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Dementia Family Carers' Quality of Life and Their Perceptions About Care-receivers' Dementia Symptoms: The Role of Resilience

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Abstract

Aim: The study examined (a) the relationship between caregivers' (CG) quality of life (QoL) and their reports about care receivers' dementia symptoms and (b) whether CG's resilience would be a mediator in this relationship. **Method:** This was a cross-sectional study based on a purposeful sampling. Face-to-face structured interviews were conducted with 118 CGs (79% females, mean age = 59, *SD* = 12). CGs provided assessment of their QoL and resilience, and proxy assessments of people with dementia (PwD) symptoms (cognitive functioning, functional activity and behavioural problems (BP)). **Results:** The BP were the only perceived dementia symptoms associated with the CGs' QoL. CGs' resilience fully mediated the relationship between perceived BP and CGs' QoL. **Implications:** Tailored training programs designed to improve CGs' QoL should focus on strengthening their personal resources, such as skills to manage the behaviour problems exhibited by PwD and their resilience to adapt to self-perceived behaviour problems common to dementia.

Keywords
family caregivers, problematic behaviour, mediation, positive psychology, personal resources

Introduction

Dementia care in Greece, similar to most European countries, is primarily provided at home by informal or unpaid caregivers (CGs) (mostly first-degree relatives) (Petmesidou, 2014). Dementia caregiving can be an extremely demanding and burdensome responsibility with significant repercussions to the quality of life (QoL) of the informal GCs of people with dementia (PwD) (Collins & Kishita, 2020; Sołtys & Tyburski, 2020). QoL is a multidimensional construct incorporating physical and psychological health, social relationships, personal beliefs and relationship with the environment, and therefore, it can provide an indicator of the overall impact of caregiving on the CG (WHO, 1998). Maintaining good QoL is of paramount importance for the CGs themselves and affecting the quality of care they provide to PwD. It is not surprising then that the CGs' QoL has increasingly received research attention and has been recently prioritized by both practitioners and policymakers (de Oliveira et al., 2015).

Recent studies (Daley et al., 2019; Frias et al., 2020; Hvidsten et al., 2020; Vun et al., 2020), systematic reviews (Farina et al., 2017; Oliveira et al., 2020; Pereira & Soares, 2015) and a meta-analysis (Contreras et al., 2020) have identified a number of factors that are associated with CGs' QoL. These included *CG's variables*, such as age, gender, physical and mental health problems, and burden, and the *care-receiver's characteristics*, such as dementia symptoms

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as perceived by the CG. Among the care-receiver's characteristics, CG's perceived increase of dementia symptoms, such as poorer cognitive functioning/cognitive deterioration (Schoenmakers et al., 2010), functional impairment/dependence in activities of basic (ADL) and instrumental daily living (IADL) (Morrison et al., 2020), and more neuropsychiatric symptoms, also known as behavioural-psychological symptoms of dementia (Koyama et al., 2017; Vun et al., 2020), are the ones found to be consistently associated with poorer CG's QoL. In a sample of 217 CGs, common behavioural and psychological symptoms of dementia were the only significant care-receiver characteristics associated with CGs' worse QoL (Vun et al., 2020). Similarly, in a sample of 160 informal CGs, the care-receivers' variables associated with CGs' worse QoL were the behavioural problems (BP) as perceived by the CG (Frias et al., 2020). Despite these attempts to examine the association between CG's QoL and perceived dementia symptoms, findings are still inconclusive. For example, Pessotti et al. (2018) found that CGs' QoL was not associated with the presence of behavioural/neuropsychiatric symptoms in PwD but with PwD's deteriorated cognitive performance. The associations between perceived dementia symptoms and CG QoL have been reported to be relatively low (e.g. Contreras et al., 2020; Papastavrou et al., 2014; Pessotti et al., 2018).

