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RESEARCH PAPER

The role of experiential avoidance and cognitive fusion in the development of anxiety symptoms among family carers of people with dementia

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Burden

Abstract

Despite high prevalence of anxiety, current interventions for family carers of people with dementia are considered to be not as effective for anxiety as they are for depression. Understanding the mechanism by which a common stressor (i.e. carer subjective burden) and underlying psychological processes influence anxiety among this population is critical to inform these interventions. Roles of two psychological processes were explored: experiential avoidance in caregiving (attempt to control distressing thoughts/feelings related to caregiving) and cognitive fusion (tendency for one's behaviour to be overly regulated by thoughts). With a sample of seventy-seven family carers, this study examined the indirect effect of carer subjective burden (ZBI-12) on anxiety (GAD-7) through experiential avoidance in caregiving (EACQ) and cognitive fusion (CFQ) using path analysis approach. The whole sample model showed a good fit to the data and accounted for 54 % of the variance in anxiety. The indirect effect of carer subjective burden on anxiety through its effect on cognitive fusion ($\beta = 0.17$), and its combined effect on experiential avoidance in caregiving and cognitive fusion ($\beta = 0.01$) were significant. Given the higher explanatory value of cognitive fusion alone, facilitating cognitive defusion through psychological interventions may be critical for preventing clinically significant levels of anxiety, particularly among those carers experiencing high levels of carer subjective burden. Results

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also demonstrated that carers with higher experiential avoidance in caregiving may be prone to cognitive fusion, which in turn could lead to greater anxiety. Therefore, early interventions targeting experiential avoidance may be beneficial for preventing increased cognitive fusion and anxiety.

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Introduction

It is estimated that in the UK 700,000 unpaid carers take care of their loved one with dementia, saving the government an estimated £11 billion each year (Alzheimer's Society, 2014). These numbers are expected to continue to increase as the number of people diagnosed with dementia continues to rise (Alzheimer's Society, 2014; Carers UK, 2022). Taking care of a person with dementia is known to impact a carer's well-being (George & Ferreira, 2020; Lindeza et al., 2020) and the prevalence of anxiety symptoms among this population is considered to be high (Kaddour & Kishita, 2020), with some studies suggesting that the prevalence is even greater than that of depressive symptoms (Cooper et al., 2007; Sallim et al., 2015). Nevertheless, current literature lacks insight into the underlying factors affecting anxiety symptoms among family carers of people with dementia (Puga et al., 2022). In addition, previous studies suggest that the existing carer interventions, such as Cognitive Behavioural Therapy, are not as effective for anxiety as for depression (Kishita et al., 2018). Therefore, understanding how different stressors and psychological processes influence anxiety symptoms among family carers of people with dementia is critical to inform future interventions.

The revised sociocultural stress and coping model adapted to the caregiving context highlights the importance of different caregiving stressors in their effects on poor health outcomes (Knight & Sayegh, 2010). One of the well-known stressors in this population is carer subjective burden (Burns, 2000). Carer subjective burden refers to personal appraisals of burden including the physical, psychological, social and emotional impact their caring role has on their life (Liu et al., 2020). A recent meta-analysis reviewing 74 studies on informal carers, of which 24 targeted carers of people with dementia, concluded that carer subjective burden is an important risk factor for anxiety symptoms among informal carers (Del-Pino-Casado et al., 2021). Given the established association between carer subjective burden and anxiety symptoms, understanding the underlying psychological processes in which such stressor affects the mental health outcome could provide important clinical implications.

Recent research has highlighted the importance of a currently under-researched psychological dimension that may have an impact on anxiety symptoms among family carers of people with dementia: experiential avoidance (Barrera-Caballero et al., 2021; Cookson et al., 2020; Kishita et al., 2020; Van Hout et al., 2023). Experiential avoidance is the attempt to alter the form, frequency or intensity of private experiences such as thoughts or feelings, even when doing

so is costly, ineffective or unnecessary (Hayes et al., 2013). However, there are also some studies reporting weak correlations between experiential avoidance and anxiety symptoms among family carers of people with dementia (Cabrera et al., 2022; Lappalainen et al., 2021; Losada et al., 2014), suggesting a lack of predictive effect of experiential avoidance alone on anxiety symptoms.

