



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

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3 **Exploring resilience in adult daughter and spousal carers of people living with dementia**
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5 **in North West England: An ecological approach.**
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7

8 **Abstract**
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10 *Objectives:* Research has shown that informal carers of people living with dementia (PLWD)
11 can be resilient in the face of caregiving challenges. However, little is known about resilience
12 across different kinship ties. The current study updates and builds on our previous work, uses
13 an ecological resilience framework to identify and explore the factors that facilitate or hinder
14 resilience across spousal and adult daughter carers of PLWD. *Methods:* We conducted in-
15 depth qualitative interviews with a purposive sample of 13 carers from North West England
16 and analysed the data using a constructivist grounded theory approach (Charmaz, 2003).
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19 *Results:* Adult daughters were motivated to care out of reciprocity, whereas spouses were
20 motivated to care out of marital duty. Spouses had a more positive and accepting attitude
21 towards caregiving and were better able to maintain continuity, which facilitated their
22 resilience. *Discussion:* Resilience emerged on multiple levels and depended on the type of
23 kinship tie, which supports an ecological approach to resilience. The implications of these
24 findings are discussed.
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42 **Key words:** Resilience; Informal carer; Spousal; Adult daughter; Ecological.
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Exploring resilience in adult daughter and spousal carers of people living with dementia in North West England: An ecological approach.

Introduction

850,000 people are currently living with dementia in the UK; this is projected to reach 2 million by 2050 (Lewis, Karlsberg Schaffer, Sussex, O'Neill & Cockcroft, 2014). With this comes a growing number of informal carers, most commonly adult children (58%) and spouses (26%) (NHS, 2010). The unpaid care provided by these carers saves the UK economy £132 billion 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, Bamberg & McCann, 2015; Pinquart & 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, 2010) and experience age-related physical (Pinquart & Sörensen, 2007), cognitive (Kim, Chang, Rose & Kim, 2012), and mental impairments (Pinquart & Sörensen, 2003). The negative impact on spouses may be exacerbated by the breakdown of the spousal relationship (Etters, Goodall & Harrison, 2008; Fitzpatrick & Vacha-Haase, 2010; Gladstone, 1995; Pinquart & Sörensen, 2011). Adult children are more likely to be balancing caregiving responsibilities with other commitments, such as their spouse, children and career (Brandao, Ribeiro & Martin, 2016; Cherry et al., 2013; Grundy & Henretta, 2006; Pinquart & 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, Dujela & Smith, 2014; Gonyea, Paris & de Saxe Zerden, 2008; Pinquart & Sörensen, 2011).