Due to the scarce and inconsistent findings, together with the need to increase CGs' QoL, the relationship between CGs' QoL and perceived dementia symptoms of PwD and the factors that could affect this relationship are of interest. A number of researchers have suggested that CGs resilience could be one of these factors (Pessotti et al., 2018; Teahan et al., 2018). A recent unified definition of resilience (Zhou et al., 2020) suggests that resilience is a *process* during which CGs use internal assets and external resources to overcome stress and adversity and obtain positive outcomes; the outcome of this process depends both on the caregiving challenges and CGs' efforts to overcome these challenges. This definition further suggests that resilience may be a mediator in the relationship between CGs' stress in the context of caregiving and CGs' outcome. Resilience is a promising positive psychological resource that may offer new possibilities for the formulation and delivery of policy and treatment actions (Teahan et al., 2018; Zhou et al., 2020).

Some published research efforts have examined the association between CGs' resilience and QoL. Although limited, evidence gathered to date has shown statistically significant associations between CGs' resilience and CGs' good mental and physical health (i.e. two components of QoL; Kimura et al., 2019), and better QoL (da Rosa et al., 2020; Palacio et al., 2020). These findings suggest that CGs' positive outcomes may depend on their resilience in the face of the caregiving challenges and demands (Kim et al., 2018; Zhou et al., 2020).

A few studies have examined the association between CGs' resilience and symptoms of PwD. Whereas Pessotti et al. (2018) have found a significant association between higher CGs' resilience and severe dementia symptoms, Dias et al. (2016) found no such relationship. Since (a) perceived dementia symptoms have been associated with worse CGs' QoL and (b) CGs' resilience has been associated both with symptoms of PwD and CGs' QoL, it would be reasonable to assume that CGs' resilience might be a mediator. One study has examined the mediating role of resilience in the relationship between other independent variables (i.e. psychological distress, such as stress, anxiety, depression and burden) and dependent variables (subjective well-being) (Jones et al., 2019). Baharudin et al. (2019) examined the mediating role of other factors (i.e. personality and coping strategies) in the relationship between BP by PwD (one of the dementia symptoms) and CG's burden (potentially one aspect of QoL).

Therefore, this study aimed to identify the perceived symptoms of PwD (i.e. functional impairment, cognitive deterioration and behavioural-psychological symptoms) associated with poorer CGs' QoL and examine whether CGs' resilience reduces the effect of dementia symptoms on their QoL. Given that neither the perceived symptoms of PwD nor CGs' resilience has been thoroughly examined in association with their QoL as yet and no definite conclusions have been reached, theoretical and empirical testing of both is needed.

Methods

This was a cross-sectional study using a convenience sample of informal CGs of PwD living at home and residing in the Prefecture of Heraklion, Crete, Greece.

Participants

To be eligible for inclusion, participants had to be the primary family CGs of PwD. The CGs reported the diagnosis of the dementia previously conducted by a neuropsychiatrist or geriatrician. An additional inclusion criterion for the CGs was their ability to understand and complete the study questionnaires. From the total of 145 potential participants that was approached, 22 refused to participate citing time constraints, and 5 could not be reached at home, leaving a final sample of 118 CGs (response rate = 81.4%).

Instruments

Caregivers. A structured questionnaire was administered to the CGs of PwD to obtain demographics and measures of their QoL and resilience.

CGs' QoL was assessed using the Greek version of the World Health Organization QoL–abbreviated version of 26 items (WHOQOL-BREF; Ginieri-Coccossis, et al., 2009). The 24 items are rated on a 5-point scale ranging from 1 to 5 to produce a total score with a potential range of 24–120

(WHO, 1998). Higher scores demonstrate higher QoL. In this study, Cronbach's alpha was .881.

