

Exploring resilience in adult daughter and spousal carers of people living with dementia in North West England: an ecological approach

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Abstract

Purpose – Research has shown that informal carers of people living with dementia (PLWD) can be resilient in the face of caregiving challenges. However, little is known about resilience across different kinship ties. This study aims to update and build on our previous work, using an ecological resilience framework to identify and explore the factors that facilitate or hinder resilience across spousal and adult daughter carers of PLWD.

Design/methodology/approach – This study conducted in-depth qualitative interviews with a purposive sample of 13 carers from North West England and analysed the data using a constructivist grounded theory approach (Charmaz, 2003).

Findings – Adult daughters were motivated to care out of reciprocity, whereas spouses were motivated to care out of marital duty. Spouses had a more positive and accepting attitude towards caregiving and were better able to maintain continuity, which facilitated their resilience.

Research limitations/implications – Resilience emerged on multiple levels and depended on the type of kinship tie, which supports an ecological approach to resilience. The implications of these findings are discussed.

Originality/value – This paper makes a novel contribution to the literature as it uses an in-depth qualitative methodology to compare resilience across spousal and adult daughter carers of PLWD. This study adopts an ecological approach to identify not just individual-level resilience resources but also interactive community- and societal-level resources.

Keywords Resilience, Informal carer, Spousal, Adult daughter, Ecological, Qualitative

Paper type Research paper

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Introduction

A total of 850,000 people are currently living with dementia in the UK; this is projected to reach 2 million by 2050 (Lewis *et al.*, 2014). With this comes a growing number of informal carers, most commonly adult children (58%) and spouses (26%) (NHS Information Centre, 2010). The unpaid care provided by these carers saves the UK economy £132bn per year (Carers UK, 2019). Therefore, identifying ways to sustain carers of people living with dementia (PLWD) in their role is becoming increasingly important (Alzheimer's Society, 2014).

Informal care for PLWD is burdensome (McCann *et al.*, 2015; Pinguart and Sörensen, 2003; Scott, 2013). Spousal and adult child carers of PLWD each experience burden differently. Spouses are likely to provide the most hours of care (NHS Information Centre, 2010) and experience age-related physical (Pinguart and Sörensen, 2007), cognitive (Kim *et al.*, 2012)

and mental impairments (Pinquart and Sörensen, 2003). The negative impact on spouses may be exacerbated by the breakdown of the spousal relationship (Etters *et al.*, 2008; Fitzpatrick and Vacha-Haase, 2010; Gladstone, 1995; Pinquart and Sörensen, 2011). Adult children are more likely to be balancing caregiving responsibilities with other commitments, such as their spouse, children and career (Brandao *et al.*, 2016; Cherry *et al.*, 2013; Grundy and Henretta, 2006; Pinquart and Sörensen, 2011; Romero-Moreno *et al.*, 2013). Adult daughters may be particularly at risk of negative outcomes, as the filial obligation that women should care for their parents may cause feelings of guilt (Chappell *et al.*, 2014; Gonyea *et al.*, 2008; Pinquart and Sörensen, 2011).

However, some carers are able to overcome burden and flourish in their role. This is consistent with a growing literature on positive aspects of caregiving (Doris *et al.*, 2018; Lloyd *et al.*, 2016). This approach is not a new one; Folkman (2008) established that positive states coexisted with negative states throughout the caregiving period. These positive states, such as reward (Pinquart and Sörensen, 2003), optimism (Zauszniewski *et al.*, 2009) and growth (O'Dwyer *et al.*, 2017), to name a few, are important because they help sustain the carer in their role. However, most work considers the adversity of caregiving with relatively little work considering the response to adversity, including the positive features of caregiving (Teahan *et al.*, 2020).

This response to adversity may be best captured by resilience. Early definitions of resilience highlighted the process of overcoming stress or adversity (Luthar *et al.*, 2000). More recently, researchers have begun to argue that resilience is not simply stress resistance or invulnerability to stress, but the ability to function positively and recover from setbacks more quickly than others with an equivalent level of exposure to negative events (Rutter, 2012). Windle (2011) conducted a comprehensive concept analysis of resilience, drawing on a range of multi-disciplinary perspectives. She 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).

There is some debate about whether resilience is a dynamic process (Bonanno and Diminich, 2013; Windle *et al.*, 2010) or a unitary outcome (Bennett, 2015; Liebenberg and Ungar, 2009). Other researchers argue that resilience is an outcome following adversity and that there are mediating processes or resilience factors that facilitate or hinder that outcome (Kalisch *et al.*, 2015; van Breda, 2018). We adopt the latter conceptualisation in the current study as it is most comprehensive.