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3 However, some carers are able to overcome burden and flourish in their role. This is
4 consistent with a growing literature on positive aspects of caregiving (Doris, Cheng, &
5 Wang, 2018; Lloyd, Patterson & Muers, 2016). This approach is not a new one; Folkman
6 (2008) established that positive states coexisted with negative states throughout the
7 caregiving period. These positive states, such as reward (Pinquart & Sörensen, 2003),
8 optimism (Zauszniewski, Bekhet, & Suresky, 2009) and growth (O'Dwyer et al., 2017), to
9 name a few, are important because they help sustain the carer in their role. However, most
10 work considers the adversity of caregiving with relatively little work considering the
11 response to adversity, including the positive features of caregiving (Teahan et al., 2020).
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24 This response to adversity may be best captured by resilience. Early definitions of
25 resilience highlighted the process of overcoming stress or adversity (Luthar, Cicchetti, &
26 Becker, 2000). More recently, researchers have begun to argue that resilience is not simply
27 stress resistance or invulnerability to stress, but the ability to function positively and recover
28 from setbacks more quickly than others with an equivalent level of exposure to negative
29 events (Rutter, 2012). Windle (2011) conducted a comprehensive concept analysis of
30 resilience, drawing on a range of multi-disciplinary perspectives. She defined resilience thus:
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40 'The process of effectively negotiating, adapting to, or managing significant sources of
41 stress or trauma. Assets and resources within the individual, their life and environment
42 facilitate this capacity for adaptation or "bouncing back" in the face of adversity'
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47 (Windle, 2011, p. 163).
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49 There is some debate about whether resilience is a dynamic process (Bonnano & Diminich,
50 2013; Windle et al., 2010) or a unitary outcome (Bennett, 2015; Liebenberg & Ungar, 2009).
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3 & Tüscher, 2015; van Breda, 2018). We adopt the latter conceptualisation in the current
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5 study as it is most comprehensive.
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8 Resilience is most commonly conceptualised as a trait or psychological attribute
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10 (Bonanno, Galea, Bucciarelli, & Vlahov, 2007; Kalisch et al.,
11
12 2015; Windle, Woods, & Markland, 2010) and has been examined in relation
13
14 to a range of psychological constructs, including but not
15
16 limited to: optimism; acceptance; emotional intelligence;
17
18 mastery; competence; self-esteem; and interpersonal control
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20 (Carbonneau et al., 2010; Cherry et al., 2013; Windle,
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22 Markland, & Woods 2008). Dementia care studies tend to
23
24 conceptualise resilience as a trait predictor of clinical
25
26 outcomes, such as depressive symptoms (O'Rourke et al., 2010),
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28 or institutionalisation and death of the PLWD (Gaugler et al.,
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30 2007). It is clear that the above psychological factors play
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32 an important role in facilitating resilience but there are
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34 problems with the concept of psychological resilience. First,
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36 conceptual overlap between the above constructs has led to
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38 definitional 'fuzziness' and inconsistent operationalisation
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40 (Cherry et al., 2013; Lerner, 2006; Ungar, 2003). Second,
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42 psychological resilience places responsibility with the carer
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44 rather than interpersonal resources or supportive services
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46 (Windle, 2011; Ungar, 2015); carers may be reluctant to
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48 increase their resilience levels if it simply made them more
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50 adept at carrying a greater load. Finally, psychological
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52 resilience neglects socioenvironmental factors known to
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3 promote resilience. For example, Cherry et al. (2013)
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5 identified a framework of three interrelated factors
6
7 influencing resilience in carers of PLWD, including
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9 psychological factors and properties of the care relationship
10
11 but also social and cultural factors.
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14 The notion that resilience is determined by the
15
16 interaction between individuals and their immediate and wider
17
18 social environments is not new (Bennett & Windle, 2015; Ungar,
19
20 2015). Indeed, even researchers who have focused on
21
22 psychological dimensions of resilience acknowledge the
23
24 existence of wider factors (Kalisch et al., 2015). This has
25
26 led some researchers to consider the social ecology of
27
28 resilience (Ungar, 2011). This has been heavily based on the
29
30 principles of Bronfenbrenner and Ceci's (1994) ecological
31
32 systems theory, whereby individuals draw on micro-level
33
34 individual characteristics and meso-, exo- and macro-level
35
36 environmental resources to reduce or prevent chronic
37
38 adversities. Integral to this approach is that resilience may
39
40 reflect the capacity of systems to adapt, rather than the
41
42 capacity of individuals to overcome challenges and
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44 environmental factors may explain as much as, if not more,
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46 variance in positive developmental outcomes from adversity
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48 than individual factors (Ungar, 2015).
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55 Based on the principles outlined above, Windle and Bennett (2011) developed an
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57 ecological resilience framework applied to carers (see Figure 1). The framework posits that
58
59 resilience can be facilitated by carers' individual assets, and community and societal
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1
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3 resources. In our previous study, we used the resilience framework to identify the factors
4 associated with resilience in spousal carers of PLWD (Masked for review, 2015). Resilient
5 carers typically stayed positive and actively maintained their relationship and loved one's
6 former self. Resilient carers were knowledgeable and appropriately supported by family and
7 friends with shared experience. Finally, resilient carers were more actively engaged with
8 services such as respite care. However, the resilience framework is theoretical and no means
9 exhaustive (Windle & Bennett, 2011) and the extent to which these factors could be
10 transferred to other carers, such as adult children, was unclear.
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28 Research suggests that resilience may differ between spousal and adult child carers.
29 Spouses draw upon positive memories of their marriage to help them to be resilient, and are
30 motivated to care out of love, commitment and marital duty (Bonanno, Wortman & Nesse,
31 2004; Cherry et al., 2013; Gaugler, Kane & Newcomer, 2007; Lloyd et al., 2016). Moreover,
32 spouses are accustomed to providing support to their partner throughout their marriage and
33 therefore may find it easier to adjust to caregiving, which may be perceived as an extension
34 of marriage (Cherry et al., 2013; Lloyd et al., 2016). Adult children may be uplifted by the
35 role reversal that occurs when caregiving for a parent, as this represents reciprocity of the
36 care they received from their parent in the past (Donorfio & Kellett, 2006; Pinquart &
37 Sörenson, 2011; Strauss, 2013). Whilst alternative roles of adult children can generate added
38 pressure, the roles may help to buffer caregiver burden, such as employment as an escape
39 from caregiving responsibilities (Chappell et al., 2014; Cherry et al., 2013; Lloyd et al., 2016;
40 McCann et al., 2015; Pinquart & Sörensen, 2003, 2011; Strauss, 2013; Wilks & Croom,
41 2008). This may explain why adult children have been found to have more positive
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3 caregiving-related experiences than spouses, including personal growth (Ott, Sanders, &
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5 Kelber, 2007).
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7
8 In our previous work, we examined resilience in spousal carers of PLWD (Masked for
9
10 review, 2015). However, we know that spouses are second to adult children in terms of the
11
12 total number of informal carers of PLWD living in the UK (NHS, 2010). There is a need to
13
14 update and build on our previous work by including a novel sample of spousal and adult
15
16 children carers and comparing resilience across each kinship tie. Therefore, the current study
17
18 uses Windle and Bennett's (2011) ecological resilience framework to explore the factors that
19
20 facilitate resilience across spousal and adult daughter carers of PLWD. The research
21
22 objective is to identify the factors that facilitate or hinder resilience in spousal and adult
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24 daughter carers, and whether these factors can be mapped on to Windle and Bennett's (2011)
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26 ecological resilience framework.
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35 **Methods**

