., 2014). Social networks are defined as: 'the structural character of social relationships, such as the number of contacts we have or how often we spend time with those people' (Soulsby & Bennett, 2015: p. 110). Approximately 27 per cent of primary carers are providing care to a spouse (NHS, 2010). Spousal carers are supported by pre-existing informal social networks (Antonucci, Birditt, Sherman, & Trinh, 2011), such as adult children, close relatives, friends and neighbours (NHS, 2010). We are unaware of any existing research that examines the types of support these people provide, nor how this support is perceived by spousal carers.

Social support has been defined as: 'a transactional process whereby our relationships provide a platform for the exchange of emotional and practical support' (Soulsby & Bennett, 2015: p. 110). Sherbourne and Stewart (1991) identified five distinct dimensions of social support: emotional (positive affect, empathic understanding); affectionate (expression of love); informational (advice, guidance, feedback); tangible (practical assistance); and positive social interaction (availability of others to do fun things together). The effect of social support depends on the outcome and group being investigated. Research on older adults shows that emotional support protects cognitive functioning more than tangible support (Ellwardt, Aartsen, Deeg, & Steverink., 2013). Pinquart and Sörensen (2000) suggest that tangible and informational support may buffer the influence of stress on subjective wellbeing. Research on carers by Han et al. (2014) shows that affectionate support and positive social

interaction reduces psychological burden and the prevalence of major depressive disorder, and tangible support reduces non-psychological burden. It seems that carers benefit from a wide variety of support functions. However, there is a lack of research addressing the effect of support on resilience in carers.

Resilience is defined as: '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). The mere availability of close social ties, such as family members, does not simply facilitate resilience (Sherman, Webster, & Antonucci, 2013); carers reject networks if they are perceived as unhelpful (Roth et al., 2005; Ellwardt et al., 2013). Thetford, Hodge, Bennett, Knox and Robinson (2015) suggested that resilience is facilitated not by the presence/absence of resources, but by the interaction of the individual with their environment.

Windle and Bennett (2011) developed an ecological resilience framework applied to carers, which posits that each carer draws on individual assets, community and societal resources which interact to facilitate or hinder resilience (see Figure 1). Ecological resilience is based on the principle that the majority of people cannot be resilient without facilitative interpersonal and socioenvironmental factors (Liebenberg & Ungar, 2009; Bennett & Windle, 2015). In our previous work we used a three-stage hybrid method to explore the resilience resources that spousal dementia carers draw on (see Donnellan, Bennett & Soulsby, 2015, for a detailed summary). We first approached the data using grounded theory, then we identified participants as resilient or not resilient. We used the following criteria: i. There must be a significant challenge: caregiving; ii. No sign of distress; iii. Maintaining a life of meaning and satisfaction (a sign of bouncing back); iv. Actively participating in life (a sign of managing);

v. Current life seen as positive (a sign of adaptation) (adapted from Bennett, 2010). Finally, we identified the factors which facilitated or hindered resilience, and whether they could be mapped onto Windle and Bennett's (2011) framework.

< Figure 1 near here>

We found that the availability of friend networks was almost always associated with resilience. However the picture was different for family members; they were not always sufficient to facilitate resilience. Indeed they hindered resilience if they created feelings of over-dependence (Donnellan et al., 2015). This complexity is reflected in the literature. Fiori, Antonucci and Cortina (2006) found that the absence of friends, but not family, increases depressive symptomology, and the quality of support mediates that relationship. According to Socioemotional Selectivity theory, the most important social contacts are aligned with the individual's self-concept and personal circumstances (Carstensen, 1991; Farran, Loukissa, Perraud, & Paun, 2004). Research has shown that subjective wellbeing is predicted more by emotionally close ties with adult children and frequency of contact with friends. Frequent contact with family and close ties with friends does not predict subjective wellbeing (Pinquart & Sörensen, 2000). Rosenmayr (1983) found 'intimacy at a distance'; older adults perceive their family relationships as important but wish to remain independent from them (Ingersoll-Dayton, Morgan, & Antonucci, 1997). This may be because seeing family regularly is likely to involve negative social exchanges and reflect increasing care demands (Pinquart & Sörensen, 2000). Although there are several important resources and outcomes associated with and resulting from resilience, in this paper we look to further explore social support as a community resource and resilience in older spousal dementia carers. The first research objective is to identify the availability and function of support offered to resilient and non-resilient older spousal dementia carers by their family and friends. The second research

objective is to identify the perceived functional aspects of support from family and friends, and examine how this varies between resilient and non-resilient participants.

