Title: The role of resilient coping in dementia carers' wellbeing

Abstract

Background: Carers of people with dementia are at risk of psychological distress. However some carers experience positives outcomes and resilient coping may account for this variance in carers' wellbeing.

Aim: To assess the role of resilient coping in dementia carers' wellbeing.

Methods: A cross-sectional survey of carers measured resilient coping, depression, anxiety, stress and burden. First, group comparisons between carers with high, medium and low resilient coping were made. Next, mediation analyses were conducted to identify if resilient coping was a mediator in the relationships between carer wellbeing and distress.

Results: Carers (n=110) were aged 30-80+ years; 66% female; 72% provided 40+ hours care per week; 23% were highly resilient. High resilient carers report significantly less distress than low resilient carers. Resilient coping was a partial mediator in the relationships between wellbeing and depression, anxiety, stress and burden.

Conclusions: Interventions promoting or maintaining resilient coping may reduce morbidity in family carers.

Key words:

Dementia, Carer, Resilience, Wellbeing.

Key points:

1) Carers with high resilient coping skills report less depression, anxiety, stress and burden than those with low resilient coping.

2) Resilient coping can act as a partial mediator between carer wellbeing and carer distress
3) Interventions which enable carers to develop or maintain resilient coping skills may help reduce morbidity associated with caring for a relative with dementia.

Reflective questions

1. Why may family carers of people with dementia be at greater risk of psychological distress?
2. How does your service assess carers' needs and wellbeing?
3. How could you support carers to develop or maintain their resilience?

Main text:

Introduction

Dementia a complex neurodegenerative disease which affects 50 million people worldwide (Patterson, 2018). It is characterised by a gradual loss of cognitive function and increasing dependence in activities of daily living. Behavioural and psychological symptoms including agitation, aggression, hallucinations, delusions and sleep disorders are common in people with dementia (Desai et al 2012). In the UK there are approximately 700 000 informal carers looking after a friend or relative with dementia (Lewis, 2014). Carers of people with dementia face different challenges to other carers, they are more likely to provide intimate care and spend more hours per week providing care (Alzheimer's Association 2016). They are also at greater risk of experiencing depression, anxiety, and stress than other carers (Schulz and Martire 2004). However, many carers experience positive outcomes and carer gain (O'Rourke et al. 2010). Previous research into this variance has considered pathological factors related to dementia; functional, cognitive and behavioural disturbance and stage of dementia (Mioshi 2013) and the socio-demographic characteristics of the carer (Roth et al. 2001). More recent research has focused on resources which promote wellbeing such as coping styles (Roche et al. 2015) and social support (Donnellan et al. 2016). Resilience has been suggested to be the intervening factor between risks associated with caring and utilisation of personal and community resources (Mohaupt 2009; Windle and Bennett 2011).

Resilience is multidimensional and embodies personal qualities and external support systems that enable one to thrive in the face of adversity (Windle et al. 2010). Traits and resources which may promote resilience include religiosity, positivity and social support (Deist and Greef 2015; MacLeod et al. 2016). Resilient coping combines individual characteristics and resources with coping behaviours. Resilient coping is associated with positive physical and psycho-social outcomes (Benard 1999). It is differentiated from other coping styles by the appreciation that the stressor (e.g. caring) is both chronic and uncontrollable and social and contextual factors have a significant impact. Identifying carers with low resilient coping may support nurses target resources and services to the most vulnerable carers.

The aims of this study were to 1) investigate factors that may affect resilient coping in carers, 2) assess whether symptoms of distress vary between carers with differing levels of resilient coping and 3) identify whether resilient coping acted as a mediator in the carer distress wellbeing relationship. A model indicating the potential role of resilient coping in the distress-wellbeing pathway is presented in Figure 1. We hypothesized that as carer distress increased carer wellbeing would decrease; and that the presence of resilient coping would mediate the relationship between carer distress and wellbeing.

