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RESEARCH ARTICLE



Contributors and Moderators of Quality of Life in Caregivers of Alzheimer's Disease Patients

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ABSTRACT

Aim and objective: This study aimed to identify the variables that contributed to Quality of Life (QoL) of Alzheimer's Disease (AD) caregivers, taking into consideration the caregiving context, stressors, role strains, and resources.

Methods: The sample included 102 caregivers of AD patients who answered the following instruments: Depression, Anxiety and Stress Scale-21; Satisfaction with Social Support Scale; Revised Memory and Behavioral Problems Checklist; Family Communication and Satisfaction Scales; Spiritual and Religious Attitudes in Dealing with Illness; and Quality of Life in Alzheimer's Disease – Caregiver Version.

Results: Caregivers who were employed, chose the caregiving role, and received help in caring showed better QoL. Also, being younger, less caregiving daily hours, caring for patients with less memory and behavior problems, lower distress, and family satisfaction predicted better QoL. Finally, spirituality was a moderator between family communication and QoL but not between family satisfaction and QoL.

Conclusion: Caregiving-context variables (age, professional status, choosing to care, receiving help in the caregiving role and duration of daily care); role strains (family dissatisfaction); stressors (caregivers' distress and patients' memory and behavioral problems); and resources (spirituality) had an impact on caregivers' QoL emphasizing the adequacy of the Stress Process Model. Intervention should also focus on spirituality given its moderating role.

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Introduction

Alzheimer's disease (AD) is the most prevalent dementia worldwide (Alzheimer's Association, 2018). The dementia prevalence in the OECD countries is 14.8 cases per one thousand inhabitants and Portugal is the fourth country with the highest number of dementia cases (19.9) (OECD, 2017).

Alzheimer's disease (AD) is characterized by a progressive cognitive and functional decline with impairment in functionality of the patient (Alzheimer's Association, 2017) in all domains of daily living, social and occupational activities.

AD impairment is higher in the moderate and severe stage with the patient showing a progressive significant decrease in physical functioning (e.g., apraxia; difficulty with body coordination with frequent falls and uncontrolled sphincter) and in cognitive functioning

(e.g., changes in memory, language, and disorientation in space and time) (Alzheimer's Association, 2017; Koca, Taşkapılıoğlu, & Bakar, 2017) and behavior changes (Kabeshita et al., 2017). In the moderate stage of AD, patients show more episodic and biographic memory problems well as mood and behavior changes (Zvěřová, 2019), executive functions and judgment (McKhann et al., 2011). In the moderate stage, sleep problems and agitation is a common behavior often as a reaction to the unknown (Kabeshita et al., 2017). In the AD severe stage of the AD, patient's dependence is very high and associated with immobility, incontinence and mutism (Zvěřová, 2019).

The severity of symptoms requires a caregiver to attend to the patients' needs (Azzazy & Riddle, 2019) as dependency increases being also associated with caregiver's high morbidity and mortality (Koca et al., 2017). Caring for a person with AD impacts the physical, emotional, relational, and financial dimensions of the caregiver's life. Therefore, AD influences not only the patient's quality of life, but also the caregiver's quality of life (QoL).

Caregivers of AD patients are often female family members: spouse, daughter or daughter-in-law (Koca et al., 2017; Reed et al., 2014) and not employed (Yurtsever et al., 2013). Studies also showed that younger caregivers showed better QoL (Raivio, Laakkonen, & Pitkälä, 2015; Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006). Often, caregivers do not choose to play this role, being forced into it, as a result of necessity (Falcão & Bucher-Maluschke, 2008).

Family caregivers of AD patients report higher levels of anxiety, stress, and depression, when compared to family members without a caregiving role (Farina et al., 2017). Also, spouse caregivers with no experience in caregiving are more likely to report negative outcomes and usually receive no help from other family members (Koca et al., 2017). Longer duration of caregiving has been associated with decreased QoL in caregivers of AD patients while caregivers' independence (i.e., having free time away from the patient) is associated with better QoL (Farina et al., 2017).

