Factors predicting quality of life in family carers of people with dementia: the role of psychological inflexibility

Milena Contreras[a], Eneida Mioshi[a], Naoko Kishita[a]

[a] *School of Health Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ, United Kingdom*

*Corresponding Author: Dr Naoko Kishita, School of Health Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ, United Kingdom. Email: N.Kishita@uea.ac.uk

Abstract

The current study aimed to investigate the impact of carer-related modifiable factors (i.e., knowledge about dementia, psychological inflexibility, self-compassion and hours of support from other family members) on quality of life (QoL) among family carers. A multiple regression analysis was conducted with QoL as a dependent variable. All factors were entered into the model simultaneously as independent variables. Ninety-one family carers with a mean age of 69.5 years old were assessed. Participants were primarily female family members looking after a person with severe Alzheimer's disease. The model's R2 was 24%. The results demonstrated that psychological inflexibility was the only significant independent variable predicting QoL ($\beta = -0.46$, p=0.00, 95% CI: -0.71 to -0.20), and higher psychological inflexibility was associated with worse QoL. These findings suggest that targeting carer's psychological inflexibility through psychological interventions such as Acceptance and Commitment Therapy may be particularly important in promoting QoL among family carers of people with dementia.

Keywords

Introduction

There is considerable evidence demonstrating that family carers of people with dementia have a lower quality of life (QoL) than non-dementia carers and non-carers (Karg et al., 2018; Pierre Moïse et al., 2004; Scholzel-Dorenbos et al., 2009). Furthermore, the existing carer interventions such as psychoeducation interventions and cognitive behaviour therapy are considered to be effective for reducing carer burden and depression in family carers of people with dementia. However, the level of evidence for such interventions in improving carers' overall QoL is still questionable (Amador-Marín & Guerra-Martín, 2017; Huis In Het Veld et al., 2015; Kishita et al., 2018).

Previous systematic reviews looking at factors associated with the QoL of family carers of people with dementia (Contreras et al., 2020; Farina et al., 2017) highlight that the majority of existing studies are focused on variables that are considered to be contextual factors (i.e., characteristics unique to the person with dementia), such as the level of cognitive impairment and neuropsychiatric symptoms. However, studies exploring the impact of carer-related modifiable factors, beyond carer depression and burden are scarce (Contreras et al., 2020). Therefore, exploring novel carer-related modifiable factors, which can predict changes in family carers QoL seems highly practical as it can provide important clinical implications.

Several potential factors will be explored in this study. Previous studies suggest that the lack of knowledge could lead to specific types of dysfunctional thoughts such as the misinterpretation of symptoms of dementia (Losada et al., 2006; Mittelman et al., 2014). For example, carers may interpret a behavioural symptom (e.g., lack of impulse control) as aggression due to the lack of knowledge, which could then lead to increased distress among family members. Such carer's dysfunctional thoughts and misattribution are often associated

with negative emotional outcomes such as depression (Losada et al., 2006; McNaughton et al., 1995).

Existing research also recognises the critical role played by psychological inflexibility in explaining the impact of caregiving on family carers of people with dementia. Psychological inflexibility refers to patterns of behaviour in which actions are rigidly guided by internal experiences (e.g. thoughts, feelings), rather than personal values (Hayes et al., 2006). The current evidence suggests that psychological inflexibility leads to higher levels of negative emotional outcomes such as depression and anxiety among family carers of people with dementia (Kishita et al., 2020; Romero-Moreno et al., 2016; Spira et al., 2007).

Furthermore, previous literature suggests that it is very common for family carers to engage in dysfunctional coping strategies such self-criticism (e.g., telling oneself "I should be more patient") (Li et al., 2012). While this approach may work in the short term to motivate oneself to do better, being warm and understanding toward ourselves (i.e., being self-compassionate) is considered to be more effective in the long term (Lloyd et al., 2019; Neff, 2003). Previous studies demonstrated that carers of people with various neurological conditions (including dementia) with higher levels of self-compassion report lower levels of carer depression and burden (Hlabangana & Hearn, 2020; Lloyd et al., 2019).

In summary, this cross-sectional study aims to explore the predictive effect of variables known to have an impact on negative emotional outcomes such as depression (i.e., knowledge about dementia, psychological inflexibility and self-compassion) on QoL in family carers of people with dementia. The relevant demographic characteristic, the support received from other relatives, will also be included in the proposed regression model as previous studies suggest that having support from other people may lead to better QoL and lower depression (Losada et al., 2006; Rapp et al., 1998).

