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How does carer resilience change over time and care status? A qualitative longitudinal study

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ABSTRACT

Objectives: Little research examines trajectories of carer resilience or the factors that facilitate or hinder resilience over time. We use qualitative longitudinal methods to examine trajectories of resilience and which assets and resources are associated with resilience and care status transitions in spousal dementia carers.

Method: Based on an original sample of 23 spousal dementia carers (Donnellan, Bennett, & Soulsby, 2015), we conducted 13 follow-up interviews, including: 5 continuing home carers, 3 former carers (institutionalised), and 5 former carers (widowed).

Results: Five participants remained resilient (stable resilient), three remained non-resilient (stable non-resilient) and four participants became resilient (non-resilient to resilient). Only one participant became non-resilient (resilient to non-resilient). Stable resilience was characterised by continuing individual assets and community resources. Carers who became resilient returned to previous resources, or gained new resources.

Conclusion: Institutionalisation and widowhood are not always barriers to resilience; spousal dementia carers can remain or even become resilient over time despite deteriorating health, institutionalisation, or death of the care recipient.

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Spousal care; dementia; resilience; transitions; longitudinal

Introduction

Spousal dementia carers experience gradual increases in stressors over time (Goldstein, Atkins, Landau, Brown, & Leigh, 2006; Kramer, 2000). These stressors are associated with impaired resilience, negatively impacting: health; quality of life; relationship satisfaction; and social support (Lavretsky, Siddarth, & Irwin, 2010; O'Connor & McCabe, 2011). However, there is growing recognition that carers can be resilient in the face of increasing adversity. Resilience has been defined 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).

Windle and Bennett (2011) developed an ecological resilience framework; carers draw on individual assets, community and societal resources which interact to facilitate or hinder resilience. In previous cross-sectional work we used the resilience framework to identify the assets and resources that facilitate or hinder resilience in spousal dementia carers (Donnellan et al., 2015). We found that 8/20 participants were resilient. A resilient carer 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 (Donnellan, Bennett, & Soulsby, 2016). Finally, resilient carers were more actively engaged with services such as respite care.

Research shows that resilience is not fixed but fluctuates across the lifespan in response to changing life circumstances (Joling et al., 2015; Luthar, 2006; Windle, Woods, & Markland, 2010). Studies have used prospective longitudinal models to examine carer resilience as a trait predictor of clinical outcomes, such as depressive symptoms (Gaugler, Davey, Pearlin, & Zarit, 2000; O'Rourke et al., 2010), and a predictor of transitions from dementia care, including institutionalisation, care recipient death and loss to follow-up (Gaugler, Kane, & Newcomer, 2007). Relatively little work has examined carer resilience as a dynamic outcome that changes through developmental trajectories and transitions (Kalisch, Müller, & Tüscher, 2015). The developmental trajectory of resilience is as important to consider as its component parts.

We know that carers transition in and out of caregiving (Gaugler et al., 2007; Lawson et al., 2013). For spousal carers, this is often through institutionalisation or death of the care recipient. Both have negative physical and psychological effects on the carer (Bond, Clark, & Davies, 2003; Schulz, Williamson, Morycz, & Biegel, 1991). Longitudinal research shows that continuing home carers are relatively more likely to experience a range of stressors, including depressive symptoms, and end of, or reduction in, paid employment (Schulz et al., 2003). Conversely, widowed former carers and former carers who institutionalise the care recipient experience fewer depressive symptoms (Schulz et al., 2003) and improvement in burden and mastery over time (Mausbach et al.,

Table 1. Participant characteristics (years) and resilience trajectory over time.