Caring for AD patients is associated with psychological distress and decreased QoL (Do, Norton, Stearns, & Van Houtven, 2015; Pereira & Soares, 2015; Tremont et al., 2013; Välimäki et al., 2016). The symptoms of psychological distress may arise from the advanced AD stage and the patient's greater dependence (Välimäki et al., 2016), as well as from the changing in family relationships and responsibilities, loss of free time, and friendships, among other factors (Koca et al., 2017). Literature shows that caregiver depression is consistently associated with decreased QoL, as well as anxiety, in spite of the latter being less studied (Farina et al., 2017). Therefore, depressive and anxiety symptoms may be responsible for the significant impact of caregiving on caregivers' QoL (Ruiz Fernández & Ortega Galán, 2019) when compared to non-caregivers (Garzón-Maldonado et al., 2017).

The family plays a central role in the caregiving process (Vellone, Piras, Venturini, Alvaro, & Cohen, 2012), since it is the most proximal context and the main support for caregivers of AD patients, namely when changes are required regarding family roles and routines, as the disease progresses (Galvin, 2013; Zacharopoulou, Zacharopoulou, & Lazakidou, 2015). Often, the role of caregiver is assumed by a family member that becomes part of the patient's care team (Galvin, 2013).

AD may trigger different family reactions such as denial, anger, sadness, and guilt (Falcão & Bucher-Maluschke, 2008). The strains associated with caregiving may impair family functioning and lead to conflict, due to the difficulty in managing the caregiver's role

with other family tasks, roles, and needs (Galvin, 2013). Caregivers of AD patients with lower family functioning reported high strain and burden. Also, in spousal caregivers of AD patients, dissatisfaction with the marital relationship has been associated with decreased psychological well-being (Raivio et al., 2015).

Social support plays an important role on QoL of caregivers of AD patients (Pereira & Soares, 2015; Zhang, Edwards, Yates, Li, & Guo, 2014). Caregivers may feel socially isolated since the patient's degree of dependency is associated with caregiver's distress (Koca et al., 2017). Having a family member that helps with the caregiving tasks will offer an opportunity to share feelings, difficulties, and strategies to deal with the patient, and is associated with lower levels of stress and better QoL (Vellone et al., 2012). Although some studies have suggested that the amount of received support does not appear to be associated with caregivers' QoL (cf. Farina et al., 2017), the satisfaction with social support has been shown to decrease caregiver burden, in AD (Han et al., 2014), particularly when support is provided by the family (Zarit, Pearlin, & Schaie, 2019). Therefore, it is important to study the moderating role of satisfaction with social support in the relationship between family functioning/communication and QoL.

Spirituality is often confounded with religiosity, although the latter may not necessarily include spirituality (Hodge, 2001). Spirituality refers to the search for the sacred or the search for transcendent meaning where the sacred indicates God or other entity perceived as such (Pargament, 2007). Spirituality may be a source of strength that helps to make sense of challenges in stressful times, helping the individual to cope (Pargament, 2007), particularly in caregivers of AD (Borrayo, Goldwaser, Vacha-Haase, & Hepburn, 2007). Spirituality may be used as a coping mechanism to deal with the new changes and demands related to the caregiving role (Beuscher & Grando, 2009) providing a positive meaning since it may help the caregiver not to focus on the patient's losses (Stuckey, 2001), contributing to caregivers' well-being and QoL (Hodge & Sun, 2012; Pereira & Soares, 2015). Caregivers who reported less spirituality reported higher depression and burden (Samadi, Mokhber, Faridhosseini, Haghghi, & Assari, 2015), which may be mitigated when the family provides support (Fields, Xu, & Miller, 2019). Therefore, it is also important to study the moderating role of spirituality in the relationship between family functioning/communication and QoL.