Methods

Participants

We purposively sampled 16 women and seven men (N=23) from two dementia support groups (n=17) and a care home (n=6) in North West England (see Donnellan et al., 2015). Three interviews have been added to this study that were not transcribed in time for inclusion in the previous study (see Table 1). Participants had been caring for their spouse for between two and ten years (mean = 5.44 ± 2.64) and had been married for between 28 and 61 years (mean = 49.61 ± 7.14). Age ranged from 62 to 89 (mean = 75 ± 7.46). All participants were retired. No information was available regarding how long participants had been participating in the support groups. Most participants currently lived with and cared for their spouse at home although three were already widowed (Mrs L., Mr Gr., Mrs Wk.) and another had admitted her husband into nursing home care (Mrs G.). Social class was measured by asking participants to describe the type of work they did for their last occupation. Three social class groups, Professional, Skilled, and Partly/Unskilled, were used from seven original British Household Panel Survey categories. The social class of the participants was broadly representative of similar demographics in the British population (Office for National Statistics, 2011).

< Table 1 near here>

The Interview

Semi-structured interviews, lasting between 25 – 90 minutes, were conducted and audio-recorded in a quiet room at each of the aforementioned venues. Each participant was

interviewed on a one-to-one basis by either the first author or by one of two assistants. Data were transcribed by the first author and a transcription assistant. An open chronological and retrospective approach was used to trace feelings and events to specific stages of the participant's life, pre- and post-dementia. Section A began with factual questions: age, marriage, care duration and employment. Section B asked about life before caregiving. Participants were prompted to describe a typical day, relationship quality, and the type of support received and how it is perceived. Section C asked about the period surrounding diagnosis or first suspicions of impairment and their initial emotional and behavioural responses. Section D asked about the present situation, repeating section B's questions. Finally participants were asked which advice they would give to someone in the same position as themselves. The study received ethical approval from the University of Liverpool Research Governance Committee.

Method of Analysis

We adapted the three-stage hybrid method from our previous study (Donnellan et al., 2015) to re-analyse our data. Existing resilience classifications were used:

1. We used a grounded theory approach (Bennett & Vidal-Hall, 2000; Charmaz, 1995) to read and code the interviews. All references to support were coded line-by-line and focused codes were then developed, before identifying the most common themes across all interviews.

2. We re-read the interviews to identify the function of support provided and which network members provided it. Support functions were identified using Sherbourne and Stewart's (1991) dimensions of support: emotional; affectionate; informational; tangible; and positive social interaction. For example, Mrs Wk.'s neighbour mowed her lawn. This was identified as tangible support. Support availability was assessed by

how many participants mentioned access to each network member. We then compared

availability and function of support across resilient and non-resilient participants. This

indicated which support members and functions were associated with resilience.

3. Finally, we re-examined the codes from stage one in order to explore participant's

   perception of support highlighted at stage 2. For example, some participants had

   tangible support from children available to them, but felt that their taking control was

   unhelpful. We examined how this varied between resilient and non-resilient

   participants. This indicated whether the relationship between support and resilience

   was straightforward or more complex.

This process was conducted independently and blind by each author. A consensus was

reached on the most prominent findings across each analysis.

Results

Although the research questions and process of analysis are sequential (see Methods), we

integrate them in our reporting of results. The structure of each section is based on the

frequency of support available from each network member, from highest to lowest. We use

parentheses in order to clearly identify each support function within the quotes.

Family support

Children

Participants spoke of support from biological and, in one case, step-children. There

are no functional differences between these subtypes so they are collapsed for the purposes of

this analysis. There is a clear gendering of support as daughters provide: tangible, emotional,

informational and affectionate support, whereas sons provide mainly tangible support:

> I was lucky because… I had two boys and two girls, and to give me a break the girls used to take me out for the day [positive social interaction] and the boys used to look after their dad [tangible]… so we worked as a team. (Mrs L. Resilient)

> [Son 1]… is very practical [tangible] and he came here the other night and I just gave him a list. He comes and says, 'what else do you need, Mother?' And [Son 2] will do all the financial stuff [tangible] for me. (Mrs La. Not resilient)

Men carers garner more support than women carers generally, especially from their daughters:

> [Daughter] knew who to contact [informational]… and she's always there if I need anything [emotional/tangible]. Every day that she's at home she calls even if it's only for half an hour but she comes to make sure everything's alright [emotional/tangible]. (Mr Wh. Resilient)