CGs' resilience was assessed with the 6-item Brief Resilience Scale (B.R.S.; Smith et al., 2008). The items were rated on a 5-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). Items 2, 4 and 6 were reverse scored. Scores range from 6 to 36. The higher scores indicate higher resilience. The B.R.S. was translated into Greek and back translated into English by two independent bilingual persons following the translation/back-translation method (Brislin, 1970). The translated instrument was compared with the original one and few slight modifications were made. Pre-test of the instrument on 10 Greek-speaking participants was conducted, and when the translation was considered acceptable by the researchers, it was used for subsequent analyses. Cronbach's alpha for the Greek resilience questionnaire was .564. The small number of items might be a reason of low alpha coefficient as discussed in the literature (Tavakol & Dennick, 2011). Besides, Hinton et al.'s (2004, p. 365) have suggested that a reliability coefficient of .50–.70 is considered moderate reliable. Based on these two arguments, we considered the alpha coefficient of .564 acceptably reliable and we included the Greek B.R.S. score in our analyses.

Caregivers' perception of symptoms by PwD. The level of cognitive functioning of PwD was evaluated with the 30-item Greek version of the Mini-Mental State Examination (Fountoulakis et al., 2000). Scores range from 0 to 30, with scores equal to or less than 24 indicating cognitive dysfunction/impairment (Folstein et al., 1975).

The functional capacities of PwD as perceived by the CGs were assessed with the 6-item Greek version of the Katz Index of Independence in (ADL; Katz et al., 1963; Tsolaki & Kounti, 2010). Items are scored with yes/no for independence. The total score ranges from 0 to 6 (full functioning/independence), with scores 2 or less indicating severe functional impairment/no independence. In this study, Cronbach's alpha was .886.

Independent living skills in eight domains of functioning as perceived by the CGs was measured with the 8-item Greek version of the Lawton–Brody Instrumental Activities of Daily Living Scale (I.A.D.L.; Lawton & Brody, 1969; Theotoka et al., 2007). Items are scored with yes/no and the total score ranges from 0 (low functioning) to 8 (high functioning). If the items for food preparation, housekeeping and laundering are excluded for men, then the summary score ranges from 0 through 5. The lower the score, the more severe the impairment. In this study, Cronbach's alpha was .785.

The behaviour problems (e.g. restlessness, suspiciousness, irritability and night wandering) as perceived by the CGs were assessed with the 14-item Problematic Behaviour Scale (Pearlin et al., 1990). Items were scored in terms of frequency on an 8-point Likert-type scale ranging from 0 (no day) to 7 (7 days). A mean total score ranges from 0 to 7 days in the previous week for all problems. Higher mean scores reflected more days in the past week that the CGs reported dealing with the behaviour problems of PwD. In this study, Cronbach's alpha was .848.

Procedure

The sample of CGs and PwD was recruited regionally through a purposeful sampling technique from various sources (listed in a descending order of the number of CGs recruited): (a) social care services, such as Older Adults' Day Care Centres and Home based Care Program where older adults and their CGs were the recipients of the services; (b) the Department of Internal Medicine, University Hospital of Crete (PAGNH), where PwD were occasionally hospitalized for health problems; (c) some Alzheimer's Societies in Greece and (d) private practices of neurologists and psychiatrists. Data were collected within a period of approximately 6 months. Both CGs and PwD were first contacted and were asked to give their preliminary consent to participate. Following consent, CGs were approached by a researcher during regular visits and face-to-face interviews were conducted at a setting of their preference/convenience (i.e., either home or service/hospital/private practice). The interviewer was knowledgeable in administering the instruments for assessing the symptoms by PwD. Before enrolment into the study, CGs signed an informed consent form, in which their rights as participants were fully explained (i.e. voluntary participation, anonymity and confidentiality). PwD orally consented to be administered the MSSE. The study was approved by the ethics committee of the institution to which the senior author is affiliated.