37 **Sample**

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39 The current study included a purposive sample of 13 informal carers of PLWD: six adult
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41 daughters and seven spouses (two husbands and five wives). According to Tongco (2007),
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43 purposive sampling is appropriate when researchers require a sample of participants who are
44
45 'willing to provide information by virtue of knowledge or experience' (i.e. informal carers of
46
47 PLWD) (p. 147). We sampled until we reached theme saturation; the point at which no new
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49 information or themes were observed (Guest, Bunce, & Johnson, 2006). Five of the
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51 participants were recruited using a snowball sampling method, for example; after being
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53 interviewed, daughter 3 recommended her sister, daughter 4, to take part. Although these
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3 participants cared for the same person, they were interviewed individually to capture their
4
5 unique caregiving experiences.
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8 Carers were recruited from two dementia support groups (n=8), and a small network
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10 of other contacts (n=5) from North West England. Two female researchers, including the
11
12 third author, approached the organisations by phone, before being invited to give a brief talk
13
14 about the research. Most spousal carers lived with their spouse at home (n=5), whereas most
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16 adult daughters lived separately from their parent (n=4), except daughter 2 who lived with her
17
18 father (n=1). Three carers were caring for PLWD who were residing in nursing home care
19
20 settings (n=3). Some carers reported caregiving for longer than the dementia care duration.
21
22 For example, daughter 3 had been caring for her mother since her father died 16 years ago
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24 and wife 3 had cared for her husband since he had a heart attack 29 years ago. See Table 1 for
25
26 a summary of participant information.
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38 **Data collection**

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40 Semi-structured interviews were conducted between June 2016 and October 2016. Interviews
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42 were conducted on a one-to-one basis by one of two female researchers, including the third
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44 author, each lasting between 30 and 142 minutes. The participants chose for their interviews
45
46 to be conducted in their own homes as they felt more comfortable in familiar surroundings.
47
48 To reduce the risk of being disturbed during spousal interviews, the PLWD was looked after
49
50 by a family member in a separate room for the duration of the interview. Both researchers
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52 were fully trained in semi-structured interviewing and worked under the close supervision of
53
54 the first author, who has ten years' experience in conducting qualitative interview studies
55
56 with older adults. The interviews were audio-recorded and transcribed by the two researchers,
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3 and all identifying information was anonymised. The study received ethical approval from
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5 the University of Liverpool Research Governance Committee.
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7
8 Section A of the interview schedule began with factual questions, such as age, family
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10 information, employment and care duration. Section B asked about life before caregiving,
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12 section C asked about the period surrounding the diagnosis and section D asked about the
13
14 present situation. Each section included a range of open questions about what life was like,
15
16 what their relationship with the PLWD was like, what roles and responsibilities they had and
17
18 what support they received. Finally, in section E, carers were asked what had been helpful to
19
20 them, what changes would make life easier for them and what advice they would give to
21
22 someone in the same position as themselves. We deliberately did not ask the carers directly
23
24 about resilience as we did not want to prime their responses in any way. Instead, our
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26 questions focused on areas known to be related to resilience and therefore any reference to
27
28 resilience resources was spontaneous and therefore more credible (Lincoln & Guba, 1985).
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38 **Data analysis**

