Exploring the impact of carer stressors and psychological inflexibility on depression and anxiety in family carers of people with dementia

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Abstract

This study aimed to explore the impact of carer stressors (neuropsychiatric symptoms of dementia, level of independence in activities of daily living, hours of caring per week), demographic factors (carer age, relationship with the person with dementia, dementia type, dementia severity, number of years since diagnosis and cohabitation status) and psychological inflexibility on depression and anxiety in family carers of people with dementia. Eighty-nine family carers with a mean age of 69.13 years old completed self-reported and interview-based questionnaires. Participants were primarily female family members aged 65 years or older looking after a person with severe Alzheimer's disease. Two final regression models (Depression model R^2=.43; Anxiety model R^2=.43) demonstrated that psychological inflexibility (β=.52) and the number of hours devoted to caregiving (β=.23) had a significant impact on carer depression, while psychological inflexibility was the only significant independent predictor of carer anxiety (β=.55). The findings demonstrated psychological inflexibility to be a common factor explaining mental health problems in this population even after controlling for other variables known to have an impact. Acceptance and Commitment Therapy (ACT) may be beneficial for concomitantly treating depression and anxiety in this population. Considering that fifty-two per cent of participants responded that they devote more than 41 hours to caregiving per week, a non-traditional face to face approach such as online ACT may have potential in future research. Future studies should also explore the suggested models in understudied subgroups of carers (e.g., carers of early-onset dementia, carers of people with early-stage dementia).

Keywords

caregivers; Alzheimer's disease; psychological inflexibility; experiential avoidance; acceptance; mindfulness

Introduction

Dementia is one of the greatest health challenges we face today (World Health Organization, 2012). In many countries, family members are considered to be an essential taskforce in caring for people with dementia. For example, the current annual economic cost of dementia in the UK is estimated at £26.3 billion (Prince et al., 2014), with health and social care costs outweighing those of cancer, coronary heart disease and stroke combined (Luengo-Fernandez, Leal, & Gray, 2015). Crucially, forty-four per cent of this annual economic cost of dementia is contributed by unpaid informal carers such as family members (Prince et al., 2014).

Recent systematic reviews demonstrated that the pooled prevalence of depression and anxiety in family carers of people with dementia are 31.2% and 32.1% respectively (Collins & Kishita, 2019; Kaddour & Kishita, 2020). These estimates are substantially higher than reported prevalence rates in the general population (Charlson et al., 2019). Furthermore, the prevalence estimate of anxiety is substantially greater in relation to dementia, than family carers of people with other conditions such as cancer (Friðriksdóttir et al., 2011) and stroke (Loh, Tan, Zhang, & Ho, 2017). Although anxiety is as prevalent as depression in family carers of people with dementia, it is often neglected in the dementia carer literature (Kaddour & Kishita, 2020).

Anxiety in family carers of people with dementia is also considered to be hard to treat. For example, a recent systematic review of carer interventions demonstrated that conventional Cognitive Behaviour Therapy (CBT) was the most commonly used form of psychotherapy for the treatment of mental health problems in this population. The findings suggested that the effect size of conventional CBT was moderate for depression, while the effect size was small for anxiety, when only studies that utilised conventional CBT was included in the analysis (Kishita, Hammond, Dietrich, & Mioshi, 2018). A recent clinical trial also highlighted a lack of efficacy of conventional CBT in maintaining therapeutic benefits on anxiety in family carers of people with dementia particularly at follow-up, concluding that active ingredients to address anxiety symptoms may be missing from such a conventional approach (Marquez-Gonzalez et al., 2020).

Furthermore, many family carers of people with dementia are older people themselves. It is well known that generalised anxiety disorder is a common problem among older people (Bower, Wetherell, Mon, & Lenze, 2015). Although conventional CBT is considered an appropriate treatment option for individuals with anxiety disorders across the lifespan (Hofmann, Asnaani, Vonk, Sawyer, & Fang, 2012), current evidence suggests that conventional CBT for generalised anxiety disorder may be less effective for older adults compared to adults of working age (Kishita & Laidlaw, 2017).

Recognising that both depression and anxiety are highly prevalent in family carers of people with dementia and that these carers are often older people themselves, identifying the common processes underlying their mental health problems (i.e., both depression and anxiety) seems highly practical. This can lead to the development of more time/resource-efficient interventions, which is critical for family carers who may have limited time for themselves.