Carers (N = 13)	Age	Marriage duration	Care duration	Follow-up	Pathway	Trajectory	
						Time 1	Time 2
Mrs W.**	65	31	4	3	Inst.	NR	R
Mrs C.*	71	50	11	3	Widowed	R	R
Mrs Wi.**	72	54	6	3	Inst.	NR	NR
Mr G.	84	55	8	3	Home	R	R
Mrs G.*	85	50	6	3	Widowed	NR	R
Mrs Go.*	72	42	7	3	Widowed	R	NR
Mrs O.*	80	60	3	3	Widowed	NR	R
Mr Go.	77	55	13	3	Home	R	R
Mr Wh.*	74	52	12	3	Widowed	R	R
Mr H.	84	56	8	3	Home	NR	NR
Mrs P.**	78	52	6	2	Inst.	NR	R
Mrs Lg.	71	45	8	1.5	Home	R	R
Mrs Hn.	67	49	4.5	1.5	Home	NR	NR

Key: *Widowed. **Institutionalised. R = Resilient. NR = Not resilient. Home = Continuing home carer. Inst.=Former carer (institutionalised). Widowed = Former carer (widowed).

2007). Kramer (2000) found that wellbeing remained stable in former carers who institutionalised their spouse, and increased in those who continued to care at home. Former carers may have a greater capacity to be resilient as institutionalisation and bereavement lead to a reduction in caregiving stressors.

Longitudinal studies in this area typically use quantitative approaches which rarely distinguish between different types of former carer (Gaugler et al., 2007; Ross, Holliman, & Dixon, 2003). In a longitudinal study of spousal dementia carers, Bond et al. (2003) found that continuing home carers experienced stable quality of life. Widowed former carers and those who institutionalised their spouse ('yielders') experienced improved quality of life, mental health and perceived health status. They could be compensating for the social isolation of continuing home care. Social activities increased in both groups, which may be explained by functional relief of caregiving responsibilities. Despite this functional relief, 'yielders' experienced only minor increases in psychological wellbeing. This fits with Larkin's (2009) qualitative work on the 'post-caring trajectory'. Widowed former carers experience the 'post-caring void'; negative emotional experiences and a reduction in contact with formal services (Jenkinson, 2004). Individuals then begin to change routines and take part in 'closure tasks'. Finally, individuals reconstruct their lives post-caring by rebuilding social relationships and pursuing leisure interests or life-long ambitions. However, these phases are unlikely to be linear or fixed in duration, and it is not clear how this applies to former carers who institutionalise the care recipient. Care status transitions may differentially facilitate resilience in spousal dementia carers over time.

The resilience framework has not been tested longitudinally; we do not know how assets and resources change over time and care status (Windle & Bennett, 2011). There is little qualitative longitudinal research in the area of carer resilience. Based on our original sample of 20 spousal dementia carers, the current study uses qualitative longitudinal methods to follow the care status transitions of 13 current and former spousal dementia carers, including: continuing home carers; former carers (institutionalised); and former carers (widowed). We address the following research objectives: i. To examine trajectories of resilience in spousal dementia carers over time and across care status, and ii. To identify which assets and resources from the resilience

framework (Windle & Bennett, 2011) are associated with resilience and care status transitions.

Methods

Participants

Original sample

We purposively sampled 23 current and former spousal dementia carers. Most participants lived with and cared for their spouse at home although three were already widowed (Mrs L., Mr Gr., Mrs Wk.) and another had admitted her husband into a nursing home (Mrs G.) (see Table 1). Participants were recruited from two dementia support groups and a care home in North West England. The first author made contact with staff at each of the organisations by phone, before being invited to give a brief talk about the research. Socioeconomic status was measured by asking participants to describe their last occupation. Three groups were used from the original British Household Panel Survey categories: Professional (n = 1), Skilled (n = 9), and Partly/Unskilled (n = 3). The socioeconomic status distribution of the participants was broadly representative of the British population (Office for National Statistics, 2011). The first author kept in touch with each of the original participants so that they could be followed up in a timely and appropriate way. No pre-arrangement to be re-interviewed was made at this stage due to the unpredictable symptomology and extended course of dementia care (Potgieter, Heyns, & Lens, 2012).

Follow-up

Participants were followed up by phone 1.5-3 years after the original interview. The follow-up period varied as we could only interview participants at their own convenience. Nine women and four men were willing to be re-interviewed: a retention rate of approximately 57%. This exceeds the minimum theme saturation threshold of 12 interviews, set by Guest, Bunce, and Johnson (2006). One participant was now deceased, one withdrew due to poor health, and three were widowed at Time 1 (T1) so were not followed up. An additional five participants were not traceable. Only participants providing care at home or those who had institutionalised their spouse at T1 were followed up.