Data analysis

Descriptive statistics including means, *SD* and percentages were generated to describe the sample and study variables. Pearson product-moment correlation coefficients or point-biserial correlation coefficients, or Spearman rank correlation coefficients as indicated, were used to examine associations between the variables. To examine the clinical characteristics of PwD associated with CGs' QoL, a multiple regression analysis (stepwise method) was conducted. Socio-demographic variables of PwD (i.e. gender, age, marital situation, educational level, when the disease started, number of hospitalizations in the past 6 months) and their clinical characteristics (i.e. cognitive status, functional activity and BP) were both entered as independent variables. Dummy variables were produced as follows (see Table 1): For gender, 0 was for male and 1 for female; for marital situation, 0 was for single/divorced/separated and 1 for married; for elementary educational level, 1 was for elementary and 0 for other; for junior high/high school education, 1 was for junior high/high and 0 for other; for employment, 0 was for not employed and 1 for employed;

Table 1. Characteristics of the caregivers and PwD (presented as percentages or *M* and *SD*).

	CGs	PwD
Sex		
Female	78.8	62.4
Male	21.2	37.6
Age	58.9 (11.5)	82.7 (7.4)
Marital situation		
Single	5.9	0.0
Married	85.6	41.5
Divorced/widowed/other	8.5	58.5
Children (yes)	90.4	96.6
Educational level		
Elementary (not finished)	9.3	50.4
Elementary	27.1	29.2
Junior high	29.7	9.7
High school	14.4	7.1
Post-lyceum education	5.9	1.8
University	13.6	1.8
Employed (yes)	38.1	3.4
Financial situation (self-perceived)		
Bad	30.5	
Moderate	55.1	
Good	14.4	
Chronic disease by CGs (yes)	40.7	
Relationship with the PwD		
Children	62.7	
Spouses	25.4	
Neighbour/other	11.9	
Help in caregiving		
No help	29.9	
Yes (family member)	41.9	
Yes (formal caregiver)	28.2	
Months of caregiving	60.2 (47.1)	
Hours of caregiving per day	11.8 (8.8)	
WHOQOL-BREF (QoL)	76.50 (17.05)	
Brief Resilience Scale (B.P.S.)	19.06 (4.27)	
Mini-Mental State Examination (MMSE)		7.41 (8.53)
Katz Index of Independence in Activities of Daily Living (ADL)		1.99 (2.20)
Lawton–Brody Instrumental Activities of Daily Living Scale (I.A.D.L.)		.86 (1.46)
Problematic Behaviour Scale (P.B.S.)		1.98 (1.57)

Note. CGs: caregivers; PwD: people with dementia; range of scores for B.P.S. (6-36), WHOQOL-BREF (24-120), ADL (0-6), I.A.D.L. (0-8(W)/0-5(M)) and P.B.S. (0-7).

for medication 0, was no and 1 was yes; for financial situation, 0 was for bad and 1 for moderate/good; for chronic disease (suffered by the CG), 0 was for No and 1 for Yes; for relationship with the PwD (as a partner), 1 was for partner and 0 for other (daughter/son or neighbour); for relationship with the PwD (as a daughter/son), 1 was for daughter/son and 0 for other (partner or neighbour); and for help in caregiving, 0 was for no help and 1 for help (by family member or formal caregiver).

To examine the indirect effects of the clinical characteristics of PwD on CGs' QoL as mediated by resilience, a mediation analysis using PROCESS v3.5 macro (Hayes, 2018) was conducted. Model 4 (simple mediation), 95% confidence interval for indirect effects and 5000 bias-corrected bootstrap samples were used. Indirect effects were considered statistically significant if the 95% CI did not contain zero.

For regression and mediation analyses, multicollinearity was examined with tolerance and variance inflation factor (VIF). All analyses were carried out using the Statistical Package for Social Sciences version 21 and a two-tailed value of $p < .05$ was considered significant.