Methods

Participants

Eligible participants had to be: a) a primary or co-carer looking after a relative with a clinical diagnosis of dementia, b) in a first-degree relationship with the person with dementia (e.g., spouse/partner, adult child) and c) aged 18 years or older. The dementia diagnosis was based on the self-report of participants (i.e. carers). Recruitment took place between July 2017 and February 2020.

Ninety-one participants were recruited from carer support groups, an NHS mental health trust and from a national online recruitment tool (Join Dementia Research). Participants were also recruited through referrals from other ethically approved dementia studies conducted by collaborators. All questionnaires and interviews were administered at participants' own homes, the university, or local NHS premises depending on their preference. Ethical approval was obtained from the NHS Research Ethics Committee. Written informed consent was obtained from all participants.

Sample size calculation

Prior to the study, the required sample size was calculated using G*Power. This calculation estimated that, based on a linear regression model with four independent variables included in the model, 85 participants would detect a medium effect size (f^2=0.15) at a 5% level of significance with 80% power.

Measures

Knowledge about dementia. The Dementia Knowledge Assessment Scale (DKAS) (Annear et al., 2017; Annear et al., 2015) is a self-report measure that assesses dementia knowledge across a range of domains including causes and characteristics, communication

and engagement, care needs, risk factors, and health promotion. The revised 25-item version rated on a 5-point scale (False, Probably False, Probably True, True, and I don't know) was used. Higher scores indicate greater knowledge about dementia.

Psychological inflexibility. The Acceptance and Action Questionnaire-II (AAQ-II) (Bond et al., 2011) assesses the degree of psychological inflexibility. Each item is rated on a 7-point scale that ranges 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.

Self-compassion. Self-compassion Scale short form (SCS-SF) (Raes et al., 2011) is a 12-item self-report questionnaire that measures the six components of self-compassion: Self-Kindness, Self-Judgment, Common Humanity, Isolation, Mindfulness and Over-Identification. Each item is rated on a 5-point scale ranging from *almost never* (1) to *almost always* (5) with higher scores indicating greater self-compassion. A total self-compassion score is calculated by reversing the negative items and then computing a total mean.

Support from other family members. Support from other family members was assessed by the number of hours devoted to caregiving each week from other relatives. The following response options were used: no support, 0-2 hours, 3-10 hours, 11-20 hours, 21-40 hours, 41-80 hours, and 81+ hours.

Dementia severity. The Frontotemporal Dementia Rating Scale (FRS) (Mioshi et al., 2010) was used to assess dementia severity. The FRS is a 30-item proxy-informant interview-based measure validated in various forms of dementia including Alzheimer's disease (Lima-Silva et al., 2013). This measure provides logit scores, which are subdivided into six stages of dementia severity: very mild, mild, moderate, severe, very severe and profound.

Demographics. Information collected included carer age and their level of education, type of relationship with the person with dementia, if they currently live with the person with

dementia in the same household and if they are members of a carer support group. The type of dementia diagnosed and average years since diagnosis were also recorded.

Carer QoL. The key outcome of this study (i.e., carer QoL) was assessed using the 5-item ICEpop CAPability measure for Older people (ICECAP-O) (Grewal et al., 2006). This instrument defines QoL in a broader sense, rather than health and was specifically designed to assess QoL among older people. Even though this measure is sensitive to changes related to age, it has also been validated in a sample of informal carers of people with dementia that included younger carers (Perry-Duxbury et al., 2020). The scale comprises five attributes: attachment (e.g. "I can have a little of the love and friendship that I want"), security (e.g. "I can only think about the future with a lot of concern"), role (e.g. "I am able to do all of the things that make me feel valued"), enjoyment (e.g. "I cannot have any of the enjoyment and pleasure that I want"), and control (e.g. "I am able to be independent in a few things"). Each attribute can be scored on four levels (1-4) that range from "not any", "a little", "a lot" to "all" with higher values indicating greater QoL. The ICECAP-O rescaled values range from 0 to 1, distinguishing 1024 possible "capability states". The tariffs assign 0, the lowest value, to the state of having no capability on all the attributes (11111), the state of having a little capability on all attributes (22222) has value 0.556, the state of having a lot of capability on all of the attributes (33333) has a value of 0.866, and 1, the highest value, is assigned when having full capability on all the attributes (44444) (Coast et al., 2008; Perry-Duxbury et al., 2020). The ICECAP-O has good psychometric properties with decent evidence about its reliability and validity (Proud et al., 2019).