- Please insert Figure 1 here -

Methods

Participants

Participants were carers of a family member with dementia. Inclusion criteria: (1) participants to be 18 years or older, and (2) able to complete a questionnaire in English. Exclusion criteria: (1) paid carers and (2) non-family members. Demographic variables investigated included carer gender, age group, relationship status, employment, education and the number of hours spent caring each week.

The study was promoted through adverts in newsletters, carer information events held by local charities and an online carer's forum ('Talking Point', Alzheimer's Society UK). Data were collected July 2016 – September 2017 via a self-completed postal survey. The study was approved by the Faculty of Medicine and Health Ethics Committee at the University of East Anglia, UK.

Instruments

Resilient coping

Resilient coping was measured using the Brief Resilient Coping Scale (BRCS)(Sinclair and Wallston 2004). The four-item scale asks respondents if statements apply to them. Answers range from 'does not describe me at all' through to 'describes me very well.' Statements cover creative responses to difficulties, emotional regulation, personal growth and replacing losses encountered in life. Scores can range from 4-20, scores above 17 indicate 'high resilient copers'; this scale has been applied in dementia carers in a previous study of our group (citation removed).

Psychological distress

The Depression Anxiety and Stress Scale (DASS-21) was used to assess psychological distress. The DASS-21 is a well-established measure of negative affect in adults and has been used in studies of family carers (Ervin et al. 2015; Kumfor et al. 2016; Wong et al. 2018). It is a self-report measure that distinguishes between stress, anxiety and depressive states (Lovibond and Lovibond 1995). The DASS-21 is an effective and valid measure of psychological distress (Crawford and Henry 2003). The scales were are analysed separately in this study to give a distinct score for each domain, depression, anxiety, and stress.

The Zarit Burden Index (ZBI) –Short version (Zarit et al. 1980) is a widely used measure which identifies burden in dementia carers, evaluating psychological distress, disease impact on quality of life, social and family relationships. Higher scores indicate greater burden. The short version, used here to reduce the time spent completing the questionnaire, is a robust, reliable measure which produces comparable results to the full version (Bédard et al. 2001).

Subjective wellbeing

Wellbeing was measured using the Personal Wellbeing Index –Adult (International Wellbeing Group 2006). The PWI- A is a two-part questionnaire. The first question asks ‘How satisfied are you with your life as a whole?’ The second section breaks this down into its component parts, asking respondents to rate their satisfaction in 8 areas: standard of living, health, personal achievement, relationships, feeling safe and part of a community, future security, and spirituality/religion. Participants rate their satisfaction with each item on a 0–10 Likert scale ranging from ‘completely dissatisfied’ (0) through ‘neutral’ (5) to ‘completely satisfied’ (10). The scale has been shown to have acceptable reliability and validity (International Wellbeing Group 2006).

Data analyses

In order to compare characteristics of carers according to their level of reported resilient coping, the sample was split into three groups as per author guidelines for the BRCS: high resilient coping, i.e. those with a score of 17 or above, medium resilient coping (scores 14-16) and those with low resilient coping (scores 4-13). Chi-square tests were then used to evaluate categorical differences between the three groups of carers.

Specific carer demographic variables were of particular interest for comparison: marital status and living situation, as these two factors, have been shown to provide specific challenges and increased the potential for psychological distress in family carers. For this reason, spousal carers were compared to non-spousal carers, and carers who live with the person with dementia were compared with those who live apart (O'Rourke et al. 2010).

Next, to identify differences in depression, anxiety, stress (DASS-21) and burden (ZBI) between carers (split by levels of resilient coping: high, medium and low), one-way ANOVAs with post hoc tests were run. To verify if data was normally distributed, all carers' scores on the DASS-21 subscales and ZBI were plotted on histograms for visual examination and Kolmogorov-Smirnoff tests were used to assess normality. Stress and burden were both normally distributed. Depression and anxiety did not meet the assumptions of normality; however, with sufficient sample size, the violation of this assumption should not cause significant problems for analysis (Elliott and Woodward 2007 p57). With this approach in mind, we proceeded with a parametric approach in the data analyses. Effect sizes for one-way ANOVA were calculated using ω^2, where values of 0.01, 0.06 and 0.14 represent small, medium and large effects respectively (Kirk 1996).