One of the well-established models, the sociocultural stress and coping model adapted to caregiving (Knight & Sayegh, 2009), suggests that stressors such as neuropsychiatric symptoms of dementia can directly influence the wellbeing of carers, but other individual factors also contribute to explaining how individuals are affected differently from distress caused by such stressors. It is, therefore, important to consider both carer stressors and individual factors in order to identify the common underlying processes and inform priorities for treatment. Recently, there has been emerging evidence on the important role psychological inflexibility plays in explaining the impact of caregiving on family carers of people with dementia.

Psychological flexibility refers to the ability to open up to uncomfortable internal struggles; allowing them to be there, to step back from thoughts when they are not helpful, get connected with the here-and-now experiences and engage in constructive actions that reflect personal values. *Psychological inflexibility*, which is the opposite of psychological flexibility, refers to the attempt to decrease internal private events (e.g., thoughts, feelings, urges) even when doing so is inconsistent with personal values. When an individual is presenting with high levels of psychological inflexibility (i.e., lower flexibility) their behaviour is likely to be largely dominated by psychological reactions (e.g., evaluative and self-descriptive thoughts), which often takes a form of avoidant behaviour. There is robust evidence that higher levels of psychological inflexibility is strongly associated with higher levels of depressive and anxiety symptoms among various populations (Bluett, Homan, Morrison, Levin, & Twohig, 2014; Ruiz, 2010).

In the context of dementia carer literature, Romero-Moreno, Mrquez-Gonzlez, Losada, Gillanders, and Fernndez-Fernndez (2014) demonstrated that psychological inflexibility as assessed by the Acceptance and Action Questionnaire (AAQ) was significantly correlated with higher levels of depression and anxiety among family carers of people with dementia.

A study conducted by Spira et al. (2007) demonstrated that psychological inflexibility (as assessed by the AAQ) was the only significant independent predictor of carer depression, when carer negative affect and neuropsychiatric symptoms of dementia were entered into the regression model simultaneously. Another more recent study conducted by Romero-Moreno, Losada, Márquez-González, and Mausbach (2016) demonstrated that psychological inflexibility (as assessed by the AAQ) moderated the relationship between neuropsychiatric symptoms of dementia and carer anxiety. These findings suggest that psychological inflexibility can have an impact on depression and anxiety among family carers of people with dementia even after controlling for carer stressor (i.e., neuropsychiatric symptoms of dementia).

One of the limitations of these previous studies is that they have only considered neuropsychiatric symptoms of dementia as a potential stressor in their model. No carer demographic factors were considered in their proposed models. A recent comprehensive meta-analysis (Schoenmakers, Buntinx, & Delepeleire, 2010), which explored factors determining the impact of caregiving on carers of older people with dementia, demonstrated that other aspects of caregiving such as higher workload and higher care need (i.e., the level of independence in activities of daily living (ADL) of the person with dementia) have a significant impact on carer depression. Indeed, previous systematic reviews have shown that the level of independence in ADL to be one of the significant predictors of long-term care placement for people with dementia (Cepoiu-Martin, Tam-Tham, Patten, Maxwell, & Hogan, 2016; Gaugler, Yu, Krichbaum, & Wyman, 2009).

Moreover, ADL deficits do not always show association with cognitive scores in various dementia subtypes (Mioshi et al., 2007; O'Connor, Clemson, Flanagan, et al., 2016; O'Connor, Clemson, Hornberger, et al., 2016), highlighting the importance of including ADL scores in studies investigating wellbeing of carers of people with dementia. (Mioshi, Hodges, & Hornberger, 2013; O'Connor, Clemson, Flanagan, et al., 2016). Understanding the impact of caregiving beyond neuropsychiatric symptoms is critical and it is important for these potential carer stressors to be considered when understanding the role of psychological inflexibility in explaining depression and anxiety in family carers of people with dementia.

Therefore, this study aims to fill the gap in the current literature by exploring whether psychological inflexibility plays a critical role in explaining depression and anxiety as a common underlying process in this population. The role of well-known carer stressors, that is, neuropsychiatric symptoms of dementia, level of independence in ADL and carer workload (hours of caring per week), will be considered simultaneously in a multiple regression model for both depression and anxiety. The role of demographic factors, which could potentially have an impact on the wellbeing of carers (i.e., carer age, relationship with the person with dementia, dementia type, dementia severity, number of years since diagnosis and whether the carer lives with the person with dementia in the same household) will also be explored.