Statistical analyses

Descriptive analyses of demographics were performed to characterise the sample.

A correlational analysis was conducted with carer QoL and carer demographic factors (age, gender and type of relationship with the care recipient) to check whether it is necessary to control these variables in the regression model. A multiple regression analysis was conducted to examine to what extent different carer-related modifiable factors predicted carer QoL. knowledge about dementia, psychological inflexibility, self-compassion and the hours of support from other family members were entered into the model as independent variables. The overall model fit was assessed using the F-test and the model's R^2. The standardised coefficients beta (β) were used to assess which of the variables had the strongest impact on the dependent variable (i.e., carer QoL).

The Tolerance value and VIF were estimated to check multicollinearity and the Mahalanobis distance to check the presence of outliers. The visual examination of the Normal Probability Plot (P-P) of the regression standardised residuals and residuals scatterplot were used to check normality, linearity and homoscedasticity of residuals.

Results

Sample characteristics

The demographic characteristics of participants are presented in Table 1. The majority of family carers were female (67.0 %), over 65 years old (69.2%), who had at least the secondary school completed (93.4%). The majority were looking after a spouse (69.2%) with Alzheimer's disease (44.0%) in the severe stage (45.1%) and 73.6% were living in the same household with the person with dementia. Pearson's correlations and means and standard deviations for all dependent and independent variables are presented in Table 2. The distribution of the data of each included variable is presented in boxplots in figure 1.

Model-checking

The Tolerance (>0.55) and the VIF (<1.83) values suggested that the presence of multicollinearity is less likely to be a concern for all independent variables. The visual examination of the Normal P-P Plot and the scatterplot of the standard residuals suggested that the assumption of normality, linearity and homoscedasticity of residuals was not violated. The Mahalanobis distance maximum value of 15.36 indicated that there were no extreme outliers.

Factors affecting family carer QoL

None of the demographic factors correlated significantly with QoL (see Table 3). Thus, these variables were not controlled in the regression model. Results of the regression analysis showed that the model with psychological inflexibility, self-compassion, knowledge about dementia and hours of support from other family members accounted for approximately 24% of the variance in carer QoL. Psychological inflexibility was the only variable significantly predicting carer QoL ($\beta = -0.46$, $p = 0.00$, 95%CI: -0.71 to -0.20) (See Table 4). These findings suggest that greater psychological inflexibility can lead to reduced QoL in family carers.

Discussion

This study aimed to explore the impact of carer knowledge about dementia, psychological inflexibility, self-compassion and support from other family members on carer QoL. The results demonstrated that psychological inflexibility was the only significant predictor of QoL in the proposed model. Previous studies have demonstrated that psychotherapeutic interventions that directly target psychological inflexibility such as Acceptance and Commitment Therapy (ACT) are beneficial for treating depression and anxiety in family carers of people with dementia (Losada et al., 2015; Márquez-González et al., 2020).

Currently, there is no clear evidence of whether ACT can also improve the overall QoL of carers, but this potential is worth investigating in future research.

Contradicting to our hypotheses, carer knowledge about dementia, self-compassion and support from other family members did not predict carer QoL. The majority of existing measures of knowledge about dementia only focus on information about Alzheimer's disease, particular stages of dementia or specific knowledge about biomedical domains (Annear et al., 2015; Carpenter et al., 2009; Gilleard & Groom, 1994; Kuhn et al., 2005; Toye et al., 2013). The DKAS, which was used in the current study, was designed to overcome the limitations of existing measures by assessing the knowledge in various domains (e.g. causes, behaviour, risk) related to all types of dementia (Annear et al., 2017; Annear et al., 2015). Despite this, the variable still did not predict carer QoL in the current study.

Self-compassion and its relationship with psychological inflexibility have been gaining more attention in recent years. Although these variables have different constructs, previous research has demonstrated that self-compassion and psychological flexibility (i.e. low levels of psychological inflexibility) have a significant correlation in diverse populations (Marshall & Brockman, 2016; McLean et al., 2018; Meyer et al., 2018; Pyszkowska, 2020). Nonetheless, when comparing both variables as predictors of emotional wellbeing, psychological flexibility seems to predict more variance than self-compassion, which is also consistent with our findings (Marshall & Brockman, 2016; Woodruff et al., 2014).