Furthermore, recent studies conducted with non-carer populations demonstrated that the combined effects of experiential avoidance and cognitive fusion are more predictive of depression, anxiety and posttraumatic stress than experiential avoidance alone (Bardeen & Fergus, 2016; Xiong et al., 2021). Cognitive fusion is the tendency to become entangled with thoughts and the inability to step back from such restricting beliefs (Hayes et al., 2013). Cognitive fusion is known to mediate the relationship between experiential avoidance and depressive symptoms in family carers of people with dementia (Kishita et al., 2022). Whether this is the case with anxiety symptoms remains unclear. In addition, previous studies within dementia caregiving have investigated mediating or moderating role of experiential avoidance or cognitive fusion separately in the association between caregiving stressors and mental health outcomes (Barrera-Caballero et al., 2021; Mausbach et al., 2012; Romero-Moreno et al., 2016). However, the combined effects of experiential avoidance and cognitive fusion within this population is currently underexplored.

Therefore, this study examines the indirect effect of carer subjective burden on anxiety symptoms through experiential avoidance and cognitive fusion. This study aimed to examine these combined effects of carer subjective burden, experiential avoidance and cognitive fusion on anxiety symptoms in family carers of people with dementia. We hypothesise that carer subjective burden will be indirectly associated with anxiety symptoms through its association with experiential avoidance in caregiving and cognitive fusion. That is, when family carers demonstrate high levels of burden, they are more likely to try controlling or getting rid of distressing thoughts and feelings related to caregiving (experiential avoidance in caregiving). In such situations, their behaviour is more likely to be overly regulated and influenced by cognitive fusion, which in turn leads to higher anxiety symptoms.

Material and methods

Study design

Screening (baseline) data from an interventional study assessing the feasibility and acceptability of an online self-help Acceptance and Commitment Therapy (ACT) pro-

gramme with family carers of people with dementia (Kishita et al., 2021) was used in this study. The original study took place between August 2020 and January 2021 in England. Inclusion criteria were met if participants (1) were primary carers; (2) provided regular care to their family member with dementia (i.e. having a regular contact with the care recipient) and (3) were interested in engaging with online self-help ACT. In total, seventy-nine eligible carers were recruited through clinician referrals from three participating sites (healthcare services), through referrals from other ethically approved dementia studies or through self-referrals from the community via advertisements in local newspapers or a national recruitment website (i.e. Join Dementia Research).

Procedures

Eligibility criteria were checked by the research team via telephone or email. After eligibility criteria were met, participants received an invitation letter and information sheet. Written consent was obtained, via post or electronically, from all participants. Full ethical approval was received from the NHS London-Queen Square Research Ethics Committee (20/LO/0025). The screening session was conducted remotely via video call or telephone, in line with governmental rules during the COVID-19 pandemic. During the screening session, participants completed all self-reported questionnaires via post or an online survey in the presence of a researcher.

Measures

Demographic information

Demographic information including carer's age, gender and relationship to the care recipient were collected to characterise the sample. Carers' gender was coded as: 1 = male and 2 = female. The relationship to the care recipient was coded as: 1 = spousal relationship and 2 = non-spousal relationship.

Anxiety symptoms

The severity of anxiety symptoms was measured using the Generalised Anxiety Disorder Scale (GAD-7; Spitzer et al., 2006). The GAD-7 is a 7-item self-report questionnaire, which assesses how often during the last two weeks participants experienced anxiety symptoms. Each item is scored on a four-point scale ranging from 0 (not at all) to 3 (nearly every day). Total scores categorise the severity of anxiety symptoms as minimal (0–4), mild (5–9), moderate (10–14) or severe (15–21). The GAD-7 has good psychometric properties with good internal consistency (Cronbach Alpha = 0.89) (Spitzer et al., 2006). The Cronbach's alpha for the current study was 0.92.

Carer subjective burden

The short version of the Zarit Burden Index (ZBI-12; Bédard et al., 2001) was used to assess carer subjective burden. The ZBI-12 consists of 12 items in two domains: personal strain (e.g. "Do you feel you have lost control of your life since your relative's illness?") and role strain (e.g. "Do you feel you should be doing more for your relative?"). Each

item is scored on a five-point scale from 0 (never) to 4 (almost always). Total scores range from 0 to 48 with higher scores indicating higher subjective burden. Previous studies with community-dwelling older caregivers (Gratão et al., 2019) and caregivers of individuals with dementia (Higginson et al., 2010) have shown that the 12-version to be equally reliable and valid to the original 22-item version (Zarit et al., 1985) for detecting clinically significant levels of subjective burden. The ZBI-12 has good psychometric properties with good internal consistency (Cronbach Alpha = 0.88) (Bédard et al., 2001). The Cronbach's alpha for the current study was 0.88.