Methods

Study Design and Setting

This study used a cross-sectional design with a sample of 89 family carers of people with dementia. Full ethical approval was obtained from the NHS Health Research Authority and Research Ethics Committee. Recruitment took place in two largely rural counties in the East of England between July 2017 and February 2020.

Participants

Eligible participants had to be a) aged 18 years or older, b) currently caring for a family member with a clinical diagnosis of dementia and c) in a first-degree relationship with the person with dementia (i.e., parent, spouse/partner, sibling, or adult child). The dementia diagnosis was based on self-report of participants. Several strategies were used to recruit participants and their participation was completely voluntary.

Clinician Referral. Potentially eligible participants attending appointments at the local NHS Mental Health Trust were informed about the study by their clinician. If interested, their contact details were forwarded to the research team with their permission.

Referral from Other Studies. Potentially eligible participants who had previously participated in other ethically approved dementia studies led by the neurodegeneration research group at the university were invited to the current study. These participants had given their consent to be contacted about participation in other studies.

Other Sources. Participants were also recruited through Join Dementia Research, a UK-based online service for matching people with researchers looking for volunteers. The research team also visited local carer groups with permission from a gatekeeper to reach out to potentially eligible participants in the community.

Measures

Demographics. Demographic information such as carer age, their relationship with the person with dementia, the type of dementia diagnosed and whether participants currently live with the person with dementia in the same household was gathered.

Depression. The nine-item Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer, & Williams, 2001) assesses the intensity of depressive symptoms. Each item is rated on a 4-point scale: Not at all (0), several days (1), more than half the days (2) and nearly every day (3). The sum of scores of individual items can indicate depression severity of none (<4), mild (5-9), moderate (10-14), moderately severe (15-19) and severe (20-27). The PHQ-9 has good psychometric properties with good internal consistency (Cronbach's alpha = .89) (Kroenke et al., 2001).

Anxiety. The seven-item Generalised Anxiety Disorder Scale (GAD-7) (Spitzer, Kroenke, Williams, & Löwe, 2006) assesses the severity of anxiety symptoms. Each item is rated on a 4-point scale: Not at all (0), several days (1), more than half the days (2) and nearly every day (3). The sum of scores can indicate anxiety severity of mild (5-9), moderate (10-14) and severe (15-21). The GAD-7 has good psychometric properties with good internal consistency (Cronbach's alpha = .92) (Spitzer et al., 2006).

Psychological Inflexibility. The Acceptance and Action Questionnaire-II (AAQ-II) (Bond et al., 2011) assesses levels of psychological inflexibility, the rigid dominance of psychological reactions (e.g., evaluative and self-descriptive thoughts) over chosen values and contingencies in guiding action. Each item is rated on a 7-point scale ranging from never true (1) to always true (7). The total score ranges from 7 to 49, with higher scores indicating greater levels of psychological inflexibility (i.e., lower scores indicate higher levels of psychological flexibility). The AAQ-II has good psychometric properties with good internal consistency (Cronbach's alpha = .88) (Bond et al., 2011).

Number of Hours of Caring. The number of hours devoted to caregiving each week was assessed using the following response options: 0-2 hours, 3-10 hours, 11-20 hours, 21-40 hours, 41-80 hours and 81 or more hours.

Neuropsychiatric Symptoms. The Mild Behavioral Impairment Checklist (MBI-C) (Ismail et al., 2017) is a 34-item proxy-informant interview-based measure, which assesses neuropsychiatric symptoms within five domains: motivation, emotional regulation, impulse control, social cognition and abnormal thoughts/perception. For each item, severity is assessed using a four-point scale: no symptom (0), mild (1), moderate (2) and severe (3). The total score ranges from 0 to 102, with higher scores indicating higher levels of neuropsychiatric symptoms. The MBI-C is a relatively new scale developed by a group of experts through a Delphi process. The MBI-C is different from traditional measures of neuropsychiatric symptoms as the measure is comprehensive and allows detecting behavioural changes that are also common in non-Alzheimer's dementias (Ismail et al., 2017).

Level of Independence in Activities of Daily Living. The Bristol Activities of Daily Living Scale (BADLS) (Bucks, Ashworth, Wilcock, & Siegfried, 1996) is a 20-item informant-rated measure, which assesses daily-living abilities within four areas: mobility, instrumental activities of daily living, self-care and orientation. Each item has its own rating criteria, with scores ranging from 0 (independence) to 3 (dependence). The total score ranges from 0 to 60, with higher scores indicating greater dependence. The BADLS has good psychometric properties (Bucks et al., 1996) with good internal consistency (Cronbach's alpha = .90) (Boyd, Wilks, & Geiger, 2018).