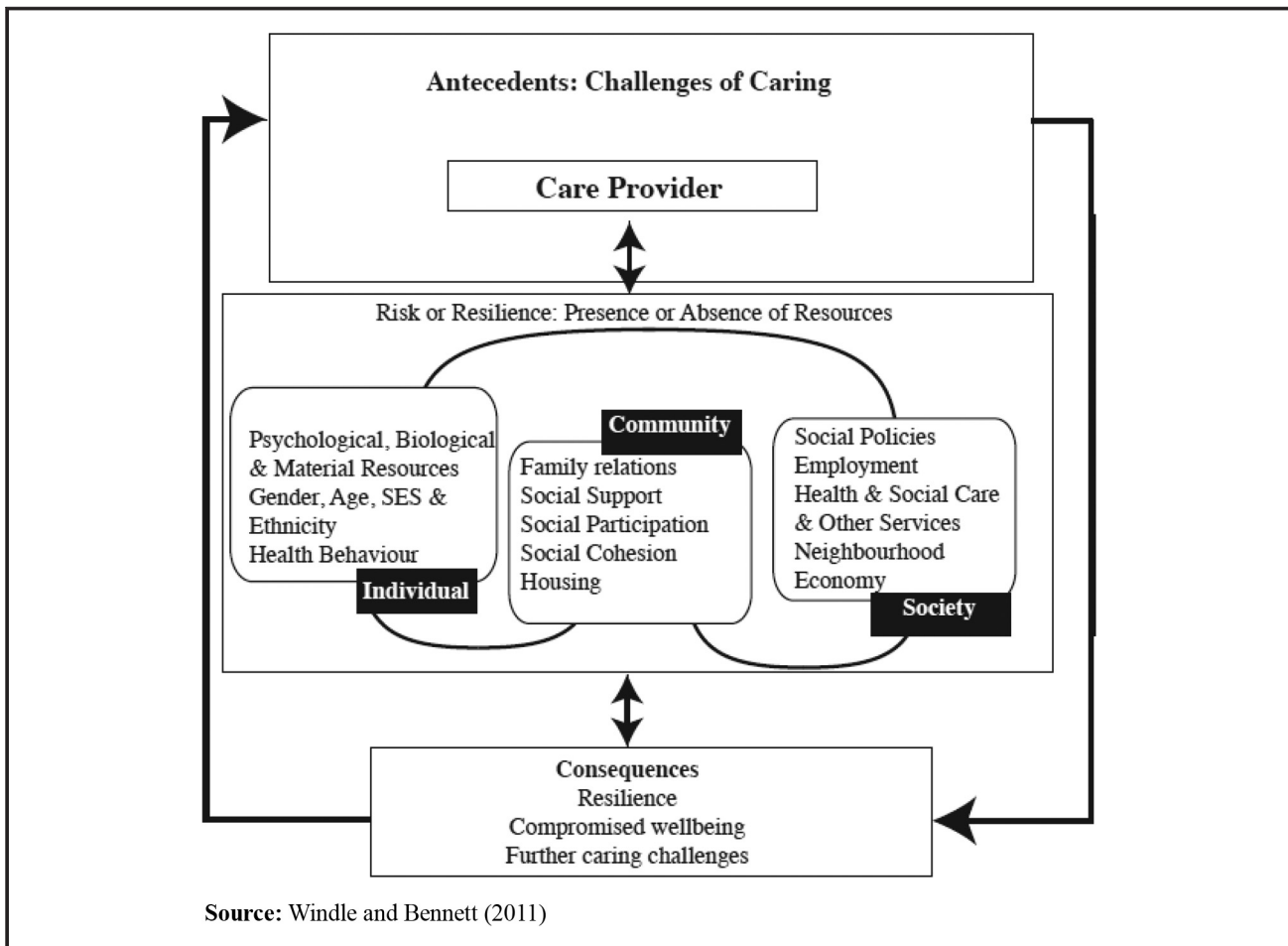
Resilience is most commonly conceptualised as a trait or psychological attribute (Bonanno *et al.*, 2007; Kalisch *et al.*, 2015; Windle *et al.*, 2010) and has been examined in relation to a range of psychological constructs, including but not limited to: optimism; acceptance; emotional intelligence; mastery; competence; self-esteem; and interpersonal control (Carboneau *et al.*, 2010; Cherry *et al.*, 2013; Windle *et al.*, 2008). Dementia care studies tend to conceptualise resilience as a trait predictor of clinical outcomes, such as depressive symptoms (O'Rourke *et al.*, 2010), or institutionalisation and death of the PLWD (Gaugler *et al.*, 2007). It is clear that the above psychological factors play an important role in facilitating resilience but there are problems with the concept of psychological resilience. First, conceptual overlap between the above constructs has led to definitional “fuzziness” and inconsistent operationalisation (Cherry *et al.*, 2013; Lerner, 2006; Ungar, 2003). Second, psychological resilience places responsibility with the carer rather than interpersonal resources or supportive services (Windle, 2011; Ungar, 2015); carers may be reluctant to increase their resilience levels if it simply made them more adept at carrying a greater load. Finally, psychological resilience neglects socio-environmental factors known to promote resilience. For example, Cherry *et al.* (2013) identified a framework of three

interrelated factors influencing resilience in carers of PLWD, including psychological factors and properties of the care relationship but also social and cultural factors.