Results

Sample's characteristics

The majority of the CGs were females, on average nearly 60 years old, married with children, had finished the compulsory education of 12 years and had moderate self-perceived financial situation. Children composed the largest proportion of CGs, followed by spouses. PwD were mostly female, over 80 years old, divorced or widowed and with elementary education. CGs reported being involved in their relatives' care for an average of 5 years and providing a mean of nearly 12 hours of caregiving per day. The majority of CGs reported that another person was involved in the caring of PwD (mostly an informal CG). PwD were mostly females, on average 83 years old, divorced or widowed with children, with low educational level (less than 6 years). The detailed demographic characteristics of the CGs and PwD are presented in Table 1.

CGs' QoL and resilience

As depicted in Table 1, participants reported good QoL and levels of resilience, with scores above means (QoL = 12.77 and resilience = 19.06).

Dementia symptoms and their association with CG's QoL

From Table 1, it can be seen that PwD were perceived by the CGs as being severely affected by the disease, that is, as having severe cognitive impairment (MMSE score below 9), moderate functional impairment to perform simple ADL (KATZ = 1.99) and severe impairment to perform complex ADL (Lawton–Brody scores = .86) and as having a mean frequency of 1.98 ($SD = 1.57$) days per week that the CGs had to be dealt with the behaviour problems by PwD. The frequency of the individual behaviour problems by PwD is presented in Table 2.

There was not a statistically significant difference between those who have dealt few days per week (≤3) and those who had dealt many days per week (≥4) with the behaviour problems of PwD, neither for their CG's QoL (13.1 vs. 12.3, respectively; $t = 0.597, p = .552$) nor their resilience (18.6 vs. 19.2, respectively; $t = -.391, p = .697$). The frequency of BP by PwD (many vs. few) was unrelated to CG's QoL and their resilience (for QoL: 14.2 vs. 12.02; t = 1,776, p = .079; for resilience: 21.3 vs. 18.8; t = 1,736, p =.086).

As can be seen in Table 3, the regression analysis for examining the clinical characteristics of PwD associated with CGs' QoL was statistically significant ($F_{(1)} = 4.670, p = .042$) and predicted 13.8% of the variance in QoL. Only behaviour problems were associated with CGs' QoL (β = −.418, t = 2.161, $p < .05$). All tolerances were close to or higher than 1.0 and all VIF less or equal to 2.5, suggesting that collinearity did not bias the analysis.

The role of resilience in the relationship between BP and QoL

Correlations were below .65, all tolerances ≥.32 and all VIF ≤3.2 suggesting that collinearity did not bias the mediation model. Path (a) depicts the relationship between PwD's BP and CGs' resilience, path (b) depicts the relationship between CGs' resilience and CGs' QoL and path (c) indicates the relationship between PwD's BP and CGs' QoL. Path (c′) depicts the relationship between PwD's BP and CGs' QoL through the mediating effect of resilience. PwD's BP had a statistically significant negative effect on CGs' resilience (B = −.04, SE = .02, p < .05) and CGs' resilience had a statistically significant positive effect on CGs' QoL (B = .25, SE = .06, $p < .001$). The direct effect of PwD's BP on CGs' QoL (path c) was not statistically significant ($B = -.02$, $SE = .01$, n.s.), but the indirect effect of PwD's BP on CGs' QoL through the mediating role of CGs' resilience (path c′) was

Table 2. Frequency of the behaviour problems experienced by PwD.

In the past week, how many days your relative:	M	SD
Keep you up at night	2.69	3.00
Repeat questions/stories	3.73	3.31
Try to dress the wrong way	2.72	3.29
Have a bowel or bladder 'accident'	1.85	2.93
Hide belongings and forget about them	2.98	3.20
Cry easily	1.48	2.50
Act depressed or downhearted	2.09	2.64
Cling to you or follow you around	3.05	3.07
Become restless or agitated	2.87	3.07
Become irritable or angry	1.77	2.92
Swear or use foul language	.98	2.30
Become suspicious, or believe someone is going to harm (him/her)	.90	2.15
Threaten people	.47	1.50
Show sexual behaviour or interests at wrong time/place	.13	.81

Table 3. Multiple regression analysis for predicting caregivers' quality of life.