Dementia Severity. The Frontotemporal Dementia Rating Scale (FRS) (Mioshi, Hsieh, Savage, Hornberger, & Hodges, 2010) is a 30-item proxy-informant interview-based measure, which assesses the severity of dementia. The scale is a well-established dementia staging tool in frontotemporal dementia and has been validated in Alzheimer's disease with superior ability to stage dementia than the Clinical Dementia Rating Scale (Lima-Silva et al., 2013). The FRS provides logit scores, which are subdivided into six stages of dementia severity: very mild, mild, moderate, severe, very severe and profound. The FRS has good psychometric properties with good internal consistency (Cronbach's alpha = .95) (Mioshi et al., 2010).

Procedure

Following identification of potentially eligible individuals, initial contact was made by the research team via telephone or email to check full eligibility requirements. An invitation letter and participant information sheet were sent to those eligible. An appointment for the assessment session was made at the participant's own home, the university or local NHS premises depending on the participant's preference. Written informed consent was obtained from all participants. Participants completed all self-reported questionnaires during the assessment session in the presence of a researcher. The FRS, which is an interview-based measure, was conducted by researchers trained to administer the tool. Travel expenses were reimbursed if the assessment did not take place at the participant's own home, but participants did not receive any other payment or compensation for their time.

Sample Size

This study recruited 91 participants. The MBI-C data were missing for two participants and thus the whole dataset for these individuals was excluded from the analysis.

This resulted in 89 participants in total. One participant did not provide the information on whether the carer currently lives with the person with dementia in the same household. This participant was further excluded from the final regression model for anxiety.

Statistical Methods

Two separate regression analyses were conducted to examine to what extent carer stressors, demographic factors and psychological inflexibility explained carer depression and anxiety. Prior to the conduct of regression analyses, descriptive statistics were computed for all variables to characterise the sample. The total number of potential independent variables was 10. These included three carer stressors (neuropsychiatric symptoms of dementia, level of independence in ADL, hours of caring per week), six demographic factors (carer age, relationship with the person with dementia, dementia type, dementia severity, number of years since diagnosis and whether the carer lives with the person with dementia in the same household) and psychological inflexibility. First, each independent variable was tested individually in simple regression models, and then those that passed a certain *p*-value threshold were included in the final multiple regression model for depression and anxiety. The *p*-value cut-off point of 0.25 was used to avoid failing to identify variables known to be important (Bursac, Gauss, Williams, & Hosmer, 2008).

Collinearity statistics with the variance inflation factor (VIF) were used to check multicollinearity. A VIF of 10 or above indicates that multicollinearity is a problem (Hair, Black, Babin, & Anderson, 2014). Visual examination of the normal probability plot (P-P) of the regression standardised residuals and residuals scatterplots were conducted to test the assumption of normality, linearity and homoscedasticity between predicted dependent variables and errors of prediction.

In the normal P-P Plot, all points should lie in a reasonably straight diagonal line from bottom left to top right, which suggests no major deviations from normality (Tabachnick &

Fidell, 2013). If the residuals show normality, linearity and homoscedasticity, they should be distributed with most of the scores plotted on the centre (along the zero point) in scatterplots and no clear or systematic pattern should be observed (e.g., higher on one side than the other) (Tabachnick & Fidell, 2013). If these assumptions are not met, the multiple regression may provide misleading results.

The overall model fit was assessed using the F-test and the model's R^2. The standardised coefficients beta (β) was used to assess which of the variables had the strongest impact on each dependent variable (i.e., depression and anxiety).

Results

Participants

The descriptive statistics of carer-related and patient-related variables are presented in Table 1 and Table 2. The majority of participants were recruited through referrals from other dementia studies (65%), followed by Join Dementia Research (19%). Participants' age ranged from 26 to 95 years old with the majority of participants (70%) being aged 65 or over. Sixty-seven per cent of the participants were female (i.e., wife, daughter or sister) and the majority of participants (70%) were currently living with the person with dementia. The most common form of dementia was Alzheimer's disease (45%) and more than half of people with dementia (64%) were either in severe or very severe stages of the disease.