There is no difference between resilient and non-resilient participants in the availability or function of support from children; it is equally wide ranging. This suggests that support function is not always sufficient to facilitate resilience. Non-resilience could be explained by the participant's perception of support from children. Both resilient and non-resilient participants prefer 'intimacy at a distance'; child support is valued but not over-intensive to maintain independence. What distinguishes them is that non-resilient participants are more likely to resist their children's over-involvement and justify it in terms of their competing demands. This may explain why child support does not always facilitate resilience:

> I try not to involve them [daughter] too much cause, as I say, they've got their own lives. (Mrs H. Not resilient)

I didn't tell them [daughter and son] a lot of the things that were going on because they had their own problems, their own families to see to. (Mrs G. Not resilient)

Last night she [daughter] rang me and she said if I wasn't working I'd come and, you know, help you and I said but you're working. (Mrs S. Not resilient)

In-Laws

Participants mainly spoke of support from children-, siblings- and parents-in-law. It is worth noting that the availability of children-in-law is dependent on the availability of children. Here we focus on the functional aspects of those in-laws regardless of this structural complexity. We found that in-law support is rarely available and includes a relatively narrower range of support functions, including tangible support and positive social interaction. This is the case for resilient and non-resilient participants:

His brother and sister… the last couple of weeks they've been coming and he loves just having them there, just chatting, and, you know, put some music on and things [positive social interaction]. That gets us through the day basically. (Mrs C. Resilient)

[Son-in-law] showers me three times a week [tangible]…Very good of him really cause he works as well. (Mr H. Not resilient)

In addition to caring for his wife, Mr H. is physically disabled. It is unclear whether his non-resilience is related to his disability. There are no functional differences in in-law support between resilient and non-resilient participants; both are equally narrow. Again the participant's perception of in-law support could be explaining non-resilience. Non-resilient participants are more likely to resist over-involvement and explain it with competing demands:

His Sister's always saying, 'how's [Husband]?', 'oh he's driving me mad', 'well you should give me a ring and we'll come up' [tangible] but they've got their own lives… why should they be burdened? He's my responsibility. I married him for better for worse and that's how it's gonna be. (Mrs Go. Resilient)

We don't encourage them [in-laws] 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. Not resilient)

Grandchildren

Participants mainly spoke of grandchildren and great-grandchildren. This category mostly comprises younger grandchildren, as opposed to adult grandchildren. We found that grandchildren are available more to non-resilient participants, providing mainly positive social interaction and affectionate support:

I can go out, they play outside, I can watch them. I love being in their company [affectionate] because it's a break and I'm talking totally different conversation; they will talk to you whereas [Husband] doesn't speak [positive social interaction]. I am glad when they come but I'm shattered when they've gone. (Mrs F. Not resilient)

The increased availability of support from grandchildren in non-resilient participants could suggest that grandchildren may not be sufficient to facilitate resilience. Interestingly, while there is evidence that non-resilient participants are more likely to prefer 'intimacy at a distance', they do not actively resist involvement of grandchildren as they do with children and in-laws:

I enjoy my grandchildren like you should do but, well, in small doses [laughs]. The 15 year old is not much use really… [Husband] just hasn't the patience to deal with children. (Mrs W. Not resilient)

Support from friends

Group friends

Participants referred to friendships made either as a direct result of dementia, such as carer support groups, or more longstanding friendships established in other settings such as community groups or the Church. We found that group friends provide a wide range of support functions to resilient and non-resilient participants, including: emotional, informational support and positive social interaction:

There's a little discussion group along the road full of very friendly people… it gets us out and he [Husband] likes watching… I don't know if he listens but he watches the expressions and sees people laughing [positive social interaction]. (Mrs Lg. Resilient)

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 [emotional]… they come out with whatever's hurting them and you're there to listen and they do the same for you [positive social interaction]. (Mrs La. Not resilient)

Support group friends provide the widest variety of support functions and shared experience. This is the case for resilient and non-resilient participants:

We are like family [affectionate]. We know each other's troubles; we exchange sad stories or glad stories every week… I think that's why I'm so stable because I talk to so many people who are in the same boat [emotional]. You don't sit there and feel sorry for yourself and you see there are ways and things to do which can keep your life quite nice. And I do them. We do them. They tell you where this is, where that is, where to get help from [informational]. (Mrs Lg. Resilient)

The girls here [support group], we've all got one another's phone numbers. We don't socialise as such but we know we're there for one another. If one of us is at home and they're having a bad day they can always ring one of the girls up and have a chat [emotional]. (Mrs Wi. Not resilient)

It's only when you come to the Carer's [support group] and share that you realise that yeah it's okay to explode, it's okay to cry, you know, cause they're going through… the same [emotional]. (Mrs Wi. Not resilient)

Despite receiving a wide variety of support and shared experience from group friends, there are participants who are not resilient. The evidence shows that non-resilient participants are more likely to use group friends for positive social interaction, whereas resilient participants are more likely to use them for informational support.