Finally, to investigate the role of resilient coping as a mediator in the carer wellbeing–carer distress relationship, mediation analyses including all carers in one single group were conducted. Each distress variable (depression, anxiety, stress, and burden) was examined separately. Significance of the indirect effect of this relationship was measured using 1000 Bootstrapped samples 95% bias-corrected confidence intervals. Effect sizes were described using the completely standardized indirect effect (Elliott and Woodward 2007; Hayes 2017). Bootstrapping was chosen over other mediation tests (such as the Sobel test) as it has been shown to be more effective for use with clinical data (Hayes and Rockwood 2017). IBM SPSS Statistics 25 and PROCESS v3 (Hayes 2017) software were used and statistical significance was set at $p<0.05$.

Results

Characteristics of resilient carers

Of the 150 mailed surveys, 110 were completed and returned (73%). As shown in Table 1, 23% (25/110) of respondents had high resilient coping, 28% (31/110) scored in the medium range, and 49% (54/110) in the low range. There was a significant difference in gender between the groups, women reported higher resilient coping. There were no significant differences between carers with high, medium or low resilient coping in relation to age group, education, relationship, residing with the person with dementia or number of hours per week spent caring.

- Please insert Table 1 here -

Are reports of psychological distress different between carers with high, medium, or low resilient coping?

Comparisons of carers with low, medium, and high resilient coping were made for each of the psychological distress variables, depression, anxiety, stress and burden (Figure 2).

- Please insert Figure 2 here -

There was a significant difference between groups (high, medium and low resilient coping; large effect size) for levels of *depression* as shown by a one-way ANOVA ($F_{(2,107)}$=10.92, p<0.001, ω^2=0.15). Post hoc tests revealed significant differences on depression between low and high groups (p<0.001, 95%CI: 2.65 to 9.20), low and medium groups (p=0.005, 95%CI 1.02 to 7.13) but not between medium and high groups (p=0.451, 95%CI -1.79 to 5.50).

There was a significant difference between groups (high, medium and low resilient coping; large effect size) for levels of *anxiety*, ($F_{(2,107)}$=6.89, p=0.002, ω^2=0.10). Post hoc tests showed significant differences in anxiety reported between the low and high resilient coping groups (p=0.006, 95%CI 0.77 to 5.60), low and medium resilient coping groups (p=0.011, 95%CI 0.53 to 5.02), but not between medium and high resilient coping groups, (p=0.930, 95%CI -2.28 to 3.09).

There was a statistically significant difference, with a large effect size, between groups for levels of *stress*, ($F_{(2,107)}$=12.16, p<0.001, ω^2=0.17). Post hoc tests revealed a significant difference in stress reported between low and high resilient coping groups (p<0.001, 95%CI 2.97 to 8.77) and low and medium resilient coping groups (p=0.023, 95%CI 0.35 to 5.76), but not medium and high resilient coping groups (p=0.100, 95%CI -0.41 to 6.04).

There was a significant difference between groups (high, medium and low resilient coping; large effect size) for levels of burden ($F_{(2,107)}$=12.43, p<0.001, ω^2=0.17). Post hoc tests revealed a significant difference between low and high resilient coping (p<0.001, 95%CI 5.51

to 16.45), low and medium (*p*=0.010, 95%CI1.23 to 11.33) but not between medium and high resilient coping groups (*p*=0.162, 95%CI -1.37 to 10.72).

Does resilient coping act as a mediator between distress and wellbeing?

Mediation analyses were conducted for the four distress variables, (Figure 3).