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40 We used a constructivist grounded theory approach to analyse the interview data (Charmaz,
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42 2003). According to Charmaz (2016), constructivist grounded theory is particularly useful
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44 when examining complex psychological phenomena which require critical questions and
45
46 deep reflexivity. It adopts the inductive approach of grounded theory but acknowledges that
47
48 social reality is constructed through relativism; the mutual co-construction of knowledge
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50 between participants and researchers (Charmaz, 2014). As the researcher is not considered a
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52 neutral observer, it is important to take their perspective into account as an inherent part of
53
54 the process. These principles are well aligned with the current study as we aimed to update
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3 and build on the findings of an earlier study by the first and second authors, as well as map
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5 the themes onto a theoretical resilience framework (Windle & Bennett, 2011).
6
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8 Firstly, the third author read through each interview in its entirety to gain a
9
10 contextualized understanding of the participants' experiences. Constructivist grounded theory
11
12 was then used to analyse the interviews line-by-line, with each line being summarised with an
13
14 open code. The most commonly recurring codes within each transcript were used to form
15
16 axial categories which summarised each interview. Common categories were then merged to
17
18 form selective themes across all interviews (Charmaz, 2014). This approach was reflexive so
19
20 that emergent themes led to re-coding. The first and third authors then re-
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22 examined the themes to identify the factors that facilitate or
23
24 hinder resilience. In line with the principles of
25
26 constructivist grounded theory (Charmaz, 2014), we examined
27
28 the extent to which these factors mapped on to the ecological
29
30 resilience framework (Windle & Bennett, 2011). Both spousal and adult
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32 daughter interviews were subjected to the same process of analysis, but comparisons were
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34 made between them at each stage to explore resilience across different kinship ties.
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42 **Strategies to ensure rigour of findings**

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44 We adopted a number of strategies to ensure the rigour of our findings. The following
45
46 paragraphs briefly outline these strategies according to Lincoln and Guba's (1985) criteria:
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48 credibility (the value, believability and confidence in the truth of the findings); transferability
49
50 (extent to which qualitative findings can be applied to other contexts); dependability (stability
51
52 of the data and how consistent and repeatable it is); and confirmability (neutrality and
53
54 accuracy of the data).
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3 In order to ensure credibility, we employed multiple researchers at the data collection
4 and analysis stages to ensure complementary as well as divergent understanding of the data.
5 We built trust and rapport with all participants both prior to and during the interviews being
6 conducted. Once the data had been analysed, we member checked this by presenting it to
7 each participant that was interviewed, and all participants were satisfied that the findings
8 accurately represented their experiences. To ensure transferability, we included as much
9 contextual detail as possible when presenting our findings, including demographic and care
10 context information.
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21 In order to ensure dependability and confirmability, the paper was independently peer
22 reviewed to ensure that the findings, interpretations and conclusions are supported by the
23 data. The interviewers kept reflexive diaries during and after interviews to document
24 methodological decisions, preconceptions, and initial impressions of the data. We regularly
25 recoded the data as new themes emerged in order to capture important findings that might
26 have been missed. Finally, all stages of analysis were conducted independently and blind by
27 the first and third authors; in the event of discrepancies between the two analysts, we did not
28 move to the next stage until a consensus was reached. Consensus was reached in most cases,
29 but if themes/classifications differed then each analyst re-examined and compared their
30 coding/criteria until an agreement was reached.
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44 **Results**

45 The constructivist grounded theory analysis revealed a number of factors which facilitated or
46 hindered resilience for the carers. The following section presents these resilience factors
47 under each level of Windle and Bennett's (2011) resilience framework, addressing the extent
48 to which they map on to the framework, and comparing across spousal and adult daughter
49 carers throughout.
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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)

Despite 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:

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2
3 I try and be quite positive about everything... and I do think... we've got some really
4 good friends now and we go out and we do things. I think "it's not all bad, come on.
5
6
7

8 Get a grip, girl" (Wife 5)
9

10 On the other hand, some carers derived fewer benefits from their caregiving duties which
11 hindered resilience. For example, adult daughters may care out of filial obligation, whereby
12 they hold responsibility for their parents' welfare:
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14

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16
17 I feel guilty that I've got carers going in... I feel it's my duty... I feel guilty that my
18 sister stays with [my mum] two nights a week because I feel that makes her a better
19 daughter than me (Daughter 3)
20
21
22

23 Filial obligation hindered some adult daughters' resilience as it caused feelings of guilt and
24 entrapment. This discrepancy in the sense of duty of adult daughters and spouses may be
25 because caregiving is more of an unanticipated extra responsibility for adult daughters,
26 whereas for spouses caregiving may be more likely to be construed as a normal and accepted
27 part of marriage that they are prepared for:
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35 The balance changes, but it's still the person you married... it's still the person you've
36 lived with all that time... you still love them. It's just different... it's not a duty. It's
37 just something that's part of life (Wife 4)
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41

42 Spouses may therefore maintain continuity in their relationship with the person living with
43 dementia, as caregiving for a spouse may be accepted as a normal aspect of the life-cycle.
44 Maintaining continuity may help carers to increase resilience and sustain their caregiving
45 responsibilities, therefore this ability may reflect the longer care duration of spouses in the
46 current sample:
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53 It was just normal. I was just used to how [my husband] was and we just carried on
54 the same... (Wife 1)
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58 Spouses' positivity, optimism and determination also helped them to maintain continuity:
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3 We hadn't been abroad for two years so it was a bit of a learning curve. But the thing
4 with that is to learn something from it and find out, well some things didn't really
5
6 work on that holiday, what can I do to make it work and to make it easier next time?
7