Existing friends

Participants talked about friends established before dementia diagnosis, for example; former co-workers or married friends. Some participants explain that existing friends have been a source of long-term support, mainly emotional support and positive social interaction. Although we found no difference in the availability of existing friends between the resilient

and non-resilient, resilient participants were more likely to receive emotional and positive social interaction from those with shared experience:

> Every now and then we meet up and go for a drink and laugh at stuff we did in the old days [positive social interaction]. That helps to take away the tension of what you're going through [emotional]. (Mr N. Resilient)

> I suppose for emotional support… [Existing friend], her mother died two years ago and she was very close to her mum erm and my mum died a bit before that so we had a bit in common there. Erm, but she knew [husband] very well as well. (Mrs Wk. Resilient)

Existing friends with shared experience may facilitate resilience more than friends without. Conversely, existing friends of non-resilient participants seem to share less experience, and serve a narrower function, specifically positive social interaction:

> I've known her for donkeys years, 50 years, and now we meet up every few weeks and we go for a meal [positive social interaction]… around tea time-ish. (Mrs P. Not resilient)

> Our friends [existing friend 1] and [existing friend 2]… they take us out for a meal [positive social interaction]. I mean they're terrific with [husband] and it's just a little bit of relief for me. They come on holiday with us as well [positive social interaction]…they're marvellous. (Mrs Cl. Not resilient)

Interestingly, non-resilient participants are relatively more likely to have existing friends that they do not see. Participants talk about how existing friends have 'dropped out' since their spouse developed dementia:

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. Not resilient)

I've lost all my friends that I had before, before he got diagnosed with this. You wouldn't believe. You're friends sort of cross over the road and you wouldn't think they would cross over the road rather than talk to you face to face. (Mrs Hn. Not resilient)

I think people are frightened if it's mental illness. If my husband had cancer or a broken leg… people would visit and I think it scares people off. That's sad. (Mrs P. Not resilient)

Indeed, some non-resilient participants explain that the reason they have drifted apart from existing friends is because they do not share an understanding of what it is like to be a carer:

The different groups you go to, the people you meet, they become your family and friends… people don't understand unless they're living with someone with Alzheimer's and you can't expect them to understand because you wouldn't in the same position. (Mrs P. Not resilient)

I met one woman that I've not seen for a long time and I said to her that my husband's got dementia… and she said, 'oh I do feel sorry for you', and I thought no you don't… It was only then when it hit me that she doesn't know how I feel. Her husband's fine, you know, she's getting on with her life. (Mrs F. Not resilient)

Neighbours

We found that neighbours are available more to resilient participants, providing mainly tangible support.

> [Husband] and [Neighbour 1] used to take it in turns to do the whole lawn [tangible]. I woke up one morning and my tyre was completely flat so [Neighbour 2] I know he will come and do that [tangible]. (Mrs Wk. Resilient)

> A couple of lads who live in this street, they're only 33, and when she went missing once, they ran these streets looking for her [tangible]. (Mr N. Resilient)

Although neighbours provide only tangible support, it is clear that they facilitate resilience. Neighbour support is specialised in that it provides a crisis management function; carers can call on their neighbours in an emergency when family and other friends are unavailable. This makes neighbours a uniquely valuable resilience resource.

Discussion

Our first research objective was to identify the availability and function of support offered to resilient and non-resilient older spousal dementia carers by their family and friends. With the exception of neighbours, we found that resilient carers were no more likely than non-resilient carers to have family and friend support available to them. Family and friends served a range of functions. Although children, existing friends and group friends provided a wider range of support than in-laws, grandchildren and neighbours, most were equal across resilient and non-resilient carers. Generally speaking, resilient and non-resilient carers have structurally and functionally similar support characteristics; non-resilient carers are no less likely to receive support. This suggests that social support is not always sufficient to facilitate resilience. This is in line with previous findings that the mere presence/absence of resources,

such as close social ties, does not simply facilitate carer resilience (Sherman et al., 2013; Thetford et al., 2015). These findings can be explained by qualitative differences in the carer's perceived satisfaction with support and their interaction with the social network (O'Rourke & Tuokko, 2000; Roth et al., 2005; Ellwardt et al., 2013).