Resilient coping as a mediator in the depression wellbeing relationship.

There was a significant direct effect between depression and carer wellbeing, showing a negative relationship between these variables (*b*= -1.65 *p*<0.01). When resilient coping was included as a mediator in the model, there was a significant indirect effect (*b*= -0.76, 95% BCa CI [-1.11 to -0.35]), showing that resilient coping mediated the relationship between depression and wellbeing with a medium to large effect size (completely standardised indirect effect = -0.22).

Resilient coping as a mediator in the anxiety wellbeing relationship.

There was a significant direct effect between anxiety and wellbeing (b= -1.92, *p*<0.01), showing a negative relationship between these variables. When resilient coping is included as a mediator there is a significant indirect effect (b= -1.04, 95% BCa CI [-1.49 to -0.60]), showing that resilient coping mediated the relationship between anxiety and wellbeing with a medium to large effect size (completely standardised indirect effect = -0.22).

Resilient coping as a mediator in the stress wellbeing relationship.

There is a significant direct effect of stress on wellbeing, showing a negative relationship (*b*= -1.52, *p*<0.01) and when resilient coping is added as a mediator there is a significant indirect effect (*b*= -0.96, 95% BCa CI [-1.40 to -0.56]), showing that resilient coping mediated the relationship between stress and wellbeing with a medium to large effect size (completely standardised indirect effect = -0.20).

Resilient coping as a mediator in the burden wellbeing relationship.

There was also a significant direct effect between burden and carer wellbeing (*b*=-0.96, *p*<0.01) showing a negative relationship between these variables. There is a significant indirect effect when resilient coping is included as a mediator (*b*= -0.42 95% BCa CI [-0.64 to -0.22]), showing that resilient coping mediated the relationship between burden and wellbeing with a small effect size (completely standardised indirect effect = -0.02).

- Please insert figure 3 here –

Discussion

Our findings indicate that resilient coping is likely to mediate the adverse relationship between psychological distress and subjective wellbeing for family carers of people with dementia. In addition, carers with high resilient coping report much less psychological distress, which has implications for care planning and support.

High, medium and low resilient carers did not differ in socio-demographic characteristics, except for gender. In our study female carers reported higher resilient coping, but this may be a reflection of the fact that the number of male participants was smaller. Interestingly, our findings stand in contrast to the normative data for the assessment of resilience (BRCS) which suggests that men, overall, have higher resilient coping than women (Kocalevent et al. 2017). However, female carers are considered to be at greater risk of pathology associated with depression, anxiety, stress and burden than male carers (Erol et al. 2015).

Providing care, may itself lead to women having unexpected opportunities to develop resilience.

Carers had worse scores across the depression, anxiety, and stress scales when compared to the normative data (Henry and Crawford 2005). Our findings are consistent with previous research on carer distress which showed higher levels of depression, anxiety and stress were associated with higher burden (Wong et al. 2018); we build upon these earlier findings by demonstrating that carers with high resilient coping have lower distress scores across all measures. This aligns with findings that resilience can improve wellbeing in other groups such as formal carers (Mealer et al. 2012;). However, we also showed that informal carers who report high resilient coping can concomitantly experience symptoms of distress, especially in relation to feelings of burden - resilience and distress can coexist. This 'resilience-paradox' has been noted in other studies (Southwick et al. 2014; Wilks and Croom 2008) and needs further investigation.

We found that resilient coping mediated the relationship between depression, anxiety, stress and burden and caregiver subjective wellbeing. Resilient coping may have a strong effect on wellbeing as it is a multi-dimensional concept involving both beliefs and behaviors that also promote subjective wellbeing (Windle et al. 2008). However, despite the medium to large effect sizes found, it is also important to note that resilient coping only partially mediated the relationships between psychological distress and subjective wellbeing. This suggests there are other mechanisms which also ameliorate or exacerbate distress in family carers.