Table 2. Resilience trajectories over time and care status.

Resilience trajectory	Pathway (1.5-3 years)		
	Continuing home carer	Former carer (institutionalised)	Former carer (widowed)
Stable resilient	Mr Go.; Mr G.; Mrs Lg.		Mrs C.; Mr Wh.
Stable non-resilient	Mr H.; Mrs Hn.	Mrs Wi.	
Resilient to non-resilient			Mrs Go.
Non-resilient to resilient		Mrs P.; Mrs W.	Mrs G.; Mrs O.

Key: Stable resilient (resilient at T1 and T2); Non resilient to resilient (non-resilient at T1, resilient at T2); Stable non-resilient (non-resilient at T1 and T2); Resilient to non-resilient (resilient at T1, non-resilient at T2).

Participants fell into one of three care pathways: continuing home carers ($n = 5/13$), former carers (institutionalised; $n = 3/13$) and former carers (widowed; $n = 5/13$). All former carers who had institutionalised their spouse had done so two years previously. Widowed former carers had been widowed for between eight months and two years (mean = 1.5 ± 7.80). We considered marriage duration to have ceased if the care recipient died and care duration to cease if the care recipient was institutionalised.

The Interviews

Time 1

The original interviews were digitally recorded during monthly carer meetings. All interviews were semi-structured and conducted either by the first author or by one of two female research assistants. Interviews took place in a private room, and lasted 25 – 90 minutes. Interviews took an open chronological and retrospective approach to allow feelings and events to be traced to specific stages within the care duration. See Donnellan et al. (2015) for a detailed summary of the interview structure.

Time 2

Follow-up interviews (T2) were conducted by the first author at the participant's home and lasted 30 minutes – two hours. All started with a recapitulation of key themes from T1. Continuing home care interviews asked about general changes since the last interview and about the present time. Participants were asked to describe a typical day spent alone and with their spouse, relationship quality, division of responsibility and type and amount of support given and received.

Former carer interviews asked about events leading up to the institutionalisation or death of the spouse, including their initial emotional and behavioural reactions. Participants were asked to describe a typical day, how their responsibilities had changed, and whether there had been changes in support. Participants were given the opportunity to talk about anything that they felt we had missed. Finally, participants were prompted to provide advice to other people in similar circumstances as themselves. The study received ethical approval from the University of Liverpool Research Governance Committee. All identifying features have been anonymised in the quotations used.

Method of analysis

We used a three-stage hybrid method in our analysis of the original and follow-up data (see Bennett, Reyes-Rodriguez, Altamar, & Soulsby, 2016; Donnellan et al., 2015; Donnellan et al., 2016). In our original study, we used a

grounded theory approach (Bennett & Vidal-Hall, 2000; Charmaz, 1995) to read and code the interviews. We then classified the participants as resilient or not, using the following criteria (adapted from Bennett, 2010):

- i. There must be a significant challenge: caregiving.
- ii. No sign of (di)stress.
- iii. Maintaining a life of meaning and satisfaction (a sign of bouncing back).
- iv. Actively participating in life (a sign of managing).
- v. Current life seen as positive (a sign of adaptation).

Finally, we identified the factors which facilitated or hindered resilience, and whether they could be mapped onto Windle and Bennett (2011) resilience framework. The follow-up analysis is summarised below:

1. First, we reflexively re-coded T1 interviews using the same method as above in order to refamiliarise ourselves with the data. If any new codes emerged they were merged with our existing codes. Next, we read through each T2 interview in its entirety. Interviews were reflexively coded line-by-line and focused codes were developed, before identifying themes based on all interviews.
2. Then, we re-read T2 interviews to identify participants as resilient or not. Each author classified each participant independently. This was done blind without knowledge of T1 classifications. We used the same criteria as in the original study (see above).
3. Finally, we reanalysed T1 and T2 codes to examine the factors from the resilience framework (Windle & Bennett, 2011) associated with stable and changed resilience classification and care status transitions.