The notion that resilience is determined by the interaction between individuals and their immediate and wider social environments is not new (Bennett and Windle, 2015; Ungar, 2015). Indeed, even researchers who have focused on psychological dimensions of resilience acknowledge the existence of wider factors (Kalisch *et al.*, 2015). This has led some researchers to consider the social ecology of resilience (Ungar, 2011). This has been heavily based on the principles of Bronfenbrenner and Ceci's (1994) ecological systems theory, whereby individuals draw on micro-level individual characteristics and meso-, exo- and macro-level environmental resources to reduce or prevent chronic adversities. Integral to this approach is that resilience may reflect the capacity of systems to adapt, rather than the capacity of individuals to overcome challenges. Environmental factors may explain as much as, if not more, variance in positive developmental outcomes from adversity than individual factors (Ungar, 2011).

Based on the principles outlined above, Windle and Bennett (2011) developed an ecological resilience framework applied to carers (Figure 1). The framework posits that resilience can be facilitated by carers' individual assets, and community and societal resources. In our previous study, we used the resilience framework to identify the factors associated with resilience in spousal carers of PLWD (Donnellan *et al.*, 2015). Resilient

Figure 1 The ecological resilience framework applied to informal carers



carers typically stayed positive and actively maintained their relationship and loved one's former self. Resilient carers were knowledgeable and appropriately supported by family and friends with shared experience. Finally, resilient carers were more actively engaged with services such as respite care. However, the resilience framework is theoretical and no means exhaustive (Windle and Bennett, 2011) and the extent to which these factors could be transferred to other carers, such as adult children, was unclear.

Research suggests that resilience may differ between spousal and adult child carers. Spouses draw upon positive memories of their marriage to help them to be resilient and are motivated to care out of love, commitment and marital duty (Bonanno *et al.*, 2004; Cherry *et al.*, 2013; Gaugler *et al.*, 2007; Lloyd *et al.*, 2016). Moreover, spouses are accustomed to providing support to their partner throughout their marriage and therefore may find it easier to adjust to caregiving, which may be perceived as an extension of marriage (Cherry *et al.*, 2013; Lloyd *et al.*, 2016). Adult children may be uplifted by the role reversal that occurs when caregiving for a parent, as this represents reciprocity of the care they received from their parent in the past (Donorfio and Kellett, 2006; Pinquart and Sörensen, 2011; Strauss, 2013). Whilst alternative roles of adult children can generate added pressure, the roles may help to buffer caregiver burden, such as employment as an escape from caregiving responsibilities (Chappell *et al.*, 2014; Cherry *et al.*, 2013; Lloyd *et al.*, 2016; McCann *et al.*, 2015; Pinquart and Sörensen, 2003, 2011; Strauss, 2013; Wilks and Croom, 2008). This may explain why adult children have been found to have more positive caregiving-related experiences than spouses, including personal growth (Ott *et al.*, 2007).

In our previous work, we examined resilience in spousal carers of PLWD (Donnellan *et al.*, 2015). However, we know that spouses are second to adult children in terms of the total number of informal carers of PLWD living in the UK (NHS Information Centre, 2010). There is a need to update and build on our previous work by including a novel sample of spousal and adult children carers and comparing resilience across each kinship tie. Therefore, the current study uses Windle and Bennett's (2011) ecological resilience framework to explore the factors that facilitate resilience across spousal and adult daughter carers of PLWD. The research objective is to identify the factors that facilitate or hinder resilience in spousal and adult daughter carers, and whether these factors can be mapped on to Windle and Bennett's (2011) ecological resilience framework.

Methods

Sample

The current study included a purposive sample of 13 informal carers of PLWD: six adult daughters and seven spouses (two husbands and five wives). According to Tongco (2007), purposive sampling is appropriate when researchers require a sample of participants who are "willing to provide information by virtue of knowledge or experience" (i.e. informal carers of PLWD) (p. 147). We sampled until we reached theme saturation; the point at which no new information or themes were observed (Guest *et al.*, 2006). Five of the participants were recruited using a snowball sampling method, for example; after being interviewed, Daughter 3 recommended her sister, Daughter 4, to take part. Although these participants cared for the same person, they were interviewed individually to capture their unique caregiving experiences.