The current study also did not find a significant impact of the support from other family members on carer QoL. In the current study, 67 per cent of the participants had less than 2 hours a week or no support from other family members. Moreover, this variable was measured using a categorical measure (e.g. 0-2 hours, 3-10 hours) rather than a continuous quantitative measure and thus this might have limited the ability to capture the wider

variance. Furthermore, information about the use of respite services and informal support (e.g. friends), community-based organisations or third parties (e.g. privately paid carers) was not included, which might have been confounding factors.

The findings of the current study have important clinical implications, which would potentially allow us to optimise currently available evidence-based interventions. Previous reviews have demonstrated that most of the existing interventions developed for this population are psychoeducational, which are aimed at increasing the carer's knowledge and teaching dementia- and caregiving-related skills (Cheng et al., 2020; Jensen et al., 2015; Kishita et al., 2018). However, these psychoeducation-based approaches are considered to have a limited impact on family carer QoL (Amador-Marín & Guerra-Martín, 2017; Cheng et al., 2020; Kishita et al., 2018).

Previous studies have also highlighted that family carers often demonstrate a great need of receiving information about the disease, symptoms, prognosis, life expectancy and end-of-life care, particularly when they receive the diagnosis (Contreras et al., 2021; Killen et al., 2016; Lee et al., 2019). Such educational needs of family carers must be met, but by itself may not be enough to improve and maintain family carer QoL. Future research should explore the way to improve awareness of their own psychological needs and facilitate access to evidence-based psychological interventions among this population.

The generalisability of these results is subject to certain limitations, such as participants' characteristics. Most of the participants included in this study were female, aged 65 or older and were looking after a spouse with moderate to severe Alzheimer's disease in a developed country. The information on the ethnicity of participants was not collected. Future research should replicate the findings of the current study with other types of carers including those with different ethnicities and races.

While the AAQ-II is one of the most used generic measures of psychological inflexibility in the literature, there is a specific measure that targets this variable in carers such as the Experiential Avoidance in Caregiving Questionnaire (EACQ) although the scale has not been validated in English. Future research may wish to consider the inclusion of the EACQ or recently developed more comprehensive measures of psychological inflexibility, which covers the broader ACT processes, such as CompACT (Francis, Dawson, & Golijani-Moghaddam, 2016).

The R^2 value of 24% suggests that there may be other variables that need to be considered in future research. For instance, this study assessed the knowledge about dementia but did not include any variables assessing whether carers have the ability to put such knowledge into practice (e.g. competencies in skills). This study also did not include any stressor variable such as the care recipient's neuropsychiatric symptoms, which would have allowed to test the capacity of the proposed variables to predict carer QoL above and beyond the stressors. Finally, it is important to emphasise that this was a cross-sectional study and thus the results regarding the causality between the variables may be limited.

Conclusion

This study found that psychological inflexibility predicted carer QoL. Future multicomponent interventions aiming to improve carer QoL could be optimised by incorporating an evidence-based treatment that targets psychological inflexibility such as ACT. It is recommended that future studies continue exploring the role of psychological inflexibility and other carer-related modifiable factors for QoL, particularly using a longitudinal design. Carers of less common types of dementia, in the early stages, and from other countries, races and ethnicities also should be targeted in future research.

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Table 1. Demographic characteristics of the sample (N=91).

Family carer characteristics		
Age (in years)	69.5	(± 12.5)
Gender (Female %)	67.0	
Educational Level %		
Unfinished Primary School	1.1	
Primary school	5.5	
Secondary school	40.7	
Vocational diploma	26.4	
Bachelor's degree	19.8	
Master's degree	5.5	
PhD	1.1	
Type of relationship %		
Wife	40.7	
Husband	28.6	
Daughter	25.3	
Son	4.4	
Sister	1.1	
Hours of support from other family members %		
No support	52.7	
0-2 hours	14.3	
3-10 hours	16.5	
11-20 hours	3.3	
21-40 hours	6.6	
41-80 hours	1.1	
81 or more hours	5.5	
Living with the care recipient (yes %)	73.6	
Member of a carer support group (yes %)	25.3	
Characteristics of people with dementia		
Dementia type		
Alzheimer's %	44.0	
Mixed %	16.5	
Vascular %	15.4	
Frontotemporal %	7.7	
Lewy bodies %	5.5	
Unknown %	8.8	
Other %	2.2	
Years since diagnosis	3.7	(± 2.4)
Dementia Severity %		
Mild	5.5	
Moderate	30.8	
Severe	45.1	
Very severe	18.7	

Table 2. Pearson's correlations among independent and dependent variables and means and standard deviations (N=91).