Results

Trajectories of carer resilience

We found that five participants remained resilient (stable resilient), three remained non-resilient (stable non-resilient) and four participants became resilient (non-resilient to resilient). Only one participant became non-resilient at T2 (resilient to non-resilient).

Continuing home carers comprise only stable participants: three stable resilient and two stable non-resilient. Former carers (institutionalised) include two who change from non-resilient to resilient, and one stable non-resilient participant. Of the five widowed former carers, two remained resilient, two became resilient, and one became non-resilient (see Table 2).

Assets and resources associated with resilience and care status transitions

The following section highlights the assets and resources associated with resilience under each care status pathway. T1 and T2 quotes are presented together wherever possible.

Stable resilient

Continuing home carers are characterised by continuing individual assets and community resources. The majority remain resilient despite all noting the deteriorating health of their spouse. A key individual asset is the ability to stay positive:

I'm positive. I laugh and I sing and she laughs... I've even said to one of the neighbours about my singing and she says, '[Mr Go.], it's a good job we've got a detached house'. (Mr Go. T1)

I try to get into her head and say, are you happy? I know she's not sad, she's happy, and I'm happy as well. (Mr Go. T2)

Another individual asset for continuing home carers is a continued desire to keep the care recipient stimulated and give life more meaning:

We often go to [park] before we go to [activity group]... If there is anything on at a museum we go there. I do the best I can to keep him out and to keep him stimulated. (Mrs Lg. T1)

Monday we're going to a wild flower centre... Tuesday will be [support group] for him. Wednesday will be a little discussion group along the road... In between that he likes to see his cousin, we go to see my sister, our daughter comes or we go to see her. So we have a very full life. (Mrs Lg. T2)

Continuing home carers have community resources such as support group friends. These are highly valued for their enduring shared experience and informational support:

We are like family. We know each other's troubles; we exchange sad stories or glad stories every week... I think that's why I'm so stable because I talk to so many people who are in the same boat. (Mrs Lg. T1)

Meeting all the people, nattering... is just so good for your soul. It's great... we're all in the same boat and we all would help each other if we could... people are very friendly... you find out all sorts of things. (Mrs Lg. T2)

Some widowed former carers remain resilient following the death of their spouse. These participants are characterised by an ability to maintain continuity. They maintain aspects of the care recipient's former self despite their death:

He's still got a brilliant sense of humour at times. (Mrs C. T1)

[Husband] changed a lot of people's perception of Alzheimer's... I never thought it took [husband] away. (Mrs C. T2; widowed for two years)

Family support is valued by these participants. The nature of this continued social support changes pre- and post-bereavement:

I've got a daughter who's a nurse... she knew who to contact... Every day that she's at home... she comes to make sure everything's alright. (Mr Wh. T1)

The daughter said... 'We've booked this holiday in Scotland. You're coming with us'. So we had a trip to Scotland... it was better cause you were doing something all the time. (Mr Wh. T2; widowed for one year)

These participants have gained individual assets, such as free time to pursue leisure interests:

I've just started going out again... come Summer I'll be out on the bowling green. (Mr Wh. T2; widowed for one year)

When I have a holiday now I can honestly relax and enjoy it... I've done like two cruises on my own... I'm fine when I'm with people. (Mrs C. T2; widowed for two years)

After becoming widowed, Mrs C. documented her caregiving experiences in a book which she then sold to a local charity. This had a therapeutic effect on her bereavement experience:

I felt as though he was still with me. I felt it got me through a lot... I wanted to get all those memories down so I could revisit them. (Mrs C. T2)

Both stable resilient continuing home carers and widowed former carers are characterised by continuing individual assets and community resources. However, the nature of these resources is likely to change for widowed former carers post-bereavement.