Carers were recruited from two dementia support groups ($n = 8$) and a small network of other contacts ($n = 5$) from North West England. Two female researchers, including the third author, approached the organisations by phone, before being invited to give a brief talk about the research. Most spousal carers lived with their spouse at home ($n = 5$), whereas most adult daughters lived separately from their parent ($n = 4$), except Daughter 2 who lived with her father ($n = 1$). Three carers were caring for PLWD who were residing in nursing

home care settings ($n = 3$). Some carers reported caregiving for longer than the dementia care duration. For example, Daughter 3 had been caring for her mother since her father died 16 years ago and Wife 3 had cared for her husband since he had a heart attack 29 years ago. See [Table 1](#) for a summary of participant information.

Data collection

Semi-structured interviews were conducted between June 2016 and October 2016. Interviews were conducted on a one-to-one basis by one of two female researchers, including the third author, each lasting between 30 and 142 min. The participants chose for their interviews to be conducted in their own homes as they felt more comfortable in familiar surroundings. To reduce the risk of being disturbed during spousal interviews, the PLWD was looked after by a family member in a separate room for the duration of the interview. Both researchers were fully trained in semi-structured interviewing and worked under the close supervision of the first author, who has ten years of experience in conducting qualitative interview studies with older adults. The interviews were audio-recorded and transcribed by the two researchers, and all identifying information was anonymised. The study received ethical approval from the University of Liverpool Research Governance Committee.

Section A of the interview schedule began with factual questions, such as age, family information, employment and care duration. Section B asked about life before caregiving, Section C asked about the period surrounding the diagnosis and Section D asked about the present situation. Each section included a range of open questions about what life was like, what their relationship with the PLWD was like, what roles and responsibilities they had and what support they received. Finally, in Section E, carers were asked what had been helpful to them, what changes would make life easier for them and what advice they would give to someone in the same position as themselves. We deliberately did not ask the carers directly about resilience as we did not want to prime their responses in any way. Instead, our questions focused on areas known to be related to resilience and therefore any reference to resilience resources was spontaneous and therefore more credible ([Lincoln and Guba, 1985](#)).

Data analysis

We used a constructivist grounded theory approach to analyse the interview data ([Charmaz, 2003](#)). According to [Charmaz \(2017\)](#), constructivist grounded theory is

Carers (N = 13)	Age (years)	Care duration (years)	Marriage duration (years)
Daughter 1	47	1	N/A
Daughter 2	73	4	N/A
Daughter 3	60	3	N/A
Daughter 4	57	4	N/A
Daughter 5	48	4	N/A
Daughter 6*	Unintelligible	Unintelligible	N/A
Husband 1	76	9	50
Husband 2*	81	4	55
Wife 1	79	9	54
Wife 2	68	7	49
Wife 3	61	5	39
Wife 4*	80	8	53
Wife 5	62	5	35

Notes: *Person living with dementia residing in residential care setting. "Daughter" refers to adult child carers and Husband/Wife' refers to spousal carers

particularly useful when examining complex psychological phenomena which require critical questions and deep reflexivity. It adopts the inductive approach of grounded theory but acknowledges that social reality is constructed through relativism; the mutual co-construction of knowledge between participants and researchers (Charmaz, 2014). As the researcher is not considered a neutral observer, it is important to take their perspective into account as an inherent part of the process. These principles are well aligned with the current study as we aimed to update and build on the findings of an earlier study by the first and second authors, as well as map the themes onto a theoretical resilience framework (Windle and Bennett, 2011).

Firstly, the third author read through each interview in its entirety to gain a contextualized understanding of the participants' experiences. Constructivist grounded theory was then used to analyse the interviews line-by-line, with each line being summarised with an open code. The most commonly recurring codes within each transcript were used to form axial categories which summarised each interview. Common categories were then merged to form selective themes across all interviews (Charmaz, 2014). This approach was reflexive so that emergent themes led to re-coding. The first and third authors then re-examined the themes to identify the factors that facilitate or hinder resilience. In line with the principles of constructivist grounded theory (Charmaz, 2014), we examined the extent to which these factors mapped on to the ecological resilience framework (Windle and Bennett, 2011). Both spousal and adult daughter interviews were subjected to the same process of analysis, but comparisons were made between them at each stage to explore resilience across different kinship ties.

Strategies to ensure rigour of findings

We adopted a number of strategies to ensure the rigour of our findings. The following paragraphs briefly outline these strategies according to Lincoln and Guba's (1985) criteria: credibility (the value, believability and confidence in the truth of the findings); transferability (extent to which qualitative findings can be applied to other contexts); dependability (stability of the data and how consistent and repeatable it is); and confirmability (neutrality and accuracy of the data).

To ensure credibility, we employed multiple researchers at the data collection and analysis stages to ensure complementary as well as divergent understanding of the data. We built trust and rapport with all participants both prior to and during the interviews being conducted. Once the data had been analysed, we member checked this by presenting it to each participant that was interviewed, and all participants were satisfied that the findings accurately represented their experiences. To ensure transferability, we included as much contextual detail as possible when presenting our findings, including demographic and care context information.