The descriptive statistics of depression and anxiety (i.e., dependent variables) for the current carer sample are presented in Table 3. Table 3 also presents the normative data for these variables (i.e., PHQ-9 and GAD-7) from the general population in a large population-based study (Bernd et al., 2008; Kocalevent, Hinz, & Brähler, 2013) as comparisons.

Preliminary Analysis

The results of single regression analyses are presented in Table 4. Three carer stressors (neuropsychiatric symptoms of dementia, level of independence in ADL, hours of caring per week), three demographic variables (carer age, dementia severity, number of years since diagnosis) and psychological inflexibility passed the *p*-value cut-off point of 0.25 for depression and thus they were entered to the final regression model.

Three carer stressors (neuropsychiatric symptoms of dementia, level of independence in ADL, hours of caring per week), three demographic variables (carer age, dementia severity, whether the carer lives with the person with dementia) and psychological inflexibility passed the *p*-value cut-off point of 0.25 for anxiety and thus they were entered to the final regression model. Relationship with the person with dementia and dementia type were not associated with both depression and anxiety.

The VIF value was below 3.04 for all independent variables in the multiple regression analysis for both depression and anxiety, suggesting that multicollinearity is less likely to be a problem. The normal P-P Plot demonstrated that all points lied in a reasonably straight diagonal line from bottom left to top right for both depression and anxiety, indicating no major deviations from normality (See Supplementary Figure 1 and 2). The scatterplot of the standard residuals demonstrated that the residuals were distributed with most of the scores plotted on the centre with no clear or systematic pattern for both depression and anxiety (See Supplementary Figure 1 and 2). The results suggested that the assumption of normality, linearity and homoscedasticity of residuals were met.

Regression Analyses

Depression. The R^2 value was .43 (F (7, 81) = 8.58, $p < .01$), suggesting that the proposed model explains 43% of the variance in depression. The standardised coefficients beta (β) was statistically significant only for the number of hours devoted to caregiving ($\beta = .23$) and psychological inflexibility ($\beta = .52$) (See Table 5).

Anxiety. The R^2 value was .43 (F (8, 80) = 8.64, $p < .01$), suggesting that the proposed model explains 43% of the variance in anxiety. The standardised coefficients beta (β) was statistically significant only for psychological inflexibility ($\beta = .55$) (See Table 6).

Discussion

The aim of this study was to explore the role of psychological inflexibility in explaining depression and anxiety in family carers of people with dementia, alongside other well-known carer stressors and demographic factors to influence mental health in this population. The findings demonstrated that psychological inflexibility and the number of hours devoted to caregiving have a significant impact on carer depression, while psychological inflexibility was the only significant independent predictor of carer anxiety.

This study demonstrated that psychological inflexibility is a common factor explaining mental health problems in this population even after controlling for other variables known to have an impact. The findings suggest that psychological interventions that directly target psychological inflexibility such as Acceptance and Commitment Therapy (ACT) may be beneficial for concomitantly treating depression and anxiety in family carers of people with dementia. Indeed, a recent clinical trial has demonstrated that psychological inflexibility can be improved through ACT among family carers of people with dementia (Losada et al., 2015).

It is important to note that the number of hours devoted to caregiving also had an impact on carer depression in the analysis - although this was not the strongest predictor. In some countries, services that allow carers to take a break from caregiving such as respite services may be available (e.g., the use of day centre programmes, sitting or befriending service or short-term residential care). However, guilt from perceptions of abandoning the person with dementia and failure in the fulfilment of their marital or familial duty often become barriers for family carers to access respite services and the literature suggests that its uptake by carers remains relatively low (Neville, Beattie, Fielding, & MacAndrew, 2015).

Given that guilt is an aversive emotion, carers presenting with high levels of psychological inflexibility may avoid performing any behaviours that elicit guilt (e.g., self-care and leisure activities) in order to try and escape from these aversive feelings (Gallego-Alberto, Marquez-Gonzalez, Romero-Moreno, Cabrera, & Losada, 2019). ACT may help these family carers by allowing them to acknowledge and embrace their feelings of guilt and engage in activities that reflect their personal values outside of caregiving (e.g., connecting with friends and the community).