8
9
10 (Wife 5)
11

12 Positivity was therefore a key asset which facilitated the resilient attitude of "you can still do
13 things, you just have to change the way you do things" (Wife 2), which helped some spouses
14 to take control, adjust and 'bounce back' from caregiving challenges in order to maintain
15 their quality of life. However, some spouses struggled to maintain continuity, and instead
16
17 focused on what they had lost:
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24 You feel like you're just as ill as them because you don't go on holiday, you don't go
25 out for meals... you feel you're on your own and they're in couples and, your whole
26
27 life changes (Husband 1)
28
29

30 Research has shown that caregiving demands can compromise marital satisfaction in spousal
31 carers, particularly when caregiving causes changes in their lifestyle and relationship, which
32 may hinder resilience:
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38 You're not a partnership anymore. You are the person who's having to think for two,
39 having to do everything for two. That's the difference... you're with someone but
40
41 you're alone. (Wife 4)
42
43

44 Changes in the marital relationship may therefore be particularly stressful due to the
45 longevity of spouses' marriages, and because they reflect a transition from partnership to
46 singlehood. Indeed, caring for a PLWD has been likened to bereavement as carers often
47 experience anticipatory grief due to the 'social death' of the person living with dementia.
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52 Anticipatory grief was evident in adult daughters:
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3 The roles got reversed a bit. I was starting to be the mum... there were times when I
4 needed [her] and she wasn't there, she was physically there for me but she couldn't
5 help me. (Daughter 6)
6
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9
10 However, some adult daughters positively appraised their new parent-child relationship
11 dynamic. Daughter 4 was emotional as she explained:
12

13
14 [My mum] shouldn't have to feel grateful because it's just role reversal... I'm very
15 grateful for everything she's done for me... (Daughter 4)
16
17

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19 Some adult daughters experienced role reversal, in which they became the parent and their
20 parent became the child. Role reversal was frequently drawn upon as motivation to carry on
21 caregiving, as some adult daughters viewed this as an opportunity to reciprocate everything
22 their parent had done for them when they were younger, which facilitated their capacity for
23 resilience.
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30 31 32 33 ***Community level***

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35 The following findings align with the family relations, social support and social participation
36 resources from the resilience framework.
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40 41 42 ***Family relations***

43
44 Adult daughters were unique in that they reported having extra family commitments in
45 addition to caring for their parents, such as their children, husband, career and household
46 chores:
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50
51 I still [tried] to fit in everything I had to do for my family... it did cause me stress.
52
53 (Daughter 1)
54
55

56 Caregiving commitments often created added stress on top of adult daughters' already busy
57 lives. Adult daughters may experience 'role overload' as they are 'sandwiched' between
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1
2
3 multiple family commitments, which could hinder their capacity for resilience. Daughter 3
4
5 explained:

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7
8 I don't do the things that I enjoy doing... my life's been taken over by other people
9
10 and I do feel quite angry about it (Daughter 3)

11
12 In some cases, adult daughters' multiple commitments meant that they had to alter their
13
14 lifestyle and lessen the time they had for themselves which hindered their resilience. These
15
16 lifestyle changes appeared to have come prematurely for adult daughters, and caused feelings
17
18 of anger, frustration and resentment. However, some adult daughters had siblings to help
19
20 relieve this burden:
21
22

23
24 I'm lucky.... if one person doesn't do something the other person does... everything is
25
26 shared out very equally... it's all about sharing the burden (Daughter 5)
27

28
29 The ability to share the caregiving role with siblings was important for resilience as it helped
30
31 to alleviate some of the pressure of caregiving and allowed adult daughters to balance their
32
33 commitments alongside their independent family lives. However, this resource appeared to be
34
35 dependent on fairness, as family 'rows' ensued if a sibling was not contributing their fair
36
37 share of caregiving responsibilities to their parent:
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39

40
41 Things were getting quite strained between my sisters... we all had little niggles with
42
43 each other over who was doing what (Daughter 1)
44

45
46 These findings highlight the facilitating and hindering role of family in adult daughter carers.
47
48 Family conflict contributed further stress on top of the pressure of caregiving, therefore
49
50 siblings could both facilitate and hinder resilience.
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53 ***Social support and participation*** 54 55 56 57 58 59 60

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2
3 Social support refers to the exchange of support between the carers' social networks. Carers
4 were often apprehensive about burdening their family members. Previously observed in
5 spousal carers of PLWD, this has been termed 'intimacy at a distance':
6
7