To ensure dependability and confirmability, the paper was independently peer reviewed to ensure that the findings, interpretations and conclusions were supported by the data. The interviewers kept reflexive diaries during and after interviews to document methodological decisions, preconceptions and initial impressions of the data. We regularly recoded the data as new themes emerged to capture important findings that might have been missed. Finally, all stages of analysis were conducted independently and blind by the first and third authors; in the event of discrepancies between the two analysts, we did not move to the next stage until a consensus was reached. Consensus was reached in most cases, but if themes differed, then each analyst re-examined and compared their coding/criteria until an agreement was reached.

Results

The constructivist grounded theory analysis revealed a number of factors which facilitated or hindered resilience for the carers. The following section presents these resilience factors

under each level of [Windle and Bennett's \(2011\)](#) resilience framework, addressing the extent to which they map on to the framework and comparing across spousal and adult daughter carers throughout.

Individual level

The findings below align largely with the psychological assets component of the resilience framework.

Psychological assets

The first asset that facilitated carers' resilience was acceptance of their current situation. Acceptance was key in facilitating resilience over time:

We seem to be happy again [...] when you first get diagnosed it's a shock, you're upset [...] once you start to accept that your mum's got it [...] you start to laugh about it (Daughter 6).

In spite of dementia care becoming more challenging over time, many of the carers in our sample became better able to overcome caregiving challenges. Acceptance also appeared to come easier to spouses; Daughter 2, who cared for both her husband and father through dementia, compared the difference between the two kinship ties:

You're husband and you're wife [...] if they're ill it's in sickness and in health [...] But with your father it's not (Daughter 2).

This suggests that the sense of duty to a spouse differs to that to a parent. Spouses frequently claimed that caregiving for their partner was intrinsically rewarding and that they were motivated to carry on caregiving for their partner for as long as possible out of love and commitment:

Even if I just got one smile out of [my wife] in a day [...] that's enough [...] I couldn't live with myself with her in a home two miles down the road [...] I'll just see it out 'til the bitter end (Husband 1).

Some spouses therefore cared out of personal desire, which was associated with deriving more positive benefits from caregiving and facilitating resilience:

I try and be quite positive about everything [...] and I do think [...] we've got some really good friends now and we go out and we do things. I think "it's not all bad, come on. Get a grip, girl" (Wife 5).

On the other hand, some carers derived fewer benefits from their caregiving duties which hindered resilience. For example, adult daughters may care out of filial obligation, whereby they hold responsibility for their parents' welfare:

I feel guilty that I've got carers going in [...] I feel it's my duty [...] I feel guilty that my sister stays with [my mum] two nights a week because I feel that makes her a better daughter than me (Daughter 3).

Filial obligation hindered some adult daughters' resilience as it caused feelings of guilt and entrapment. This discrepancy in the sense of duty of adult daughters and spouses may be because caregiving is more of an unanticipated extra responsibility for adult daughters, whereas for spouses caregiving may be more likely to be construed as a normal and accepted part of marriage that they are prepared for:

The balance changes, but it's still the person you married [...] it's still the person you've lived with all that time [...] you still love them. It's just different [...] it's not a duty. It's just something that's part of life (Wife 4).

Spouses may therefore maintain continuity in their relationship with the PLWD, as caregiving for a spouse may be accepted as a normal aspect of the life cycle. Maintaining continuity may help carers to increase resilience and sustain their caregiving responsibilities, therefore this ability may reflect the longer care duration of spouses in the current sample:

It was just normal. I was just used to how [my husband] was and we just carried on the same [...] (Wife 1).

Spouses' positivity, optimism and determination also helped them to maintain continuity:

We hadn't been abroad for two years so it was a bit of a learning curve. But the thing with that is to learn something from it and find out, well some things didn't really work on that holiday, what can I do to make it work and to make it easier next time? (Wife 5).

Positivity was therefore a key asset which facilitated the resilient attitude of "you can still do things, you just have to change the way you do things" (Wife 2), which helped some spouses to take control, adjust and "bounce back" from caregiving challenges in order to maintain their quality of life. However, some spouses struggled to maintain continuity, and instead focused on what they had lost:

You feel like you're just as ill as them because you don't go on holiday, you don't go out for meals [...] you feel you're on your own and they're in couples and, your whole life changes (Husband 1).

Research has shown that caregiving demands can compromise marital satisfaction in spousal carers, particularly when caregiving causes changes in their lifestyle and relationship, which may hinder resilience:

You're not a partnership anymore. You are the person who's having to think for two, having to do everything for two. That's the difference [...] you're with someone but you're alone (Wife 4).