Cognitive fusion

Cognitive Fusion Questionnaire (CFQ; Gillanders et al., 2014) is a general measure of cognitive fusion and is not specifically designed for specific populations or conditions. The CFQ assesses the degree of attachment to distressing thoughts (the tendency for behaviour to be overly influenced by such thoughts) in general and consists of 7 items. Each item is scored on a seven-point scale from 1 (never true) to 7 (always true). Total scores range from 7 to 49, with higher scores indicating higher levels of cognitive fusion. The CFQ has good psychometric properties with good internal consistency (Cronbach Alpha = 0.88) (Gillanders et al., 2014). The Cronbach's alpha for the current study was 0.94.

Experiential avoidance in caregiving

The Experiential Avoidance Caregiving Questionnaire (EACQ; Losada et al., 2014) is a 15-item self-report measure specifically designed for family carers of people with dementia to assess experiential avoidance in the caregiving context. That is, this measure assesses the tendency to control, avoid or suppress distressing thoughts and feelings related to caregiving. The original version of the EACQ was developed in Spanish, however, an English translated version of the EACQ has also been used in research (George & Ferreira, 2020; Kishita et al., 2022; Smith et al., 2018). The EACQ asks participants to score each question on a five-point scale ranging from 1 (not at all) to 5 (a lot). Total scores vary between 15 and 75 with higher scores indicating higher levels of experiential avoidance in caregiving. The EACQ has good psychometric properties with acceptable internal consistency (=0.70) (Losada et al., 2014). The Cronbach's alpha for the current study was 0.73.

Statistical analysis

All analyses were performed using IBM SPSS statistical software (Version 28) and AMOS 28. Data were examined for accuracy with no extreme outliers detected. All variables followed a normal distribution although a tendency towards leptokurtosis was observed for the GAD-7. However, when appropriate transformations were performed (i.e., a logarithmic transformation of the GAD-7), analyses yielded identical results. Therefore, only non-transformed analyses are reported. The percentage of missing data across the eight variables varied between 1.27 % and 2.53 %. Little's MCAR tests were conducted for all variables, which suggested that

data were missing at random. Of the 79 datasets, data for the EACQ was missing for two participants. One participant did not have the EACQ data due to a technical error and another participant did not wish to complete the measure. AMOS 28 does not allow conducting certain analyses (i.e. calculation of modifications indices) when there are missing values, and thus participants with missing data were removed from the dataset rather than imputing them. This resulted in a dataset of 77 family carers.

A descriptive analysis was performed to categorise the sample using demographic information. To examine the associations between all variables and account for possible problems with multicollinearity, bivariate correlations were conducted between the demographic (i.e. carers' age, carers' gender and relationship to care recipient) and care-related variables (i.e. carer subjective burden (ZBI-12), cognitive fusion (CFQ) and experiential avoidance in caregiving (EACQ)), and the outcome variable (i.e. anxiety symptoms (GAD-7)). All variables significantly correlated with anxiety symptoms on a 0.05 level were included in the final path model.

Path analysis was conducted to test the proposed model of an indirect effect of carer subjective burden on anxiety symptoms through experiential avoidance in caregiving and cognitive fusion. The multiple mediation analysis used 1,000 bootstrap samples and 95 % bias-corrected confidence intervals (CI) around the standardised estimate of the effect as recommended by Preacher and Hayes (2004). Fitness of the final model was assessed using chi-square (χ^2) statistic. In addition, the root mean square error of approximation (RMSEA), the comparative fit index (CFI) and goodness-of-fit index (GFI) were also assessed. An excellent fit of the data to the model was considered at values under 0.06 for RMSEA and over 0.95 for CFI and GFI as indicated by Hu and Bentler (1998). Standardised root-mean-square residual (SRMR) was evaluated with a cutoff value close to 0.08 (Hu & Bentler, 1998). The Hoelter index was also used to test the adequacy of the sample size. By convention, Hoelter's $N > 200$ suggests the sample size is acceptable. Hoelter's N under 75 is considered unacceptably low to accept a model by chi-square (Hoelter, 1983).