Variables	1	2	3	4	M (SD)
1 Quality of life (ICECAP-O: 0-1)	-				0.73 (0.16)
2 Psychological inflexibility (AAQ-II: 7-49)	-0.46*	-			19.70 (10.50)
3 Self-compassion (SCS-SF: 1-5)	0.33*	-0.65*	-		3.28 (0.70)
4 knowledge about dementia (DKAS: 0-50)	-0.02	0.12	0.02		27.86 (8.59)
5 Support from other family members (1-6)	0.08	0.18	-0.11	0.09	1.22 (1.72)

Note: *p<0.05 (two-tailed).

ICECAP-O high scores denote a better quality of life; AAQ-II high scores denote greater levels of psychological inflexibility; SCS-SF high scores denotes greater self-compassion; DKAS high scores indicate greater knowledge about dementia; Support from other family members high scores denote more hours of support from other family members.

Table 3. Pearson's correlations between demographics and the dependent variables (N=91).
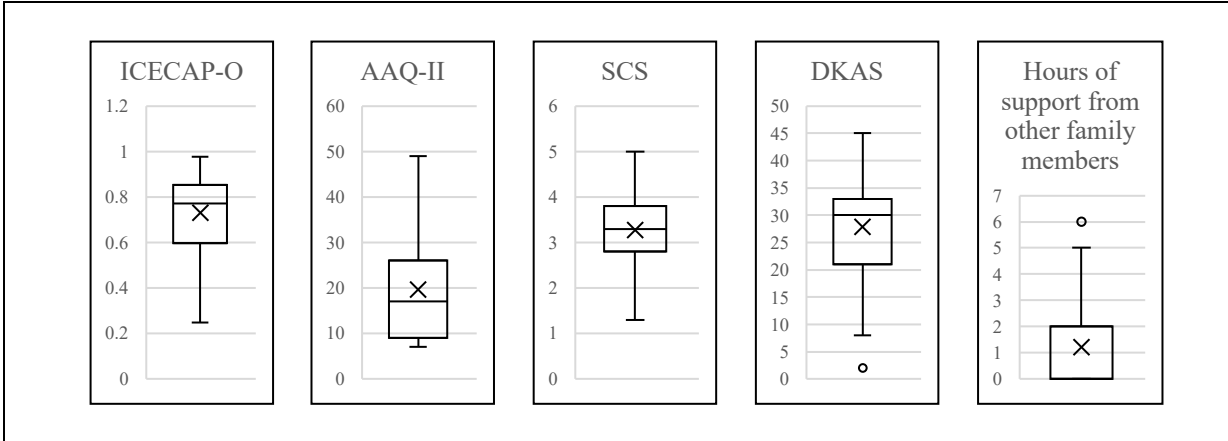
Demographics	Carer QoL
1 Carer age	0.14
2 Carer gender	0.13
3 Carer type of relationship with the care recipient	0.04

Note: *$p<0.05$ (two-tailed).

Table 4. Results of multiple regression analysis (N=91).

Predictors	Carer Quality of life			95% CI	
	β	t	P	Lower	Upper
Psychological inflexibility	-0.46	3.58	0.00	-0.71	-0.20
Self-compassion	0.05	0.36	0.72	-0.20	0.29
knowledge about dementia	0.02	0.17	0.86	-0.17	0.21
Hours of support from other family members	0.16	1.68	0.10	-0.03	0.35

F	6.61
d.f.	4
R^2	0.24

Figure 1: Boxplots showing the distribution of the data

Note: ICECAP-O high scores denote a better quality of life; AAQ-II high scores denote greater levels of psychological inflexibility; SCS-SF high scores denotes greater self-compassion; DKAS high scores indicate greater knowledge about dementia; Support from other family members high scores denote more hours of support from other family members.