Changes in the marital relationship may therefore be particularly stressful due to the longevity of spouses' marriages and because they reflect a transition from partnership to singlehood. Indeed, caring for a PLWD has been likened to bereavement as carers often experience anticipatory grief owing to the "social death" of the person living with dementia. Anticipatory grief was evident in adult daughters:

The roles got reversed a bit. I was starting to be the mum [...] there were times when I needed [her] and she wasn't there, she was physically there for me but she couldn't help me (Daughter 6).

However, some adult daughters positively appraised their new parent-child relationship dynamic. Daughter 4 was emotional as she explained:

[My mum] shouldn't have to feel grateful because it's just role reversal [...] I'm very grateful for everything she's done for me [...] (Daughter 4).

Some adult daughters experienced role reversal, in which they became the parent and their parent became the child. Role reversal was frequently drawn upon as motivation to carry on caregiving, as some adult daughters viewed this as an opportunity to reciprocate everything their parent had done for them when they were younger, which facilitated their capacity for resilience.

Community level

The following findings align with the family relations, social support and social participation resources from the resilience framework.

Family relations

Adult daughters were unique in that they reported having extra family commitments in addition to caring for their parents, such as their children, husband, career and household chores:

I still [tried] to fit in everything I had to do for my family [...] it did cause me stress (Daughter 1).

Caregiving commitments often created added stress on top of adult daughters' already busy lives. Adult daughters may experience "role overload" as they are "sandwiched" between multiple family commitments, which could hinder their capacity for resilience. Daughter 3 explained:

I don't do the things that I enjoy doing [...] my life's been taken over by other people and I do feel quite angry about it (Daughter 3).

In some cases, adult daughters' multiple commitments meant that they had to alter their lifestyle and lessen the time they had for themselves which hindered their resilience. These lifestyle changes appeared to have come prematurely for adult daughters and caused feelings of anger, frustration and resentment. However, some adult daughters had siblings to help relieve this burden:

I'm lucky [...]. if one person doesn't do something the other person does [...] everything is shared out very equally [...] it's all about sharing the burden (Daughter 5).

The ability to share the caregiving role with siblings was important for resilience as it helped to alleviate some of the pressure of caregiving and allowed adult daughters to balance their commitments alongside their independent family lives. However, this resource appeared to be dependent on fairness, as family "rows" ensued if a sibling was not contributing their fair share of caregiving responsibilities to their parent:

Things were getting quite strained between my sisters [...] we all had little niggles with each other over who was doing what (Daughter 1).

These findings highlight the facilitating and hindering role of family in adult daughter carers. Family conflict contributed further stress on top of the pressure of caregiving, therefore siblings could both facilitate and hinder resilience.

Social support and participation

Social support refers to the exchange of support between the carers' social networks. Carers were often apprehensive about burdening their family members. Previously observed in spousal carers of PLWD, this has been termed "intimacy at a distance":

I don't like my husband seeing me getting upset [...] my son can't handle me crying [...] I seem to open up more to my friends (Daughter 6).

Like spousal carers, we found that most adult daughters also preferred to obtain social support from their friends. Friends from support groups were particularly useful in facilitating resilience:

They know how you feel because they've gone through it themselves (Daughter 2).

Social support from fellow carers was helpful as they were understanding and could offer knowledge and advice as they were in a similar situation and had shared experiences. Conversely, social support from non-carer friends could be unhelpful:

They [non-carer friends] say how are things [...] how is <wife> getting on and it's all drivel you know. She's got Alzheimer's, you know, do you want to know every second of the day? You're back in the pressure can then, you know (Husband 1).

The role of social support in resilience appears to be more complex than a matter of being either present or absent. Indeed, social support may only facilitate resilience if it comes from a place of mutual, shared experience. For example, carers who participated in support groups were more resilient because the group provided not just a source of positive social interaction, but a peer support forum to share with and learn from people like themselves. This was particularly valued by the spousal carers:

We used to have a lot of friends but over the past few years, I don't know what happens really, but you seem to lose people along the way [...] but, what has happened now [...] we've got a lot of really very close friends now through the groups (Wife 5).

This suggests that support groups may be drawn upon by spousal carers to replace the social support they had lost; spousal carers for PLWD frequently report that they lose friends and become isolated. Joining support groups was often identified as a turning point whereby carers, who were previously not coping well, became more resilient. This represented a transition from isolation to attaining a supportive social network.

Societal level

Finally, the findings below align with the employment and health and social care resources from the resilience framework. The analysis indicates that it was not always the case that societal resources directly influenced resilience, but instead may foster the conditions in which individual and community level factors operated.

Employment

Adult daughters were typically younger than spouses and were therefore more likely to still be in employment. Adult daughters' work commitments meant that they had time constraints, and so they were less able to access formal help than spousal carers, who were more likely to be retired. This hindered their capacity for resilience. Daughter 4 explained why she did not attend a support group:

Only because of my work commitments [...] they tend to have these meetings in the afternoons [...] (Daughter 4).