Stable non-resilient

Continuing home carers have continuing characteristics over time. For some, stable non-resilience reflects the declining function of the care recipient. Focusing on aspects that have become lost or irreparably changed is typical of non-resilience:

He will say to me sometimes, 'you don't love me, do you?', and I'll say of course I love you. (Mrs Hn. T1)

He just doesn't bother with me at all now... He actually swears at me which he never would have done before. (Mrs Hn. T2)

For other continuing home carers, stable non-resilience is characterised by a continued resigned attitude:

Everything is at a standstill now. It's just a matter of waiting until something happens... there's no future. (Mr H. T1)

It's not going to improve... it can only go one way, it can only get worse. (Mr H. T2)

Only participants who were non-resilient at T1 institutionalised their spouse. Former carers who institutionalised their spouse are characterised by continuing negative emotions, such as anger and guilt:

It's me just feeling a bit guilty I suppose... I seem to be more angry cause he can't put things together. (Mrs Wi. T1)

I went to the garden centre... and I went, oh, I should be there [visiting husband] instead of here sat drinking this cup. I felt guilty. (Mrs Wi. T2; institutionalised spouse two years ago)

Stable non-resilient continuing home carers and former carers who institutionalised their spouse are both characterised by continuing negative emotions which reflect the declining function of the care recipient.

Resilient to non-resilient

Only one participant changed from resilient to non-resilient. Following the death of her husband, Mrs Go. loses key psychological assets that she had before:

I have changed... My confidence in doing things and going places has gone. (Mrs Go. T2; widowed for one year)

Initially, Mrs Go. was able to rationalise the negative emotions associated with being a carer. However she develops more negative emotional characteristics after the death of her husband, such as guilt:

I do get upset and sad at times... but it's life, isn't it? You've just got to get on with it. (Mrs Go. T1)

I feel guilty that I should have done more for him. (Mrs Go. T2)

Both the assets that this widowed former carer loses, and the negative emotional characteristics that she gains, are individual- rather than community- or societal-level.

Non-resilient to resilient

Some participants become resilient in the face of admitting their spouse into a care facility. They now have more time to spend pursuing their hobbies and interests:

We were both members of the gym... but last August I decided to join again. I wouldn't have done that if he was at home. (Mrs W. T2; institutionalised spouse 2 years ago)

On a community level, Mrs W. now enjoys more time socialising with family:

I've got a daughter and two granddaughters... They come every Thursday for their tea which is very nice because it got to the stage where I wasn't really seeing them. (Mrs W. T2)

Some former carers who institutionalise their spouse previously had longstanding friends who they could not see often. They now spend their free time doing new things and meeting new people:

I do have a couple of friends... just keep in touch on the phone really and occasionally meet up... I have a couple of friends who I can't go and see now. (Mrs P. T1)

We went to the Lowry to see Farewell to Arms. Bit heavy but I enjoyed the day and met people I hadn't before. (Mrs P. T2; institutionalised spouse two years ago)

Some previously experienced negative emotions which were exacerbated by the institutionalisation of their spouse. On a societal level, participants manage this through health service use:

Every time I open my mouth I seem to say something wrong... it makes you feel unhappy all the time. (Mrs W. T1)

I went to see a counsellor for five weeks. She was brilliant... We talked about things I've never talked about before and she said, 'turn the guilt into regret'. That really was the turning point. (Mrs W. T2; institutionalised spouse two years ago)

Some of these participants now take the opportunity to volunteer and 'give back' to other people in similar circumstances:

It took me a long time to go out and do that originally [volunteering] but I do think it's vital that anybody does join and get involved. (Mrs P. T2; institutionalised spouse two years ago)

Widowed former carers develop more resources and less negative emotion when the spouse dies. On an individual level, widowed former carers have now accepted their circumstances:

It's a lot better now because I've realised, don't be stupid, you're on your own, you're your own boss. (Mrs G. T2; widowed for 2 years)

Over time, Mrs G. goes from being isolated to spending more time pursuing her hobbies:

I never see anybody other than when I go out shopping. (Mrs G. T1)

I go out for a half hour music lesson twice a week now. That's my relaxation, you know, because I love music. (Mrs G. T2)

Former widowed carers and those who institutionalise their spouse become resilient through accepting and managing negative emotional characteristics and gaining novel individual assets, community and societal resources.