The second research objective was to identify the perceived functional aspects of support from family and friends, and examine how this varies between resilient and non-resilient participants. Most carers, whether resilient or not, spontaneously and consistently demonstrated 'intimacy at a distance' when discussing support functions from children, in-laws and grandchildren; they perceive them as important but wish to remain independent from them (Rosenmayr, 1983; Ingersoll-Dayton et al., 1997). This complements the notion that support resources facilitate resilience up until a point, after which they become hindering (Donnellan et al., 2015). Non-resilient carers were more likely to act on 'intimacy at a distance' by resisting over-involvement of children and in-laws, and justify it in terms of their competing demands. One explanation is that seeing family regularly is likely to involve negative social exchanges and reflect increasing care demands (Pinquart & Sörensen, 2000). Tangible support may also emphasize the care recipient's impairment (Reinhardt, Boerner, & Horowitz, 2006) and contribute to distress and low self-efficacy (Uchino, 2009). 'Intimacy at a distance' may be more damaging for non-resilient carers if they have fewer alternative individual and societal resources from the resilience framework (Windle & Bennett, 2011). An abundance of support resources could indicate resilience, but it could indicate non-resilience if the resources do not match current need. Non-resilient carers may be at increased risk of isolating themselves from family members. We recommend that family support be made available on the carer's own terms as not to relinquish their feelings of independence and autonomy. These perceptions may moderate the effect of family support on resilience in older spousal dementia carers.

Resilient carers were more likely to receive informational support from group and existing friends with shared experience. Conversely, friends of non-resilient carers seem to share less experience, and serve a narrower function; such as positive social interaction. This suggests that shared experience may facilitate resilience. Socioemotional Selectivity Theory predicts that support perceived as congruent with the carer's self-concept and personal circumstances is especially beneficial for subjective wellbeing (Carstensen, 1991; Farran et al., 2004). Our findings emphasize the importance of clubs, church groups and support groups as societal resources within which individual and community resources can be shared. Indeed, research shows that support groups can increase emotional and informational dimensions of support, and reduce psychological distress, depressive mood and burden (Han et al., 2014).

Existing friends were more likely to disengage from non-resilient carers (Clay et al., 2008). Again, shared experience may explain this; they have little in common anymore. We suggest that friends with common ground share more understanding and are therefore perceived as more supportive than friends without common ground. Harris (2013) suggested that friendships are best maintained in the context of dementia through understanding, accepting and recognising the person's values and limitations. It may be that carers play their own role in actively disengaging from their friends over time (Hough et al., 2005; Han et al., 2014). Spencer and Pahl (2006) note that longstanding friends are relatively multifaceted compared to new friends and this may cause differences in the type of support offered and the way it is perceived. Existing friend support varies pre- and post-dementia whereas family support is more stable over time. Other supports, such as group friends, are gained. Practical attempts to reduce loneliness or increase the number of social relationships may be futile; practitioners and policy makers should not rely solely on the presence or absence of support networks but the perceived satisfaction with social support (O'Rourke & Tuokko, 2000;

Thetford et al., 2015). These perceptions may moderate the effect of friend support on resilience.

Unexpectedly we found that grandchildren were more available to non-resilient carers. They provided mainly positive social interaction and affectionate support; a relatively narrow and lower level function than, for instance, support from children. This may simply reflect age-differences between participants; non-resilient are slightly older than resilient participants so may have older and more capable grandchildren. Positive social interaction and affectionate support from grandchildren may be too narrow and low level to facilitate resilience. These functions could explain why carers prefer 'intimacy at a distance', but do not actively resist support from grandchildren as they do children and in-laws. Positive social interaction and affectionate support from grandchildren may be less likely than tangible support from children and in-laws to threaten the carer's sense of independence. Most of the grandchildren in the study are younger, and so they are also less likely to have competing demands that carers can use to justify this resistance. Further research is needed to explore these findings in more detail. Differences in availability make it difficult to assess functional differences between resilient and non-resilient carers. We found that neighbours were more available to resilient carers. Neighbours were qualitatively different from friends; they were not identified as friends by carers. However neighbour support was functionally unique; they provided tangible crisis management at times when family and close friends were unavailable. It was clear that this reduced feelings of burden and stress (Han et al., 2014). Research shows that supportive neighbourhoods and neighbours are essential resilience resources for dementia carers (Toot et al., 2013).