The Stress Process Model (Pearlin, Mullan, Semple, & Skaff, 1990) has been applied to the study of caregivers in general and particularly in caregivers of AD patients (Judge, Menne, & Whitlatch, 2010). This model suggests that the background caregiving context variables influence the stress process, affecting the primary stressors, the secondary strains, and the outcomes. In this study, caregivers' age, professional status, duration of care, being a caregiver for the first time, and having chosen to care were analyzed as caregiving context variables. Patients' memory and behavioral problems were included as objective primary stressors, psychological distress as the subjective primary stressor and family dissatisfaction and poor family communication as role strains. Spirituality was considered the internal resource and satisfaction with social support the external one. Finally, caregivers' QoL was the outcome.

The Stress Process Model also includes social support and coping as possible mediators that, according to the authors, serve to lessen the intensity of stressors on the outcomes. Given that transversal designs are not appropriate for mediation analysis (Maxwell & Cole, 2007), in the present study, satisfaction with social support and coping (spirituality) were

analyzed as moderators. Therefore, this study applied the Stress Process Model in a sample of Portuguese caregivers of AD patients analyzing moderators instead of mediators.

From a heuristic point of view, it is very important to analyze the moderating role of spirituality and satisfaction with social support since moderators also buffer the impact of stressors on outcomes and will therefore inform interventions that intend to promote caregiver's QoL.

The specific aims of this study were: i) to explore the differences on QoL according to background caregiving context variables; ii) to find the variables that contributed to caregivers' QoL; iii) to test the moderating role of spirituality and satisfaction with social support in the relationship between family variables and QoL.

The authors hypothesized that:

H1) Professionally active caregivers, with previous experience of caring, receiving help in caring, who chose to care, and caring for a patient in a less advanced stage of AD will show better QoL;

H2) Being younger, less daily caregiving hours, lower psychological distress, higher family satisfaction and communication, more spirituality and social support and less patients' memory/behavioral problems, perceived by caregivers, will contribute to better QoL;

H3) Spirituality and social support will moderate the relationship between family variables and QoL.

Material and Methods

Participants and Procedures

The sample included 102 informal caregivers of AD patients, of which 79.4% were female, with a mean age of 53.14 ($SD = 13.33$). The majority of caregivers were married or cohabitant, were caregivers for the first time, chose to care for the patient, received help in caregiving and spent between 13 and 24 hours per day on caregiving tasks. The AD patients were mostly women, with a mean age of 77.9 years ($SD = 8.67$). The majority of the patients were in a moderate stage of the disease with a mean duration of memory problems of 5.55 years (see [Table 1](#)).

The study followed a cross-sectional design with a convenience sample of informal caregivers. To validate the caregiver status of each participant, time spent with the patient was taken into consideration. Caregivers needed to have at least two weekly contacts with the patient, and be the responsible person in the patient's care. The caregiver could be a member of the patient's family, but not a professional/health assistant hired to help the patient. Inclusion criteria comprised being caregiver of patients diagnosed with moderate and severe AD, followed in the Neurological and Psychiatry Services of three major public hospitals. Exclusion criteria comprised caregiver's severe psychiatric disorders, caring for patients in the early stages of AD or institutionalized patients.

All procedures were in accordance with the ethical standards of the institution and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The ethical committees of the three public hospitals approved the study. The neurologists identified the patients who met the inclusion criteria and at the end of the consultation invited the caregivers, who accompanied patients, to participate in this study. On the day of the patient's consultation, after signing an informed

Table 1. Descriptive statistics for demographic variables of caregivers and patients (N = 102).

Continuous measure	Min	Max	Mean	SD
Age (Caregiver)	20	85	53.14	13.33
Duration of care (in years)	0	25	5.59	4.16
Age (Patient with AD)	54	93	77.90	8.67
Duration of memory problems (years)	0	16	5.55	3.40
Categorical measure		% Caregivers	% Patients	
Gender				
Female		79.4		64.7
Male		20.6		35.3
Education level				
Without education		3.9		42.2
4 th grade		37.3		52
6 th grade		15.7		1.0
9 th grade		13.8		3.0
Equal or higher 12 th grade		29.5		2.0
Employment status				
Employed		50.0		
Unemployed		24.5		
Retired		25.5		
Marital Status				
Single		15.7		12.7
Married or Cohabitant		67.6		45.1
Divorced or Separated		10.8		2.0
Widower		5.9		40.2
Caregiver for the first time				
No		24.5		
Yes		75.5		
Choosing the caregiver role				
No		24.5		
Yes		75.5		
Having help in caregiving				
No		24.5		
Yes		75.5		
Duration of daily care				
1 to 12 hours/day		39.2		
13 to 24 hours/day		60.8		
Have psychological/psychiatric support				
No		84.3		
Yes		15.7		
Stage of Alzheimer				
Moderate				56.9
Severe				43.1