Results

Sample characteristics

Sample characteristics are presented in Table 1. The study sample ($N = 77$) had a mean age of 63.47 years ($SD = 10.64$) and included mostly women (73 %). Participants' age ranged from 32 to 85 with 43 % of participants being older than 65 years. Most participants cared for a spouse (52 %) with Alzheimer Disease (44 %). On average, participants have been providing care for 53.39 months ($SD = 41.77$), with 44 % of them devoting 81 or more hours to caregiving each week.

Correlations of main variables

The result of the correlation analysis is presented in Table 2. Significant correlations were identified between anxiety symptoms and the carer's age and gender, meaning younger

female carers were more likely to experience anxiety symptoms. The relationship to the care recipient was not associated with anxiety symptoms. In addition, correlation analysis indicated a significant association between experiential avoidance in caregiving, cognitive fusion and anxiety symptoms. These results demonstrated that greater experiential avoidance in caregiving was associated with greater cognitive fusion and anxiety symptoms, and greater cognitive fusion was associated with greater anxiety symptoms.

Path analysis of a proposed model

Path analysis was conducted as presented in Fig. 1. The final model showed a relatively good fit to the data ($\chi^2 (5, N = 77) = 4.315, p = .505$; CFI = 1.00; GFI = 0.982; RMSEA = 0.000; SRMR = 0.0685; Hoelter's $N = 195$). The examined variables accounted for 54 % of the variance in anxiety symptoms.

As shown in Fig. 1, the standardised direct effect of carer subjective burden on anxiety symptoms was 0.23 ($p = .074, 95\% \text{ CI} = -0.02-0.47$), which was not significant. The indirect effect of carer subjective burden on anxiety symptoms through its effect on experiential avoidance in caregiving was 0.02 ($p = .095, 95\% \text{ CI} = -0.00-0.08$). This indirect effect was also not significant due to the lack of association between experiential avoidance in caregiving and anxiety symptoms. The indirect effect of carer subjective burden on anxiety symptoms through its effect on cognitive fusion was 0.17 ($p = .002, 95\% \text{ CI} = 0.06-0.31$). This significant indirect path indicates that higher carer subjective burden is likely to lead to higher cognitive fusion, in turn leading to higher anxiety symptoms.

The indirect effect of carer subjective burden on anxiety symptoms through its effect on experiential avoidance in caregiving and cognitive fusion was 0.01 ($p = .008, 95\% \text{ CI} = 0.00-0.05$). This significant indirect path indicates that higher carer subjective burden is likely to lead to higher experiential avoidance in caregiving, in turn leading to higher cognitive fusion, which then leads to higher anxiety symptoms. In addition, female gender was associated with higher anxiety symptoms. However, carer's age was not associated with anxiety symptoms or cognitive fusion in the final model.

Discussion

This cross-sectional study examined the indirect effect of carer subjective burden on anxiety symptoms through experiential avoidance in caregiving and cognitive fusion. Overall, the proposed model explained 54 % of the variance in anxiety symptoms in family carers of people with dementia. Consistent with recent studies examining the role of experiential avoidance and cognitive fusion in predicting mental health outcomes (Cookson et al., 2020; Kishita et al., 2022), the relationship between carer subjective burden and anxiety symptoms was significantly mediated by experiential avoidance in caregiving and cognitive fusion. However, the indirect effect of carer subjective burden on anxiety symptoms through its effects on experiential avoidance in caregiving was not significant in the model, suggesting that addressing experiential avoidance in caregiving alone might not be sufficient to eliminate the aggravation

Table 1 Demographics variables (N = 77).

Carer demographic variable (N = 77)	Percentage or M (SD)
Age	63.47 (10.64)
Age Range	32–85
Female	73 %
Type of relationship with care recipient	
Spousal relationship	52 %
Non-spousal relationship	48 %
Hours of caring per week	
0-2 h	4 %
3-10 h	21 %
11-20 h	10 %
21-40 h	7 %
41-80 h	14 %
81 + h	44 %
Length of care (in months)	53.39 (41.77)
Anxiety symptoms (GAD-7), score range 0–21	6.45 (5.27)
Carer subjective burden (ZBI-12), score range 0–48	24.87 (9.03)
Experiential Avoidance in Caregiving (EACQ), score range 15–75	41.42 (8.95)
Cognitive Fusion Questionnaire (CFQ), score range 7–49	24.25 (9.96)
Care recipient demographic variables	Percentage or M (SD)
Dementia Type	
Alzheimer's	44 %
Mixed	29 %
Vascular	12 %
Frontotemporal	3 %
Lewy Bodies	4 %
Unknown	9 %

Note: CFQ, Cognitive Fusion Questionnaire; EACQ, Experiential Avoidance in Caregiving Questionnaire; GAD-7, Generalised Anxiety Disorder Scale; ZBI-12, Zarit Burden Interview.