A key strength of the current study is that we included relatively unstudied social network members; for example, in-laws and neighbours. There are unique functional differences between each support member. Previous studies have suggested that spousal

carers are supported mostly by pre-existing social networks (Antonucci et al., 2011). We show that carers can gain support over time, such as group friends. Our in-depth qualitative methodology is another strength. It allows us to capture the complex dynamic processes of social support, and ground social networks within a richer context. This informs future qualitative and quantitative work to draw out the theoretical and practical implications established in this paper. However, qualitative research precludes causality; directionality between support and resilience cannot be assumed. We have shown that family and friend support serves a range of specific functions which facilitate or hinder resilience. However, there are examples in our data where the social interactions of resilient carers are targeted towards shared experience and informational support. Non-resilient carers may actively disengage from existing friends, and resist family support which is over-intensive. This fits with the resilience framework (Windle & Bennett, 2011) which posits that resources facilitate resilience which then feeds back to create further challenges and resources. Further discussion of directionality goes beyond the research objectives of this study. More research is needed to explore these complex mechanisms of support and resilience.

There are a number of other important considerations. 17 participants were sampled from dementia support groups whereas six were from a care home. This has implications for social support; perhaps some of our sample are supported differently than other carers. Future research should look to recruit a more representative sample. Spousal carers are often not the only primary carer. Future research may wish to interview carer dyads; for example, wife-daughter caring for father, or husband-neighbour caring for wife. Research has examined parental dyads when the mother has dementia (Ward-Griffin, 2007), but no research has studied these from the perspective of the carer. This may uncover hidden dimensions of the dyadic relationship. Due to the unpredictable course and extended duration of dementia (Potgieter, Heyns, & Lens, 2012), future studies may wish to examine the longitudinal effects

of social support in carers. Most longitudinal studies in this area use quantitative approaches (Ross et al., 2003; Gaugler, Kane, & Newcomer, 2007) but qualitative longitudinal research (QLR) is complex and rare (Calman, Brunton, & Molassiotis, 2013). By following the same cohort of carers and interviewing them through transitions into institutionalisation or widowhood using the resilience framework (Windle & Bennett, 2011), we would gain a more dynamic picture of support in carers.

In conclusion, our findings suggest that social support is not a straightforward resilience resource. Family and friends provide a range of supports to older spousal dementia carers but it is not always sufficient to facilitate resilience. Support functions may facilitate resilience only if they are perceived to match need. We recommend that carers should be supported by appropriately involved family members that foster independence and like-minded friends with shared interests, ideally within a group setting where expertise and experience can be acquired and shared. The findings bridge the gap between individual and community dimensions of the resilience framework (Windle & Bennett, 2011), although more work is needed to address the complex relationship between support and resilience. Future research should acknowledge the full structural composition of support, and the multidimensional function it serves for carers over time.

References

Antonucci, T.C., Birditt, K.S., Sherman, C.W., & Trinh, S. (2011). Stability and change in the intergenerational family: A convoy approach. *Ageing and Society*, *31*(7), 1084-1106.

Bennett, K. M. (2010). How to achieve resilience as an older widower: turning points or gradual change? *Ageing and Society, 30*(3), 369-382.

Bennett, K. M., Vidal-Hall, S. (2000). Narratives of death: A qualitative study of widowhood in later life. *Ageing and Society, 20,* 413-428.

Bennett, K. M., & Windle, G. (2015). The importance of not just individual but community and society factors in resilience in later life. [Peer commentary on "A conceptual framework of the neurobiological study of resilience", by R. Kalisch, M. B. Müller, & O. Tüscher]. *Behavioral and Brain Science, 38*, 1-79.

Calman, L., Brunton, L., & Molassiotis, A. (2013). Developing longitudinal qualitative designs: lessons learned and recommendations for health services research. *BMC Medical Research Methodology, 13*(14), 1-10.

Carstensen, L. (1991). Selectivity theory: Social activity in life-span context. *Annual Review of Gerontology and Geriatrics*, *11*, 195-217.

Charmaz, K. (1995). Grounded theory. In Smith, J. A., Harré, R. & van Langenhove, L. (eds), *Rethinking Methods in Psychology* (27-49). London: Sage.

Clay, O.J., Roth, D.L., Wadley, V.G., & Haley, W.E. (2008). Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and white dementia caregivers. *International Journal of Geriatric Psychiatry, 23*(8), 857-62.

Donnellan, W.J., Bennett, K.M., & Soulsby, L.K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging & Mental Health, 19,* 932-939.

Ellwardt, L., Aartsen, M., Deeg, D., & Steverink, N. (2013). Does loneliness mediate the relation between social support and cognitive functioning in later life? *Social Science & Medicine, 98*, 116-24.