8 I don't like my husband seeing me getting upset... my son can't handle me crying... I
9
10 seem to open up more to my friends. (Daughter 6)
11
12

13 Like spousal carers, the current study found that most adult daughters also preferred to obtain
14 social support from their friends. Friends from support groups were particularly useful in
15 facilitating resilience:
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18 They know how you feel because they've gone through it themselves. (Daughter 2)
19
20

21 Social support from fellow carers was helpful as they were understanding and could offer
22 knowledge and advice as they were in a similar situation and had shared experiences.
23
24

25 Conversely, social support from non-carer friends could be unhelpful:
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28 They [non-carer friends] say how are things... how is <wife> getting on and it's all
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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)

1
2
3 This suggests that support groups may be drawn upon by spousal carers in order to replace
4 the social support they had lost; spousal carers for PLWD frequently report that they lose
5 friends and become isolated. Joining support groups was often identified as a turning point
6 whereby carers, who were previously not coping well, became more resilient. This
7 represented a transition from isolation to attaining a supportive social network.
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17 *Societal level*

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

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33 Adult daughters were typically younger than spouses and were therefore more likely to still
34 be in employment. Adult daughters' work commitments meant that they had time constraints,
35 and so they were less able to access formal help than spousal carers, who were more likely to
36 be retired, thus this hindered their capacity for resilience. Daughter 4 explained why she did
37 not attend a support group:
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44 Only because of my work commitments... they tend to have these meetings in the
45 afternoons... (Daughter 4)
46
47
48

49 Furthermore, employment was identified as being another source of stress. Daughter 1
50 explained what would have made life easier for her:
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52
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54 More time off work, seriously, if you're having to care and go to work, juggling all
55 that... it's enough to give you a breakdown (Daughter 1)
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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:

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2
3 There are things out there but you don't know how to access them. You don't know
4 about them... there should be somebody there to say to you, "look, do this. Go there".
5
6

7
8 (Wife 4)
9

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

22 The current study found that, despite dementia care becoming increasingly challenging over
23 time, informal carers draw on a range of individual, community and societal level resources
24 which facilitated their capacity for resilience. This suggests that our collective findings are to
25 a large extent rigorous and transferable (Lincoln & Guba, 1985) and contrasts with the
26 historical focus in the literature on negative outcomes, such as caregiver burden (Etters et al.,
27 2008).
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37 Building on our previous work (Masked for review, 2015), we identified and directly
38 compared resilience resources between spousal and adult daughter carers. On an individual
39 level, our spouses expressed a sense of satisfaction at fulfilling their marital duty, and our
40 adult daughters were motivated to reciprocate the care they had received from their parents
41 (Cherry et al., 2013; Lloyd et al., 2016). In some cases, this care reciprocation was positive
42 and facilitated resilience (Donorfio & Kellett, 2006; Lloyd et al., 2016) but for others there
43 was a sense of obligation which hindered resilience as it caused feelings of guilt, entrapment
44 and 'role overload' (Brandao et al., 2016; Cherry et al., 2013; Donorfio & Kellett, 2006;
45 Gonyea et al., 2008; Grundy & Henretta, 2006; Lloyd et al., 2016; Romero-Moreno et al.,
46 2013). This discrepancy in the sense of duty of adult daughters and spouses may be because
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3 caregiving is more of a premature (Pinquart & Sörensen, 2011), unanticipated extra
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5 responsibility for adult daughters, whereas for spouses, caregiving may be construed as a
6
7 ‘normal’ and accepted part of old age or marriage (Chappell et al., 2014; Doris et al., 2018;
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9 Gaugler et al., 2007; Lloyd et al., 2016).

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12 On a community-level, some of the adult daughters had siblings to share the
13
14 caregiving role with, which helped to relieve the pressure of caregiving and allowed them to
15
16 balance their commitments alongside their independent family lives (Brandao et al., 2016;
17
18 Lloyd et al., 2016). However, this resource appeared to be dependent on perceived fairness,
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20 as family ‘rows’ ensued if a sibling was not contributing their fair share of caregiving
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22 responsibilities to their parent (McCann et al., 2015). Social support from friends and family
23
24 was perceived as generally helpful by both our spouses and adult daughters (Masked for
25
26 review, 2016; Lloyd et al., 2016; Wilks & Croom, 2008). For spouses in particular, some
27
28 friends were perceived to disengage from them, and in some cases, offers of support from
29
30 friends hindered resilience as carers felt as though they did not understand their specific
31
32 challenges. This was further highlighted by how valued fellow carers and support groups
33
34 were by some of the most isolated carers in the sample; fellow carers offered knowledge and
35
36 understanding as they were in a similar situation (Masked for review, 2015; 2016).