The mediation effects of resilient coping were similar across models for depression, anxiety, stress and burden, which indicates that improving resilience may be useful alongside other interventions, specifically targeting these symptoms. Cognitive based therapies (CBT) seem to be very effective in reducing carer anxiety and depression (Kishita et al. 2018). When this is considered alongside positive results from resilience training in other population groups (e.g. healthcare employees; parents), (Kaboudi et al. 2018; Werneburg et al. 2018) it seems that a potential combination of CBT-based approaches with resilience training such as SMART (Chesak et al. 2015; Sood et al. 2014) may be a beneficial and cost-effective mechanism to support family carers.

Limitations should be noted. Our sample was recruited via self-referral from community organisations and via online forums, and for this reason, our sample may be biased towards less distressed carers who may be more willing and able to take part in this type of research. Also, future research should investigate the influences of resilient coping on broader outcomes for both the carer and person with dementia.

Our findings suggest that psychological distress is not an inevitable consequence of caring, and that resilient coping is as likely - if not a more frequent response to adverse life events than severe psychological distress (Bonanno 2004). These findings have clear implications for nurses and allied health professionals working with carers of people with dementia and other neurological conditions. As a preventative measure to reduce morbidity associated with distress, practitioners may offer care and support which promotes or maintains resilience. Strategies which assist carers to develop skills and attributes associated with resilient coping, namely problem solving, managing emotions, and replacing losses (for example in a support network) may have particular benefits in promoting wellbeing and improving long term outcomes.

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Table 1. Carers' Demographic information and comparisons between groups. The sample was split in regards to resilient coping scores: low, (BRCS score 0-13), medium (BRCS score 14-16) and high resilience (BRCS score ≥17).

	Low resilience BRCS ≤13 (n=54)	**Medium resilience** BRCS 14-16 inc (n=31)	**High resilience** BRCS ≥17 (n=25)	**Chi square tests** (n=110)
Gender				**$X^2_{(1)}$=7.11,*p*=0.03***
Male	24 (44%)	5 (16.1%)	8 (32%)	
Female	30 (56%)	26 (83.9%)	17(68%)	
Age group				$X^2_{(2)}$= 1.29,*p*=0.86
≤ 69 years	19 (35.2%)	12 (38.7%)	11 (44%)	
70-79 years	20 (37%)	13 (41.9%)	9 (36%)	
80+ years	15 (27.8%)	6 (19.4%)	5 (20%)	
Education				$X^2_{(2)}$= 0.59,*p*=0.96
Up to 12 years formal education	23 (42.6%)	14 (45.2%)	9 (36%)	
Up to 14 years formal education	15 (27.8%)	9 (29%)	8 (32%)	
15 years + in formal education	16 (29.6%)	8 (25.8%)	8 (32%)	
Relationship to person with dementia				$X^2_{(1)}$ =1.56,*p*=0.46
Spouse	36 (66.7%)	19 (61.3%)	13 (52%)	
Other	18 (33.3%)	12 (38.7%)	12 (48%)	
Person with dementia resides with family carer				$X^2_{(1)}$= 3.97,*p*=0.13
Yes	45 (83.3%)	20 (64.5%)	18 (72%)	
No	9 (16.7%)	11 (35.5%)	7 (28%)	
Hours spent providing care per week				$X^2_{(1)}$= 3.51,*p*=0.17
Up 40 hours	11 (20.4%)	12 (38.7%)	8 (32%)	
41+ hours	43 (79.6%)	19 (61.3%)	17 (68%)	

Significant differences are highlighted in bold. *<0.05

Figures and legends:

Figure 1. Proposed model of the relationship between carer distress, resilient coping and carer wellbeing.