Furthermore, employment was identified as being another source of stress. Daughter 1 explained what would have made life easier for her:

More time off work, seriously, if you're having to care and go to work, juggling all that [...] it's enough to give you a breakdown (Daughter 1).

Caregiving therefore represented a stressful "third shift" that adult daughters had to balance on top of their family and work commitments. Although employment hindered resilience in some carers, other carers drew positive benefits from employment. Daughter 4 explained how going to work provided her with a form of social support, a community resource:

When I'm at work [...] we'll have a laugh about it. I think going to work helps me a lot (Daughter 4).

Carers who were retired or unemployed believed that employment would help them to be resilient as it could offer them social support and a temporary escape from caregiving:

I think I miss being away from this kind of environment [...] I miss the social side of it where you're talking to other people (Daughter 3).

Employment may therefore help adult daughters to buffer the adversity of caregiving and facilitate resilience.

Health and social care

On an individual level, many carers valued respite care as it provided them with a temporary escape from their caregiving duties:

You just feel like you're cracking up, and that's how I did feel when I wasn't getting the respite and the relief of occasionally meeting my pals (Husband 1).

The current study demonstrates that respite care is an important societal resource for adult daughter carers of PLWD. Accessing respite care services was frequently acknowledged as a turning point whereby carers who had been coping poorly became more resilient, as these services helped them to "feel free from it all" (Daughter 5). However, the use of formal services was limited as many carers did not know how to access them at an individual level:

There are things out there but you don't know how to access them. You don't know about them [...] there should be somebody there to say to you, "look, do this. Go there" (Wife 4).

Many carers felt that they were poorly supported following their relatives' diagnosis and were not provided with the knowledge, advice and guidance that they needed. Carers were therefore unable to access services that would facilitate their resilience as they were unaware of them.

Discussion

The current study found that, in spite of dementia care becoming increasingly challenging over time, informal carers drew on a range of individual, community and societal level resources which facilitated their capacity for resilience. This supports our previous work (Donnellan *et al.*, 2015) and suggests that our collective findings are to a large extent rigorous and transferable (Lincoln and Guba, 1985). It also contrasts with the historical focus in the literature on negative outcomes, such as caregiver burden (Etters *et al.*, 2008).

Building on our previous work (Donnellan *et al.*, 2015), we identified and directly compared resilience resources between spousal and adult daughter carers. On an individual level, our spouses expressed a sense of satisfaction at fulfilling their marital duty, and our adult daughters were motivated to reciprocate the care they had received from their parents (Cherry *et al.*, 2013; Lloyd *et al.*, 2016). In some cases, this care reciprocation was positive and facilitated resilience (Donorfio and Kellett, 2006; Lloyd *et al.*, 2016) but for others there was a sense of obligation which hindered resilience as it caused feelings of guilt, entrapment and "role overload" (Brandao *et al.*, 2016; Cherry *et al.*, 2013; Donorfio and Kellett, 2006; Gonyea *et al.*, 2008; Grundy and Henretta, 2006; Lloyd *et al.*, 2016; Romero-Moreno *et al.*, 2013). This discrepancy in the sense of duty of adult daughters and spouses may be because caregiving is more of a premature (Pinquart and Sørensen, 2011), unanticipated extra responsibility for adult daughters, whereas for spouses, caregiving may be construed as a "normal" and accepted part of old age or marriage (Chappell *et al.*, 2014; Doris *et al.*, 2018; Gaugler *et al.*, 2007; Lloyd *et al.*, 2016).

On a community level, some of the adult daughters had siblings to share the caregiving role with, which helped to relieve the pressure of caregiving and allowed them to balance their commitments alongside their independent family lives (Brandao *et al.*, 2016; Lloyd *et al.*, 2016). However, this resource appeared to be dependent on perceived fairness, as family "rows" ensued if a sibling was not contributing their fair share of caregiving responsibilities to their parent (McCann *et al.*, 2015). Social support from friends and family was perceived as generally helpful by both our spouses and adult daughters (Donnellan *et al.*, 2016; Lloyd *et al.*, 2016; Wilks and Croom, 2008). For spouses in particular, some friends were perceived to disengage from them, and in some cases, offers of support from friends hindered resilience as carers felt as though they did not understand their specific

challenges. This was further highlighted by how valued fellow carers and support groups were by some of the most isolated carers in the sample; fellow carers offered knowledge and understanding as they were in a similar situation (Donnellan *et al.*, 2015, 2016).