	Beta	*T*	*p*
Problematic Behaviour Scale (B.P.S.)	−.418	−2.161	.042
Mini-Mental State Examination (MMSE)	.146	.711	.485
Katz Index of Independence in Activities of Daily Living (ADL)	−.026	−.129	.899
Lawton–Brody Instrumental Activities of Daily Living Scale (I.A.D.L.)	.103	.525	.605
Gender	.131	.647	.525
Age	.214	1.072	.296
Marital situation	−.299	−1.436	.166
Children	.057	.286	.778
Educational level	−.186	−.956	.350
Employed	−.353	−1.915	.069
Medication	.043	.216	.831
Duration of disease (in years)	−.121	−.572	.573
Number of hospitalizations (past 6 months)	.313	1.665	.111

Note. For gender, 0 was for male and 1 for female; for marital situation, 0 was for single/divorced/separated and 1 for married; for educational level, 1 was for elementary school and 0 for other; for employment, 0 was for not employed and 1 for employed; Medication refers to medication use for health and/or mental health problems by PwD; Number of hospitalization (past 6 months) refers to PwD.

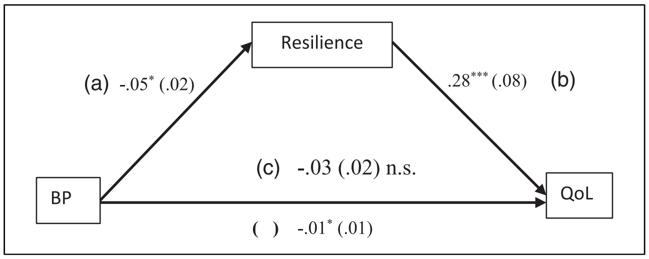

Figure 1. Graphical representation of the statistically significant mediating effect of caregiver's resilience in the relationship between behavioural problems (BP) of people with dementia and CGs' quality of life. *B*-coefficients and SE in parenthesis are presented for each path. $^{*}p < .05$; $^{**}p < .01$; $^{***}p < .001$. Direct effect (path c): b = −.0246 (.01) n.s. Indirect effect (path c′): b = −.0129 (.0072), 95% CI [−.0283 to −.0003], $p < .01$.

statistically significant ($B = -.01$, $SE = .01$, $p < .05$). The total effect of BP on QoL estimated by resilience was 23.04%. Thus, CGs' resilience fully mediated this relationship (Figure 1).

Discussion

Given that the number of PwD is likely to triple by 2050 (WHO, 2017), affecting up to 152 million people worldwide, and that long-term care is mainly provided at home by informal CGs (Petmesidou, 2014), safeguarding the informal CGs will be more crucial than ever in the upcoming years. In keeping with the recommendations by Feast et al. (2016) that future research should explore pathways between behavioural and psychological symptoms in dementia, CGs' variables and CGs' outcomes, this study examined (a) the dementia symptoms that are associated with CG's QoL and (b) whether CG's resilience would be a mediator in this relationship.