In the current study, fifty-two per cent of participants responded that they devote more than 41 hours to caregiving per week (i.e., approximately 6-12 hours per day including weekends). This may limit the opportunity for family carers to access psychological services for their own psychological needs. One way to address the challenges of treatment accessibility in this population is to design a service that can be accessed at home when the carer is available. A recent systematic review on family carers of people with dementia demonstrated only a small overall effect of online or DVD delivered conventional CBT interventions on depression ($g = 0.27$), suggesting that there is still room for improvement (Scott et al., 2016). Online ACT for family carers of people with dementia may be a potential alternative.

The study has some limitations that should be considered while interpreting the results. Participants for this study were primarily female family members aged 65 years or older looking after a person with severe Alzheimer's disease. Carers' relationship with the person with dementia and dementia type were not associated with both depression and anxiety in single regression analyses. However, this could have been due to the variability of the study sample. Given their younger age, individuals with early-onset dementia and their family carers are considered to have different types of support needs than those of individuals with late-onset dementia (Aplaon, Belchior, Gélinas, Bier, & Aboujaoudé, 2017). Nevertheless, individuals with early-onset dementia and their family carers are often neglected in studies exploring the benefits of non-pharmacological interventions (Richardson et al., 2016). Currently, family members supporting a person with early stages of dementia are also neglected in the literature (Szabo, Whitlatch, Orsulic-Jeras, & Johnson, 2016). This present study also had a limited number of participants from these understudied subgroups. These groups of carers require more attention in future research and the role of psychological inflexibility should be investigated among these carers.

A further limitation is that information on the ethnicity of participants was not collected as part of the study. However, the UK censuses data (Office for National Statistics, 2016) shows that more than 95% of the population is from white ethnic groups in the two counties where the study took place. Psychological inflexibility is considered not only as a transdiagnostic process but also as a transcultural process independent of a specific language community (Monestès et al., 2016). The role of psychological inflexibility in family carers of people with dementia across different cultural contexts is worth investigating as this could inform the development of a transcultural intervention for this population.

There are some methodological limitations in this study, which should be considered. Although the AAQ-II has been most widely used in research as a generic measure of psychological inflexibility, the recent literature suggests the construct validity of the AAQ-II is questionable (Rochefort, Baldwin, & Chmielewski, 2018; Tyndall et al., 2019). Hayes et al. (2004) also suggest that the AAQ may not be sensitive enough for detecting changes in treatment using ACT as ACT targets particular thoughts and feelings that are difficult for particular clients and thus a more specific measure of psychological inflexibility should be considered for the targeted population. A specific measure, which targets psychological inflexibility in the carer population, the Experiential Avoidance in Caregiving Questionnaire (EACQ), has been developed and validated in Spanish (Losada, Romero-Moreno, Márquez-González, & López, 2014). The inclusion of the EACQ or a recently developed more comprehensive measure of psychological inflexibility, which covers the broader ACT processes (CompACT) (Francis, Dawson, & Golijani-Moghaddam, 2016), is recommended in future carer studies.

The number of hours devoted to caregiving was measured using the categorical data with a relatively wide range of time for each category (e.g., 21-40 hours). The highest response option was 81 hours or more and considering that 37% of the participants selected this category, this may have caused the ceiling effect and decreased the sensibility of the assessment. The number of hours devoted to caregiving was not a significant independent predictor of carer anxiety in the final regression model. However, the standardised coefficients beta for this variable was the second largest following psychological inflexibility in single regression analyses for carer anxiety. The impact of the number of hours devoted to caregiving on carer anxiety should be considered further in future research.

The sample size may have had an impact on the results. The sample size required for a regression analysis in order to achieve a power level of 0.80, a significance level of 0.05, and a medium effect size (0.15) is 103 when seven independent variables are included in the model. The sample size needed is 49 when the expected effect size to be large (0.35). The R^2 value was .43 with the effect size (Cohen's f^2) of .75 for both depression and anxiety in the current study. The adjusted R^2 value was .38 for both depression and anxiety and the effect size (Cohen's f^2) was .61, which is still a large effect. Finally, this study used a cross-sectional design, which may limit the conclusion regarding the causality between the variables of interest. It is recommended for the findings to be replicated using a longitudinal design with a larger sample in the future.

Conclusion

Despite limitations, this study provides evidence that psychological inflexibility plays a critical role in explaining both depression and anxiety in family carers of people with dementia. The number of hours devoted to caregiving seems to also influence carer depression. Further studies targeting understudied subgroups of carers and interventional studies of face-to-face and/or online ACT and exploring whether ACT can have an impact on the feelings of guilt and increased use of respite services are recommended as a direction for future research.