Discussion

Our first research objective was to examine trajectories of resilience in spousal dementia carers over time and across care status. Despite a gradual increase in stressors over time (Goldstein et al., 2006; Kramer, 2000), the majority of carers remained either resilient or non-resilient (Bond et al., 2003). Interestingly, former carers were more likely than continuing home carers to become resilient (Kramer, 2000; Schulz et al., 2003). This suggests that care status transitions are not always associated with negative physical and psychological effects (Bond et al., 2003; Goldstein et al., 2006; Kramer, 2000; Schulz et al., 1991). Rather, institutionalisation and/or bereavement may remove or reduce the number of stressors, and elicit short- and long-term improvements in psychological health (Mausbach et al., 2007). Care status transitions differentially facilitate resilience, supporting the notion that resilience can increase over time (Gaugler et al., 2000).

Our second research objective was to identify which assets and resources from the resilience framework (Windle & Bennett, 2011) are associated with resilience and care status transitions. Stable resilient carers were characterised by continuing individual assets and community resources (O'Connor & McCabe, 2011) and stable non-resilient carers were characterised by continuing negative emotions (Gaugler et al., 2000). This is in line with the factors identified in our previous work (Donnellan et al., 2015; Donnellan et al., 2016), suggesting that assets and resources are stable rather than fluctuating (Windle et al., 2010). Unlike continuing home carers, former carers who institutionalised their spouse reported more free time to return to previous resources and gain new resources. This suggests that functional relief of caregiving responsibilities is an important mechanism through which resilience resources are facilitated following a care status transition (Bond et al., 2003). Widowed former carers were characterised by reduced negative emotions (Schulz et al., 2003) and gained individual assets and community resources (Bond et al., 2003; Larkin, 2009). In line with our previous work, resources emerge from each level of the resilience framework (Donnellan et al., 2015; Windle & Bennett, 2011), suggesting that care

status transitions provide an opportunity to draw on more assets and resources over time.

The findings have practical implications for the design and application of dementia carer support services. Firstly, we found that carers move between care settings and care status transitions differentially facilitate resilience. This suggests that carers are heterogeneous and there is no 'one-size-fits-all' solution for support services (Bennett, 2015). Services need to be tailored to the specific needs and circumstances of carers (Hanratty & Holmes, 2011); some services may matter more than others at different times and in different contexts (Bennett, 2010). Secondly, current services tend to be practical and problem-focused, and do not routinely assess the rewarding aspects of caregiving (Seddon & Robinson, 2015). We show that caregiving is not entirely burdensome and resilience is not fixed; non-resilient carers can become resilient over time despite deteriorating care recipient health and care status transitions. By aiming to facilitate resilience as well as alleviate disorder, practitioners and policy makers may design more efficacious carer support services. Finally, assets and resources emerge from across the resilience framework (Windle & Bennett, 2011) and these change over time and care status. Practitioners and policy makers should take an ecological approach, designing psycho-social support services that reflect the dynamic interplay between individual assets, community and societal resources (Windle, 2011).

The current study has a number of limitations. First, our small sample size may limit comparisons of resilience across care status transitions, and the practical implications drawn from them. However, qualitative longitudinal research allows us to characterise and contextualise these complex transitions (Calman, Brunton, & Molassiotis, 2013). Second, resilience and care status transitions may simply be driven by differences in care recipients' health status. For example, Bond and Clark (2002) found that dementia severity was the best predictor of institutionalisation. Former carers may have been caring for spouses with substantially greater levels of impairment at T1, explaining their institutionalisation or death at T2 (Kramer, 2000). However, we found that care durations varied across groups, and all participants reported deteriorating health of the care recipient. Thus any confounding effect of care recipient health status is likely to be small. Finally, we cannot assume directionality from our findings. For example, it is unclear whether resilient carers are more likely to remain caring at home, or whether continuing home care provides stability to remain resilient over time. Further research is necessary to explore the complex associations between resilience and care status pathways.

In conclusion, spousal dementia carers can remain or become resilient over time despite deteriorating health, institutionalisation, and death of the care recipient. Institutionalisation and widowhood are not always barriers to resilience; indeed, they differentially facilitate resilience. This is important as studies rarely distinguish between different types of former carer. Stable resilience was characterised by continuing assets and resources. Former carers gained a range of resources from each level of the framework, suggesting that care status transitions provide an opportunity to draw on more assets and resources over time.

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