The BP by PwD (e.g. aggressiveness, overactivity, behaviours that required constant monitoring, such as aimless wandering, and restlessness) – and not the cognitive or functional impairment – contributed to worse CGs' QoL. These results support evidence from previous studies and reviews that the behavioural and psychological symptoms rather than the cognitive or functional impairment of PwD associate with worse CG well-being (see systematic review by Feast et al., 2016), more depressive symptoms (Bejjani et al., 2015), higher burden (Baharudin et al., 2019; Gresswell et al., 2018; Pessotti et al., 2018), more distress (Shikimoto et al., 2018) and poorer CG QoL (Farina et al., 2017; Frias et al., 2020; Koyama et al., 2017; Vun et al., 2020). The results of the present study have expanded those of Koyama et al. (2017) who have reported that the behavioural and psychological symptoms were related with one component of QoL, the mental QoL, and those of Vun et al. (2020), who have only examined the behavioural and psychological symptoms. In their meta-analysis of 27 studies, Contreras et al. (2020) also found that the cognitive functioning and the ADL of PwD did not correlate with CGs' QoL. It is reasonable to assume that symptoms of agitation rather than symptoms of dependence (e.g. ADL and IADL) could be more challenging for the CGs (Hendricks-Lalla & Pretorius, 2020) and may require more effort to cope with and therefore may be more detrimental to their QoL. As suggested by previous research, a possible explanation of this finding could be that CGs erroneously believe that the cognitive or functional impairment are age-related problems and thus rather anticipated (Salthouse, 2010), whereas BP are not considered as a consequence of ageing. BP, may overwhelm CGs, cause severe distress that exceed their coping resources and thus may undermine their QoL. Also, not accepting the disease-related symptoms of the PwD may be detrimental for the QoL of the CGs.

However, the correlation between the BP of PwD and CG QoL was relatively low, which is in keeping with Contreras et al. (2020) findings.

In the mediation model, BP correlated negatively with CGs' QoL (c′) and resilience (a). Previous research indicates that behavioural changes of PwD are associated with CGs' worse QoL (Farina et al., 2017). No other study was found in the published literature to suggest that dementia BP have an indirect effect on CGs' QoL that can be mediated by CGs resilience. To authors' knowledge, this is the first study to indicate that the BP of PwD negatively associate with CGs' resilience. In our study, dementia BP had a hindering effect on CGs' resilience since the more BP by PwD (e.g., restlessness, suspiciousness, irritability and night wandering), the lower the resilient score of the CGs. However, the CGs of this sample had relative high scores of resilience, despite the significant demands of caregiving (i.e. they provided many hours of caregiving daily to PwD, with significant behaviour problems and both cognitive and functional impairments). We postulate that the prolonged care (an average of 5 years) may have provided an opportunity for the CGs to adapt to the behavioural challenges by PwD, thereby increasing their own resilience as suggested by some literature (Gaugler et al., 2007). However, the opposite argument may be true; the lower score of CGs' resilience may have caused or exacerbated BP to PwD. Abundant research evidence indicates that CGs' resilience is related to the availability of social support and the meaningful relationships with family and friends (Cross et al., 2018; Palacio et al., 2020). Given that familism values (i.e. strong emotional ties with the family/close family relationships, feelings of loyalty, reciprocity, filial piety and solidarity) are highly appreciated in the Greek culture (Koukouli et al., 2020), it is not entirely surprising that the CGs in this sample remained resilient despite the caregiving demands.

Resilience was found to be a significant mediator in the relationship between BP by PwD and CGs' QoL. In fact, when resilience was introduced as a mediator, the effect of BP on CGs' QoL was no longer significant, and resilience counterbalanced the negative impact of dementia BP on CGs' QoL. In essence, whereas an external/environmental factor (i.e. dementia problematic behaviour) jeopardizes CGs' QoL, an internal/personal resource by the CG (i.e. resilience) outweighs adversity and diverts CGs' outcome from negative (diminished QoL) to positive (increased QoL). This is in keeping with Kim et al. (2018) who found that problematic behaviour by dementia patients (an exogenous variable) negatively affected family adaptation, whereas resilience (an endogenous variable), when considered, improved family adaptation. This finding suggests that mediators, such as resilience, that significantly impact on the relationship between behaviour problems and CG's QoL may be important targets of intervention. Since the majority of the CGs of PwD are informal CGs and home-based caring for the PwD by the informal CGs has been associated with decreased rates of costly hospital admissions and institutionalizations (Knapp et al., 2016), policy and intervention efforts are urgently needed to support CGs (WHO, 2017). This finding also emphasizes the importance of enhancing CGs' personal resources (i.e. resilience) as opposed to solely focusing on the dementia behaviour problems for the CG to have favourable outcomes (i.e. better QoL). In summary, our study findings suggest that interventions focusing at enhancing CGs' resilience are likely to improve CGs' QoL to a greater extent than interventions focusing exclusively on difficult behaviours of PwD. Targeting modifiable behaviours has important implications for practitioners since CGs' resilience may be enhanced as opposed to dementia symptoms that cannot be reversed or improved at the present.