37
38
39 On a societal-level, formal services, such as support groups and respite care, often
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41 represented key turning points after which the carers became more resilient (Bennett, 2010;
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43 Gaugler et al., 2007). For others, the use of formal services was limited as they were either
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45 unaware of them (Brandao et al., 2016) or did not know how to access them (Masked for
46
47 review, 2015). In line with Masked for review (2015), resilience depended on more than
48
49 whether community and societal resources were present or absent, as resources that were
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51 facilitating for some carers were hindering for others. For instance, for some adult daughters,
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53 employment was viewed as a temporary escape from their caregiving commitments (Cherry
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3 et al., 2013; Pinqart & Sørensen, 2003, 2011), whereas for others it was seen to be another
4
5 source of stress. Here it was not the societal resource itself that facilitated resilience but how
6
7 this influenced the carers' individual assets and community resources. This represents an
8
9 interaction between each level of the resilience framework (Windle & Bennett, 2011) and
10
11 supports an ecological systems approach to resilience (Bennett & Windle, 2015;
12
13 Bronfenbrenner & Ceci, 1994; Ungar, 2015). Our findings suggest that perceived need,
14
15 utility, and satisfaction with societal resources was crucially important (Cherry et al., 2013;
16
17 Masked for review, 2016).

21
22 The current study built on previous research by examining resilience in a new sample
23
24 of spousal and adult child carers of PLWD. To our knowledge, it is the first study to provide
25
26 an in-depth insight into resilience resources across different kinship ties, directly comparing
27
28 the experiences of spouses and adult daughters of PLWD. By identifying not just individual
29
30 level but community and societal level resources, we have demonstrated that resilience is not
31
32 just a trait or psychological attribute (Bonanno et al., 2007; Gaugler et al., 2007; Kalisch et
33
34 al., 2015; O'Rourke et al., 2010; Windle et al., 2010), but a social ecological construct
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36 (Bennett & Windle, 2015; Bronfenbrenner & Ceci, 1994; Ungar, 2015). However, the current
37
38 study has a number of important limitations. First, carers who were recruited from support
39
40 groups may have been inherently more resilient than carers who did not attend support
41
42 groups. Therefore, the influence of resilience, assets and resources may have been
43
44 overestimated. Second, whilst we collected a range of carer demographic data, there were
45
46 some key demographic statistics that we did not capture despite them being featured within
47
48 the resilience framework, e.g. ethnicity and socioeconomic status (Windle & Bennett, 2011).
49
50 This is problematic given the fact that characteristics like these are likely to influence carers'
51
52 capacity for resilience. It also limits the transferability of our findings meaning that we
53
54 cannot infer anything about carers from different ethnic groups or socioeconomic classes.
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3 Future studies should aim to collect larger, more representative samples with data on a full
4 range of potentially relevant demographic characteristics. Finally, this study captured
5 resilience cross-sectionally. This is problematic because research indicates that resilience is
6 not fixed but fluctuates over time (Joling et al., 2015; Luthar, 2006; Windle, Woods, &
7 Markland, 2010). Furthermore, a carer's capacity for resilience (e.g. ability to 'bounce back')
8 may be heavily dependent on their pre-caring distress levels. We did not collect data on this
9 which means it was impossible to assess resilience proportionate to baseline pre-caring
10 functioning. Future prospective qualitative and quantitative longitudinal research is necessary
11 to identify and explore trajectories of resilience over time (Bennett, 2010; Masked for review,
12 2019; Dias et al., 2015).

13
14
15 Our findings have practical applications. By identifying the unique challenges and
16 perceived beneficial resilience resources in specific groups of informal carers (e.g. spousal
17 and adult children), practitioners and policy makers may be better able to target and tailor
18 support more efficiently to those who need and are ready to accept support (Gaugler et al.,
19 2007). The interactivity seen between some of our resources suggests that such support for
20 individual challenges could be targeted at a community or societal level, for example;
21 dementia-friendly neighbourhoods (Mitchell & Burton, 2010) and carer-friendly work
22 policies and funding (Yeandle et al., 2002). This is advantageous on a theoretical level as it
23 takes responsibility away from the carer, which is a common criticism of more traditional
24 resilience research (Windle, 2011; Ungar, 2015).

25
26
27 By attempting to promote some of the resilience resources and uplifts that we identify
28 rather than exclusively mitigating challenges, practitioners may be able to help carers to
29 adjust to their role and maintain continuity within their lifestyle and relationship with the
30 PLWD. The kinship differences that we identify suggest that supportive interventions which
31 are individualised and tailored to different caregiving relationships are most likely to be
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3 effective in facilitating resilience and sustaining carers in their role (Gaugler et al., 2007).