On a societal level, formal services, such as support groups and respite care, often represented key turning points after which the carers became more resilient (Bennett, 2010; Gaugler *et al.*, 2007). For others, the use of formal services was limited as they were either unaware of them (Brandao *et al.*, 2016) or did not know how to access them (Donnellan *et al.*, 2015). In line with Donnellan *et al.* (2015), resilience depended on more than whether community and societal resources were present or absent, as resources that were facilitating for some carers were hindering for others. For instance, for some adult daughters, employment was viewed as a temporary escape from their caregiving commitments (Cherry *et al.*, 2013; Pinquart and Sørensen, 2003, 2011), whereas for others it was seen to be another source of stress. Here, it was not the societal resource itself that facilitated resilience but how this influenced the carers' individual assets and community resources. This represents an interaction between each level of the resilience framework (Windle and Bennett, 2011) and supports an ecological systems approach to resilience (Bennett and Windle, 2015; Bronfenbrenner and Ceci, 1994; Ungar, 2015). Our findings suggest that perceived need, utility and satisfaction with societal resources was crucially important (Cherry *et al.*, 2013; Donnellan *et al.*, 2016).

The current study built on previous research by examining resilience in a new sample of spousal and adult child carers of PLWD. To our knowledge, it is the first study to provide an in-depth insight into resilience resources across different kinship ties, directly comparing the experiences of spouses and adult daughters of PLWD. By identifying not just individual level but community and societal level resources, we have demonstrated that resilience is not just a trait or psychological attribute (Bonanno *et al.*, 2007; Gaugler *et al.*, 2007; Kalisch *et al.*, 2015; O'Rourke *et al.*, 2010; Windle *et al.*, 2010), but a social ecological construct (Bennett and Windle, 2015; Bronfenbrenner and Ceci, 1994; Ungar, 2015). However, the current study has a number of important limitations. First, carers who were recruited from support groups may have been inherently more resilient than carers who did not attend support groups. Therefore, the influence of resilience, assets and resources may have been overestimated. Second, whilst we collected a range of carer demographic data, there were some key demographic statistics that we did not capture in spite of them being featured within the resilience framework, e.g. ethnicity and socio-economic status (Windle and Bennett, 2011). This is problematic given the fact that characteristics like these are likely to influence carers' capacity for resilience. It also limits the transferability of our findings meaning that we cannot infer anything about carers from different ethnic groups or socio-economic classes. Future studies should aim to collect larger, more representative samples with data on a full range of potentially relevant demographic characteristics. Finally, this study captured resilience cross-sectionally. This is problematic because research indicates that resilience is not fixed but fluctuates over time (Joling *et al.*, 2015; Luthar, 2006; Windle *et al.*, 2010; Donnellan *et al.*, 2019). Furthermore, a carer's capacity for resilience (e.g. ability to "bounce back") may be heavily dependent on their pre-caring distress levels. We did not collect data on this which means it was impossible to assess resilience proportionate to baseline pre-caring functioning. Future prospective qualitative and quantitative longitudinal research is necessary to identify and explore trajectories of resilience over time (Bennett, 2010; Donnellan *et al.*, 2019; Dias *et al.*, 2015).

Our findings have practical applications. By identifying the unique challenges and perceived beneficial resilience resources in specific groups of informal carers (e.g. spousal and adult children), practitioners and policymakers may be better able to target and tailor support more efficiently to those who need and are ready to accept support (Gaugler *et al.*, 2007). The interactivity seen between some of our resources suggests that such support for individual challenges could be targeted at a community or societal level, for example;

dementia-friendly neighbourhoods (Mitchell and Burton, 2010) and carer-friendly work policies and funding (Yeandle *et al.*, 2002). This is advantageous on a theoretical level as it takes responsibility away from the carer, which is a common criticism of more traditional resilience research (Windle, 2011; Ungar, 2015).

By attempting to promote some of the resilience resources and uplifts that we identify rather than exclusively mitigating challenges, practitioners may be able to help carers to adjust to their role and maintain continuity within their lifestyle and relationship with the PLWD. The kinship differences that we identify suggest that supportive interventions which are individualised and tailored to different caregiving relationships are most likely to be effective in facilitating resilience and sustaining carers in their role (Gaugler *et al.*, 2007). Finally, and perhaps most fundamentally, carers may feel less weight of responsibility to manage stress if researchers and practitioners take an ecological resource-based approach to resilience, highlighting not just the individual assets necessary to manage stress but also the supportive community and wider societal resources (Windle, 2011; Ungar, 2015).

In conclusion, we found that informal carers of PLWD draw on a range of factors to facilitate or hinder their capacity for resilience. There are important similarities but also differences in terms of resource use for spousal and adult daughter carers. Our findings represent a move away from deficit models of caregiver burden (Etters *et al.*, 2008) towards an interactive ecological model of carer resilience (Windle and Bennett, 2011). There is a need for future research and formal services to distinguish between different kinship ties and to continue exploring resilience from an ecological perspective.

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Further reading

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