Table 2 Pearson's r correlations (N = 77).

Variables	1	2	3	4	5	6	7
1. Carer age	1.000						
2. Carer gender	-0.379**	1.000					
3. Spousal Relationship	-0.680**	0.297**	1.000				
4. Carer subjective burden	-0.184	0.137	-0.099	1.000			
5. Experiential avoidance in caregiving	-0.006	-0.070	-0.150	0.309**	1.000		
6. Cognitive Fusion	-0.271*	0.163	0.023	0.765**	0.394**	1.000	
7. Anxiety symptoms	-0.317**	0.292**	0.011	0.632**	0.356**	0.701**	1.000

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

of anxiety symptomatology. This is in contrast with significant mediating paths of experiential avoidance found in the relationship between caregiving stressors and depressive symptomatology in family carers of people with dementia (Mausbach et al., 2012). Considering the high level of comorbidity between depression and anxiety in family carers of people with dementia (Mineka & Zinbarg, 2006), this lack of relationship between experiential avoidance and anxiety symptoms is surprising. However, this may be explained by the weak correlation found between experiential avoidance in caregiving questionnaire and anxiety symptoms, which is consistent with the findings of previous

studies conducted with family carers (Cabrera et al., 2022; Lappalainen et al., 2021; Márquez-González et al., 2018). Noteworthy, the model demonstrated a significant path from carer subjective burden to anxiety symptoms through its effect on cognitive fusion alone. This indirect effect of cognitive fusion alone demonstrated a higher explanatory value than the combined indirect effect of experiential avoidance in caregiving and cognitive fusion.

Previous studies within dementia caregiving have separately investigated mediating roles of experiential avoidance or cognitive fusion in the association between caregiving stressors and mental health outcomes (Barrera-

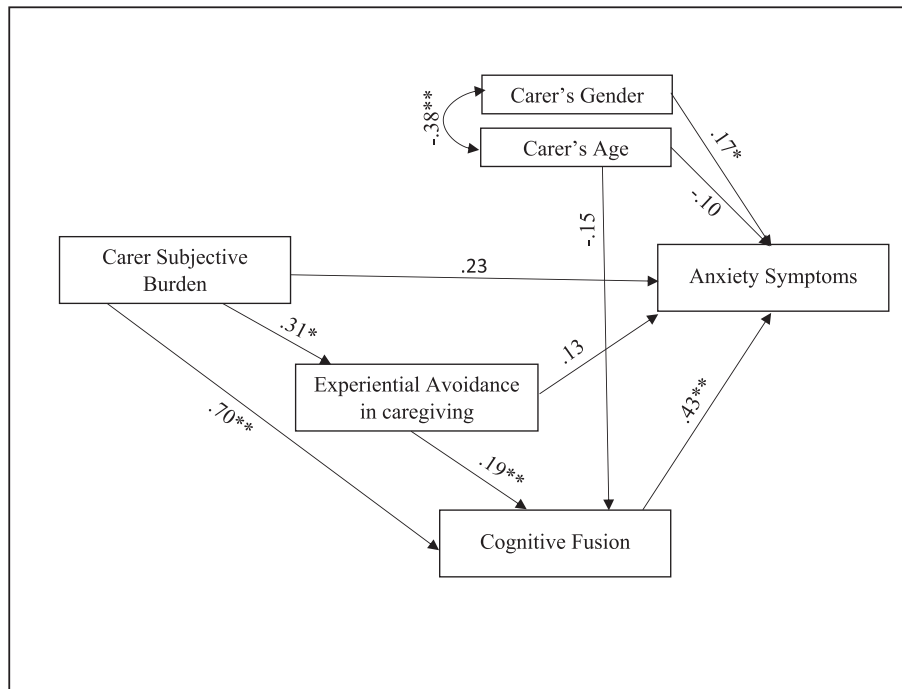


Fig. 1 Conceptual overall path analysis model with standardised coefficients. *Note.* ** $P < .01$ and * $P < .05$, significant levels of standardised coefficients. The examined variables accounted for 54 % of the variance of anxiety symptoms. The errors have been omitted for ease of presentation.