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5 Finally, and perhaps most fundamentally, carers may feel less weight of responsibility to
6
7 manage stress if researchers and practitioners take an ecological resource-based approach to
8
9 resilience, highlighting not just the individual assets necessary to manage stress but also the
10
11 supportive community and wider societal resources (Windle, 2011; Ungar, 2015).

12
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14
15 In conclusion, we found that informal carers of people living with dementia draw on a
16
17 range of factors to facilitate or hinder their capacity for resilience. There are important
18
19 similarities but also differences in terms of resource use for spousal and adult daughter carers.
20
21 Our findings represent a move away from deficit models of caregiver burden (Etters et al.,
22
23 2008) towards an interactive ecological model of carer resilience (Windle & Bennett, 2011).
24
25 There is a need for future research and formal services to distinguish between different
26
27 kinship ties and to continue exploring resilience from an ecological perspective.
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33 **Disclosure statement:** The authors declare that there is no
34
35 conflict of interest.
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Table 1. Demographic details of carers.

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

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2				
3	Wife 3	61	5	39
4				
5	Wife 4*	80	8	53
6				
7				
8	Wife 5	62	5	35
9				

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

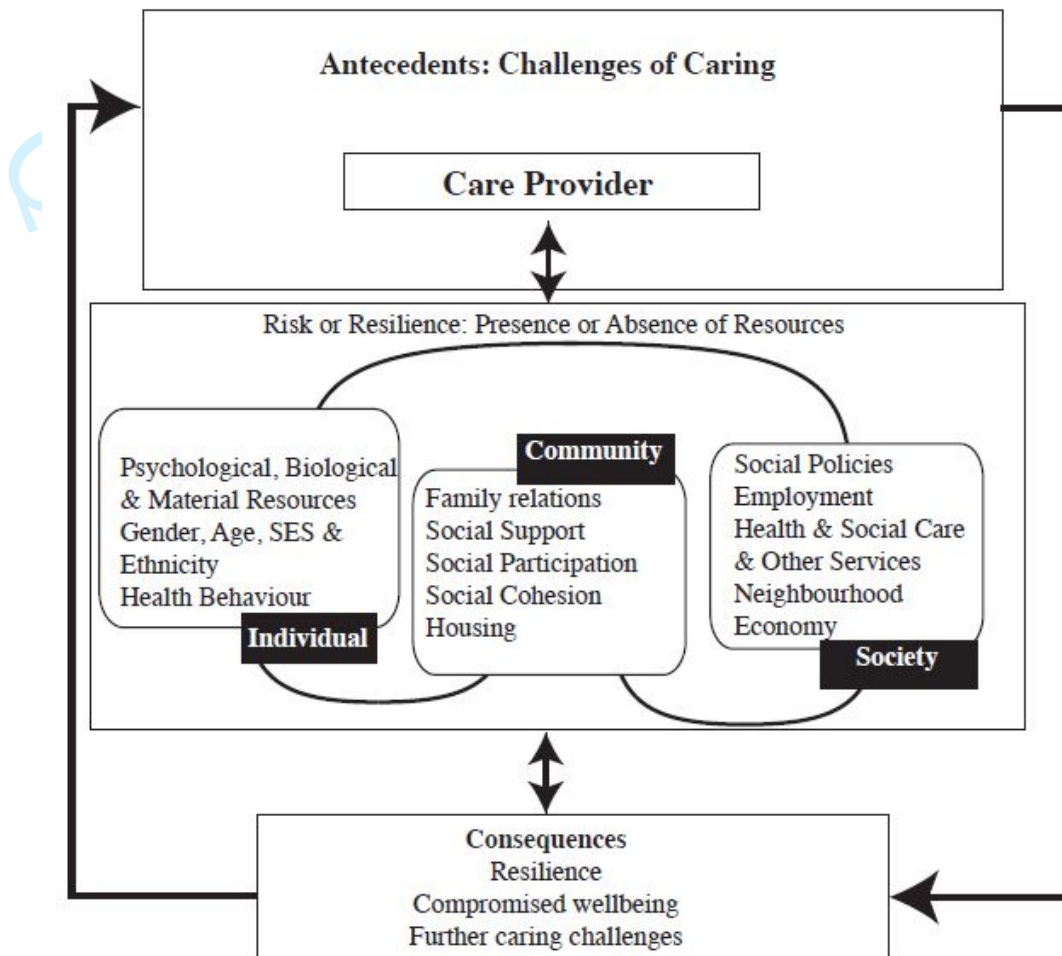


Figure 1. The ecological resilience framework applied to informal carers (Windle & Bennett, 2011).