Limitations

This study has several limitations, which should be taken into consideration in future research. The self-report measures may have accounted for participants' response bias. If different instruments would have been selected (e.g. for the assessment of BP), this study might had yielded different results (Contreras et al., 2020). For example, the Carer Well-being and Support Questionnaire (CWS) has been recently suggested as the most appropriate instrument for assessing QoL in informal CGs of PwD (Dow et al., 2018). The reliability of the B.R.S. was marginally acceptable. It is quite possible that the translated items were not quite comprehensible or were misconceived by some participants. Another limitation concerns the use of purposeful sampling. Although the sample size was relatively adequate because of the sampling method and its constitution (i.e. CGs were mostly daughters), it cannot be considered representative of the population of dementia CGs in Greece. The sample included severely impaired PwD (cognitively, functionally and behaviourally) and relatively resilient CGs. We cannot, therefore, know what the results would be if less impaired PwD or less resilient CGs were included in the study. This study cannot establish causal inference because of its cross-sectional nature, the use of correlational statistics and lack of longitudinal measures. Future studies should examine the effect of individual BP on CGs' outcome, as suggested by Feast et al. (2016). Qualitative data could have enriched our findings providing useful insights on CGs' experiences and their understanding of the relationship between BP of PwD, CGs' resilience and QoL. Interviews with CGs that manage well with caregiving and with those who do not manage well could have provided a better picture of the barriers and/or facilitators of being a successful family CG. Well-designed longitudinal studies should also examine determinants, mediators and moderators during the trajectory of the illness to achieve a better understanding of CGs' QoL.

Conclusions

Although most dementia research still predominantly focuses on the CGs' problems, loss and deficits (e.g., stress and burden), the study findings suggest that favourable outcomes for the CG (i.e. better QoL) are related to enhanced CGs' resources (i.e. resilience). We have demonstrated that although CGs' QoL was negatively related to the behavioural symptoms of PwD, CGs' resilience was associated with increased QoL regardless of the level of behavioural challenges. Interventions to strengthen CGs' resilience, such as educational or training programs, support groups or telehealth, through which CGs are likely to enhance their skills to deal with the most stressfully perceived dementia symptoms (i.e. behaviour problems), could potentially contribute to better QoL. Since Knapp et al. (2016) have found that, among other factors, agitation and depression (two BP) were independent predictors of the probability of admission to inpatient settings for PwD, it is vital to train CGs to more successfully manage BP to inhibit or delay institutionalization. Training the CGs about the BP that PwD may exhibit and how common they are could potentially help the CGs deal with their caregiving demands.

In addition, education that addresses acceptance of the current (and future) deterioration of dementia-related symptoms might improve CGs' resilience. Interventions stemming from positive psychology and targeting at enhancing the positive aspects of human functioning (i.e. resilience; Lefdahl-Davis et al., 2020) may not only complement but also surpass the effectiveness of interventions guided by the traditional problem-focused approach emphasizing solely the patient and their symptoms. The effectiveness of such interventions needs to be examined further (Töpfer & Wilz, 2020). Enhancing CGs' resilience and skills through tailored-based interventions and services, such as education and training, will ensure maintaining the home-based caregiving with positive outcomes for the CG, the care they provide and the care recipient.

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Ethical Approval Statement

This study was in accordance with the 1964 Helsinki Declaration and its later amendments. Approval was obtained from the Research Ethics Committee of the Hellenic Mediterranean University (No. of approval: 13/07-04-2020).

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