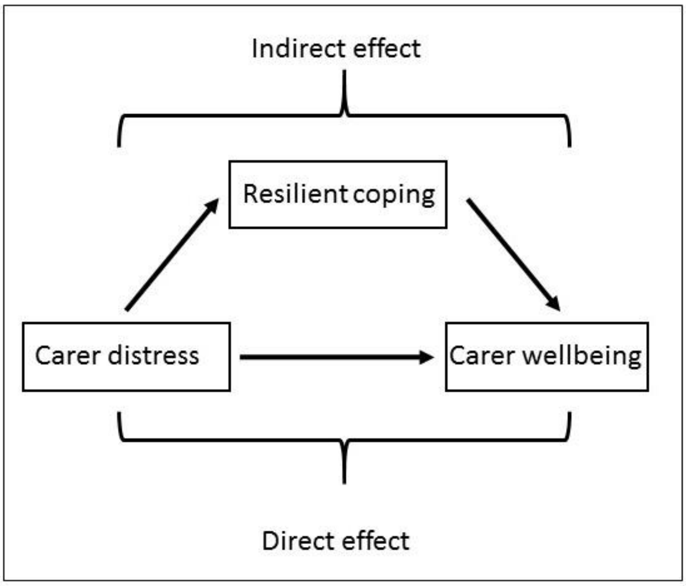

Figure 2 Comparisons of carers with low, medium, high resilient coping for depression, anxiety, stress, and burden. ———— Indicates mean score, * between-group differences *p*≤0.05

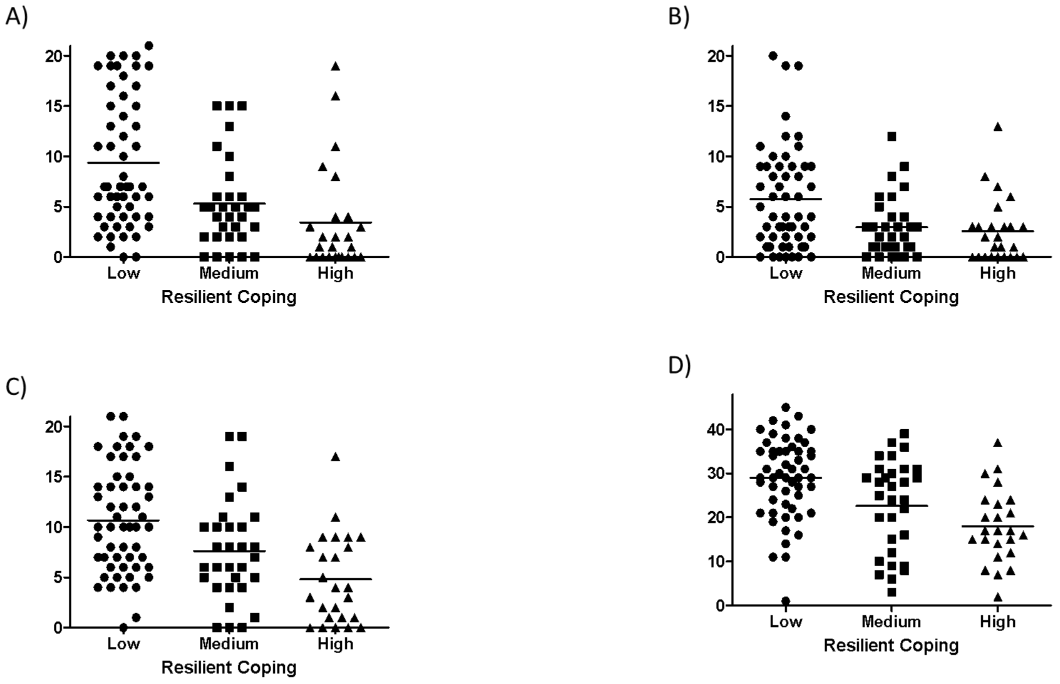

Figure 3. Four separate mediation analyses testing whether resilient coping mediates the relationship between carer wellbeing and carer distress variables A) depression B) anxiety C) stress and D) burden.