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Table 1 Descriptive statistics of carer demographic variables

Carer variables	**Percentage or *M* (*SD*)**
Carer age	69.13 (12.49)
Relationship with the person with dementia	
Wife	40%
Husband	28%
Daughter	26%
Son	5%
Sister	1%
Living with the person with dementia	
Yes	70%
No	29%
Not specified	1%
Hours of caring per week	
0-2 hrs	4%
3-10 hrs	17%
11-20 hrs	10%
21-40 hrs	17%
41-80 hrs	15%
81+ hrs	37%
Source of recruitment	
Clinician referral	8%
Referral from other dementia studies	65%
Join Dementia Research	19%
Self-referral	8%
Psychological inflexibility (AAQ-II)	19.69 (10.62)

Note. AAQ-II = Acceptance and Action Questionnaire-II

Table 2 Descriptive statistics of patient demographic variables

Patient variables	**Percentage or *M* (*SD*)**
Dementia type	
Alzheimer's disease	45%
Vascular dementia	14%
Lewy body dementia	6%
Frontotemporal dementia	7%
Mixed dementia	20%
Not specified	8%
Dementia severity (FRS)	
Very mild	0%
Mild	6%
Moderate	30%
Severe	46%
Very severe	18%
Profound	0%
Number of years since diagnosis	3.62 (2.39)
Neuropsychiatric symptoms (MBI-C) Score range 0-102 *Higher scores indicate higher levels of neuropsychiatric symptoms*	30.06 (18.01)
Level of independence in ADL (BADLS) Score range 0-60 *Higher scores indicate greater dependence*	23.73 (14.29)

Note. ADL = Activities of daily living, BADLS = Bristol Activities of Daily Living Scale, FRS = Frontotemporal Dementia Rating Scale, MBI-C = Mild Behavioral Impairment Checklist.

Table 3 Means and standard deviations of dependent variables and their normative data from the general population

Anxiety (GAD7)		Depression (PHQ9)		
Normative data from the general population (Löwe et al., 2008) (N = 5030)	Current study sample Carers (N = 89)	Normative data from the general population (Kocalevent et al., 2013)		Current study sample Carers (N = 89)
		Female (N = 2692)	Male (N = 2326)	
2.95 (3.41)	6.06 (5.66)	3.1 (3.5)	2.7 (3.5)	7.22 (6.32)

Note. Numbers in brackets refer to standard deviation. PHQ9 = Patient Health Questionnaire 9-item version, GAD7 = Generalised Anxiety.

Table 4 Results of single regression analyses

	Depression		Anxiety	
Potential independent variables	Standardised Coefficients Beta	*p* (*p < .25)	Standardised Coefficients Beta	*p* (*p < .25)
Carer age	**-.23**	**.03***	**-.26**	**.02***
Relationship with the person with dementia	.03	.80	-.01	.90
Living with the person with dementia	-.09	.40	**-.13**	**.22***
Hours of caring per week	**.35**	**.00***	**.28**	**.01***
Psychological inflexibility	**.60**	**.00***	**.63**	**.00***
Dementia type	.03	.76	.10	.37
Dementia severity	**.22**	**.04***	**.22**	**.04***
Number of years since diagnosis	**.13**	**.21***	.12	.26
Neuropsychiatric symptoms	**.25**	**.02***	**.26**	**.02***
Level of independence in ADL	**.24**	**.02***	**.22**	**.04***

Table 5 Results of regression analysis – Depression ($N = 89$)

Independent variables	Standardised Coefficients Beta	*t*	*p*
Carer age	-.10	-.99	*n.s.*
Dementia severity	.00	.00	*n.s.*
Number of years since diagnosis	-.00	-.04	*n.s.*
Hours of caring per week	.23	2.43	<.05
Neuropsychiatric symptoms	-.03	-.29	*n.s.*
Level of independence in ADL	.09	.69	*n.s.*
Psychological inflexibility	.52	5.66	<.01
$R^2 = .43$, F (7, 81) = 8.58, $p < .01$.			