Note: AD = Alzheimer's Disease

consent, caregivers answered the questionnaires during approximately 30 minutes. Participation was voluntary.

Measures

Depression, Anxiety and Stress Scale-21 (DASS-21) (Apóstolo, Mendes, & Azeredo, 2006; Lovibond & Lovibond, 1995)

The instrument evaluates the psychological distress through 21 items distributed in three subscales: "depression", "anxiety" and "stress", scored from 0 (nothing was applied to me) to 3 (applied to me always). Scores range between 0 and 21 for each subscale and from 0 to 63 for the total scale. A high score indicates more distress. In the original version, the subscales presented the following Cronbach's alphas: .84 (depression), .90 (anxiety) and .91 (stress). In the present study, only the total scale was used with an alpha of .87.

Revised Memory and Behavioral Problems Checklist (Pereira & Abreu, 2015; Teri et al., 1992)

The instrument measures the “frequency” of memory and behavioral problems of the patient in the last week, as well as the “reaction” of the caregiver to them in 24 items. Two scores are obtained (frequency and reaction). The items are distributed by three subscales: “memory”, “depression” and “behavior problems”. Scores range between 0 to 96 and a high total score indicates the occurrence of more memory and behavior problems and greater responsiveness of the caregiver. In its original version, the frequency dimension presented a Cronbach alpha of .75, the Caring Reaction of .87, and the total scale of .80. In the present study, only the frequency of problem dimension was used, with an alpha of .95. Regarding the subscales, the memory problems subscale had an alpha of .88, the depression subscale of .95 and the behavior problems of .91.

Family Communication Scale (Olson & Barnes, 2004; Pereira & Teixeira, 2013).

The instrument assesses family communication through 10 items. Family communication is defined as the systemic capacity for positive communication within marital or family systems and is perceived as a facilitator that can modify levels of cohesion and flexibility (Olson, Gorall, & Tiesel, 2006). Scores range between 10 and 50 with high scores indicating better family communication. In the original study, the alpha was .90. The alpha in this sample was .94.

Family Satisfaction Scale (Olson, 2004; Pereira & Teixeira, 2013)

This scale evaluates the degree of satisfaction with family cohesion and flexibility. Family satisfaction is the degree to which family members feel happy with and fulfilled by each other. Scores range between 10 and 50 with higher scores indicating higher family satisfaction (Olson et al., 2006). In the original study, the internal consistency was .93 and in the present study was .95.

Spiritual and Religious Attitudes in Dealing with Illness (Büssing, Ostermann, & Matthiessen, 2004; Pereira, Vilaça, Pedras, Vieira, & Lima, 2020)

This instrument evaluates, in 15 items, the impact of spirituality on the way people deal with chronic illness. Items are scored from 0 (not applicable at all) to 4 (apply fully) and grouped in three subscales: “seeking spiritual support,” “trust in a higher source,” and “reflection.” Scores from total scale ranged between 0 and 60 with a high score indicating higher spirituality. In the original version, the instrument presented a Cronbach alpha of .94 for the total score, .91 (seeking spiritual support and confidence in a higher source), and .86 (reflection). In this study only the total score was used with an alpha of .87.

The Social Support Satisfaction Scale (Olson, 2004; Pereira & Teixeira, 2013)

The instrument assesses satisfaction with social support, with 15 items grouped into the following subscales: Satisfaction with Friends, Satisfaction with Intimacy, Satisfaction with Family and Satisfaction with Social Activities. It is possible to obtain a total score, ranging from 1 to 75, in which higher scores indicate a higher perception of satisfaction with social support. Cronbach’s alpha for the total scale was .85 in the Portuguese version (Pais-Ribeiro, 1999) and in this study .86.