Farran, C.J., Loukissa, D., Perraud, S., & Paun, O. (2004). Alzheimer's disease caregiving information and skills. Part II: family caregiver issues and concerns. *Research in Nursing & Health, 27*(1), 40-51.

Fiori, K.L., Antonucci, T.C., & Cortina, K.S. (2006). Social network typologies and mental health among older adults. *Journals of Gerontology. Series B (Psychological Sciences and Social Sciences), 61*(1), 25-32.

Gaugler, J.E., Kane, R.L., & Newcomer, R. (2007). Resilience and transitions from dementia caregiving. *Journals of Gerontology, 62*(1), 38-44.

Han, J.W., Jeong, H., Park, J.Y., Kim, T.H., Lee, D.Y., Lee, D.W., Ryu, S.H., Kim, S.K., Yoon, J.C., Jhoo, J., Kim, J.L., Lee, S.B., Lee, J.J., Kwak, K.P., Kim, B.J., Park, J.H., & Kim, K.W. (2014). Effects of social supports on burden in caregivers of people with dementia. *International Psychogeriatrics, 26*(10), 1639-48.

Harris, P.B. (2013). Dementia and friendship: the quality and nature of the relationships that remain. *International Journal of Aging and Human Development, 76*(2), 141-64.

Hough, E., Magnan, M., Templin, T., & Gadelrab, F. (2005). Social network structure and social support in HIV-positive inner city mothers. *Journal of the Association of Nurses and AIDS care, 16*, 14-24.

Ingersoll-Dayton, B., Morgan, D., & Antonucci, T. (1997). The effects of positive and
negative social exchanges on aging adults. *Journal of Gerontology: Social Sciences,
52*, 190-99.

Liebenberg, L., & Ungar, M. (2009). Introduction: The challenges in researching resilience.
In L. Liebenberg, & M. Ungar (Eds.), *Researching Resilience* (3-25). Toronto:
University of Toronto Press.

NHS Information Centre. (2010). Survey of carers in households in England 2009/10.
Available online at:
http://www.ic.nhs.uk/webfiles/publications/Soical%20Care/carersurvey0910/Survey_
of_Carers_in_Households_2009_10_England_Provisional_Results_post_publication.
pdf. [01/03/2015].

O'Rourke, N., & Tuokko, H. (2000). The psychological and physical costs of caregiving: The
Canadian Study of Health and Aging. *Journal of Applied Gerontology, 19*(4), 389-
404.

Office for National Statistics. (2011). 2011 Census: Aggregate data (England and Wales)
[computer file]. UK Data Service Census Support. Retrieved from
http://infuse.mimas.ac.uk.

Pinquart M., & Sörensen, S. (2000). Influences of socioeconomic status, social network, and
competence on subjective wellbeing in later life: A meta-analysis. *Psychology and
Aging, 15*, 187-224.

Potgieter, J. C., Heyns, P. M., & Lens, W. (2012). The time perspective of the Alzheimer
caregiver. *Dementia, 11*(4), 453-471.

Reinhardt, J.P., Boerner, K., & Horowitz, A. (2006). Good to have but not to use: differential impact of perceived and received support on well-being. *Journal of Social and Personal Relationships, 23*(1), 117-29.

Rosenmayr, L. (1983). *Die Späte Freiheit: Das Alter, ein Stück bewusst gelebten Lebens* [The Late Freedom: Old Age – A piece of consciously experienced life]. Berlin, Germany: Severin and Siedler.

Ross, L., Holliman, D., & Dixon, D.R. (2003). Resiliency in family caregivers: Implications for social work practice. *Journal of Gerontological Social Work, 40*(3), 81-96.

Roth, D.L., Mittelman, M.S., Clay, O.J., Madan, A., & Haley, W.E. (2005). Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychology and Aging, 20*(4), 634-44.

Sherbourne, C.D., & Stewart, A.L. (1991). The MOS-SSS social support survey. *Social Science & Medicine, 32*(6), 705-14.

Sherman, C.W., Webster, N.J., & Antonucci, T.C. (2013). Dementia caregiving in the context of late-life remarriage: support networks, relationship quality, and well-being. *Journal of Marriage and Family, 75*, 1149-63.

Soulsby, L.K., & Bennett, K.M. (2015). How relationships help us to age well. *The Psychologist, 28*(2), 110-13.

Spencer, L., & Pahl, R. (2006). *Rethinking friendship: Hidden solidarities today.* Princeton, NJ: Princeton University Press.