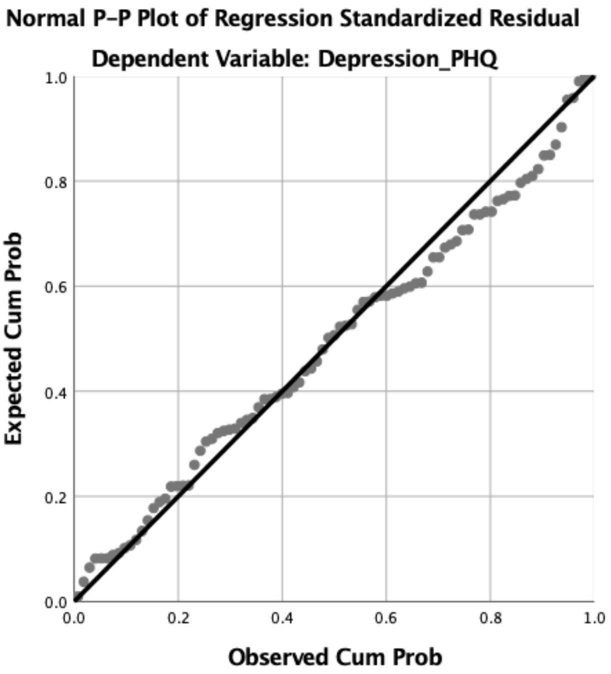
Note. ADL = Activities of daily living, *n.s.* = not significant.

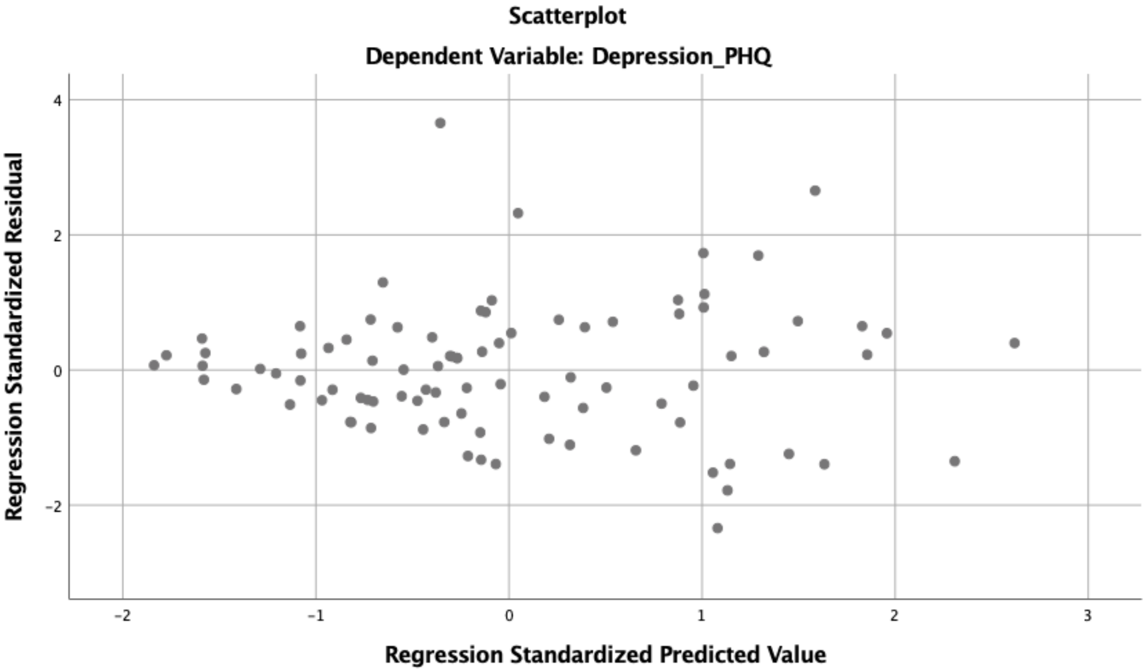
Table 6 Results of regression analysis – Anxiety ($N = 88$)

Independent variables	Standardised Coefficients Beta	*t*	*p*
Carer age	-.08	-.81	*n.s.*
Dementia severity	.04	.25	*n.s.*
Living with the person with dementia	-.06	-.50	*n.s.*
Hours of caring per week	.17	1.61	*n.s.*
Neuropsychiatric symptoms	-.02	-.13	*n.s.*
Level of independence in ADL	.02	.12	*n.s.*
Psychological inflexibility	.55	5.99	<.01
$R^2 = .43$, F (7, 80) = 8.64, $p < .01$.			

Note. ADL = Activities of daily living, *n.s.* = not significant.

Supplementary Figure 1 Normal P-P Plot and scatterplot of the standardised residuals – Depression





Supplementary Figure 2 Normal P-P Plot and scatterplot of the standardised residuals – Anxiety