Caballero et al., 2021; Mausbach et al., 2012; Van Hout et al., 2023). To the best of our knowledge, this is the first study to investigate the combined mediating roles of experiential avoidance in caregiving and cognitive fusion on the relationship in family carers of people with dementia. Findings support the importance of experiential avoidance and cognitive fusion as relevant variables for understanding anxiety symptoms among this population. Given the higher explanatory value demonstrated for the indirect effect of cognitive fusion alone, results suggest that cognitive fusion might independently mediate the association between carer subjective burden and anxiety symptoms in this population. This study therefore highlights that undermining cognitive fusion through psychological interventions may be critical for preventing clinically significant levels of anxiety symptoms. This may be particularly the case among those carers experiencing high levels of carer subjective burden.

Nevertheless, family carers with higher experiential avoidance may be prone to cognitive fusion, which in turn could lead to a higher risk of developing anxiety symptoms. The progression of dementia is often associated with a significant increase in caregiver subjective burden (Froelich et al., 2021), which has been linked to augmented levels of experiential avoidance in previous literature (Van Hout et al., 2023). Findings of Bardeen and Fergus (2016) reported how the relationship between cognitive fusion, depression, anxiety and stress symptomatology became significantly stronger as levels of experiential avoidance increased. Therefore, interventions targeting early-stage experiential avoidance may prove beneficial in alleviating the risk of cognitive fusion and anxiety symptom development during the advanced caregiving phases. Nevertheless,

our current dataset does not strongly support this hypothesis. While our findings revealed a statistically significant point estimate of 0.01 in the experiential avoidance-cognitive fusion pathway, the inclusion of a 95 % confidence interval containing 0 underscores the presence of ambiguity in the observed association. Nonetheless, the enduring significance of the experiential avoidance-cognitive fusion connection warrants additional investigation to address this study limitation.

Psychological interventions, such as Acceptance and Commitment Therapy (ACT), which aims to reduce experiential avoidance and cognitive fusion and increase value-based meaningful activities, have been found to be effective in improving mental health problems among family carers of people with dementia (Fauth et al., 2022; Han et al., 2022). ACT is considered to be particularly effective for family carers of people with dementia presenting high levels of cognitive fusion (Barrera-Caballero et al., 2022; Kishita et al., 2021). Our findings thus provide additional support to the use of interventions, which can directly target cognitive fusion, for reducing anxiety symptoms among family carers of people with dementia.

While this study successfully examined the roles of cognitive fusion and experiential avoidance in anxiety symptoms among family carers of people with dementia, there are some limitations that need consideration. Firstly, the cross-sectional nature of this study does not allow for any causal assumptions to be made. Secondly, half of the participants in this study experienced minimal to mild anxiety symptoms. In addition, this study did not collect information on the ethnicity of participants. Given the location, i.e. counties in the east of England where more than 90 %

of the population is White British, the sample was not diverse. This limits the generalizability of the findings to the general dementia carer population. Future studies should therefore investigate a wider population and include those from different ethnic backgrounds and a clinical population (i.e. participants with more severe anxiety symptoms). Furthermore, the well-established model for explaining carer distress, the sociocultural stress and coping model, suggest potential other mediating variables that could potentially affect how carers respond to caregiving stressors and distress from these stressors: social support and cultural values (Knight & Sayegh, 2010). Further investigations on the role of social support and cultural values may provide a more comprehensive understanding of anxiety symptomatology in family carers of people with dementia. Finally, this study had a sample size of 77 in the path analysis, which is smaller than required according to the Hoelter's Index. Since Hoelter's N was still above 75, this model can still be considered acceptable by chi-square, with a good fit to the data. However, replication of these findings in a larger more diverse sample is recommended.

Conclusions

Despite limitations, this study adds to the currently limited body of evidence of the pathways involving anxiety symptoms among family carers of people with dementia. Targeting cognitive fusion using psychological interventions, such as ACT, may be particularly useful among family carers experiencing high levels of subjective burden. In addition, the provision of interventions in the early stages of dementia caregiving that can target experiential avoidance may help decrease the likelihood of increased cognitive fusion and anxiety symptoms among family carers of people with dementia.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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