Thetford, C., Hodge, S., Bennett, K.M., Knox, P., & Robinson, J. (2015). Resilience and vision impairment. *Journal of Aging Studies, 35*, 37-48.

Toot, S., Hoe, J., Ledgerd, R., Burnell, K., Devine, M., & Orrell, M. (2013). Causes of crises
and appropriate interventions: The views of people with dementia, carers and
healthcare professionals. *Aging & Mental Health, 17*(3), 328-335.

Uchino, B.N. (2009). Understanding the links between social support and physical health: A
life-span perspective with emphasis on the separability of perceived and received
support. *Perspectives on Psychological Science, 4*(3), 236-55.

Ward-Griffin, C. (2007). Mother-adult daughter relationships within dementia care: A critical
analysis. *Journal of Family Nursing, 13*(1), 13-32.

Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical
Gerontology, 21*, 252-69.

Windle, G., & Bennett, K.M. (2011). Resilience and caring relationships. In M. Ungar (Eds.),
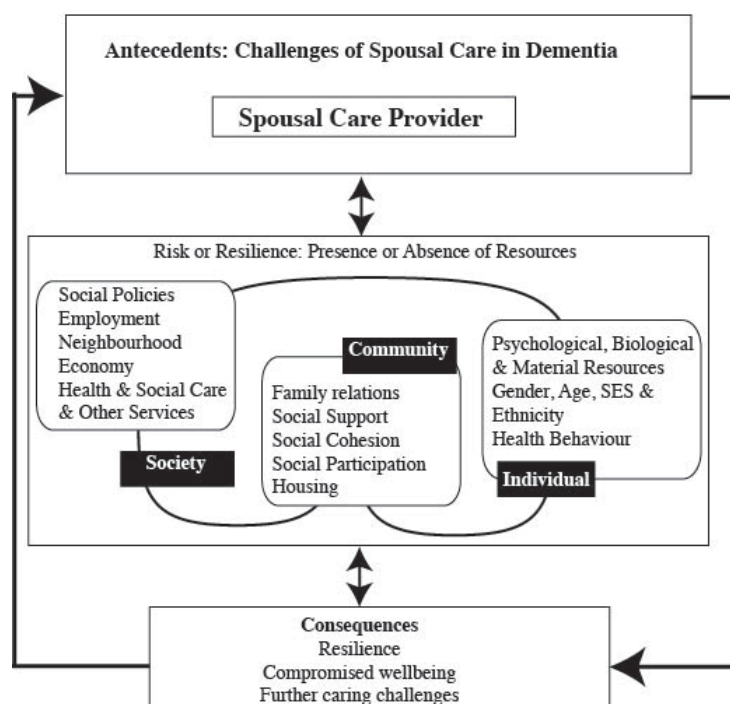*The Social Ecology of Resilience* (pp. 219-232). New York: Springer.

Figure 1: The Resilience Framework applied to spousal carers (Windle & Bennett, 2011).

Table 1: Demographic characteristics and resilience classification of carers.

Carers (N=23)	Age (years)	Marriage duration (years)	Care duration (years)	Social class	Resilient/Not resilient
Mrs W.	62	28	3	Skilled	Not resilient
Mrs C.	68	48	9	Skilled	Resilient
Mrs Wi.	69	51	4	Skilled	Not resilient
Mrs F.	71	51	3	Unskilled	Not resilient
Mrs L.*	73	53	10	Unskilled	Resilient
Mr G.	81	52	5	Skilled	Resilient
Mrs G.**	82	49	5	Skilled	Not resilient
Mrs Go.	69	40	5	Unskilled	Resilient

Mrs O.	77	59	2	Unskilled	Not resilient
Mrs S.	86	61	6	Unskilled	Not resilient
Mr Go.	74	52	10	Skilled	Resilient
Mr Wh.	71	50	10	Skilled	Resilient
Mr H.	81	53	5	Skilled	Not resilient
Mrs P.	75	49	4	Skilled	Not resilient
Mr N.	71	41	7	Skilled	Resilient
Mr Gr.*	88	56	9	Skilled	Not resilient
Mrs H.	89	58	7	Skilled	Not resilient
Mrs La.	83	55	2.5	Professional	Not resilient
Mr Ha.	80	52	3	Professional	Resilient
Mrs Cl.	69	49	3	Unskilled	Not resilient
Mrs Wk.* ⴕ	72	44	4	Professional	Resilient
Mrs Lg. ⴕ	69	43	6	Professional	Resilient
Mrs Hn. ⴕ	65	47	2.5	Unskilled	Not resilient

Key: *Widowed **Institutionalised ⴕ New participant