Quality of Life in Alzheimer's Disease – Caregiver Version (Bárrios et al., 2013; Logsdon, Gibbons, McCurry, & Teri, 1999).

The instrument assesses the caregiver's QoL of AD patients, comprising 13 items representative of several domains ("physical health", "energy", "mood", "living situation", "memory", "family", "marriage", "friends", "self as a whole", "ability to do chores", "ability to do things for fun", "money" and "life as a whole"). Scores range between 13 and 52 and a high score indicates better QoL. In the original version the Cronbach alpha was .89, and in this study, the alpha was .86.

Data Analysis

To characterize the sample, frequencies, means, and standard deviations were calculated. Pearson correlation coefficients were performed prior to the regression analysis to assess the associations between independent variables and QoL. To determine the differences on QoL according to caregiving context variables, t-tests for independent samples were performed. Employment status was recoded into a categorical variable (employed vs. unemployed/retired).

The variables significantly associated with QoL were introduced in the regression analyses. In the first step of the hierarchical regression model, the variables age and duration of daily care were introduced since they are caregiving context variables according to the Stress Process Model that influence caregivers' QoL (outcome).

In the second step, the variables patient's memory/behavior problems, caregivers' psychological distress, family satisfaction, and satisfaction with social support were introduced because they were considered an objective primary stressor, a subjective primary stressor, a role strain, and an external resource, respectively, which influence QoL according to the Stress Process Model.

Contrary to what has been hypothesized, spirituality was not introduced in the regression model, because was not significantly associated with QoL. Regarding distress, only the total scale was introduced, due to the multicollinearity between the distress scales (depression, anxiety, and stress). Also, family communication was not entered in the model, because of the multicollinearity with family satisfaction ($VIF > 4$). Therefore, only family satisfaction was introduced because presented a higher correlation with QoL.

Finally, the moderating role of spirituality and satisfaction with social support was tested using the macro Process for SPSS (Hayes, 2013). Since the moderators were both continuous variables, the Johnson-Neyman technique was used (Hayes & Rockwood, 2017; Johnson & Neyman, 1936; Preacher & Hayes, 2008). The graphic representation generated with this technique shows regions of significance for the range of values of the moderator when the relationship between the independent and dependent variable is significant (Hayes, 2013; Hayes & Matthes, 2009; Hayes & Montoya, 2017).

The data were analyzed through the IBM SPSS version 24.0.

Results

Differences in QoL according to Background Caregiving Context Variables

Caregivers who were employed ($t(100) = 2.733, p = .007$, Cohen's $d = .54$), chose the caregiving role ($t(100) = -3.602, p < .001$, Cohen's $d = -.83$), and received help in caring

($t(100) = -2.017, p = .046$, Cohen's $d = -.46$) showed better QoL compared to those who were not professionally active, did not choose the caregiving role and received no help in caring, respectively. There were no significant differences in QoL according to the disease's stage ($t(100) = .401, p = .689$), and being a caregiver for the first time ($t(100) = -.754, p = .453$).

Contributors to QoL

Preliminary analyses included correlations between the variables (hypothesis 2) presented in Table 2.

The hierarchical regression model was significant ($F(6, 95) = 23.699; p < .001; f^2 = 1.494; R^2 = .599$) and explained 59.9% of the variance. In the first step, being a younger caregiver and spent 1 to 12 hours in daily care contributed significantly to better QoL, explaining 14.3% of the variance. In the final model, less memory and behavioral problems in AD patients, lower distress, and more family satisfaction contributed significantly to better caregivers' QoL. Also, age and duration of daily care kept their significant contribution to QoL. However, satisfaction with social support did not contribute significantly to caregivers' QoL (Table 3).

Moderating Role of Spirituality between Family Communication/Family Satisfaction and QoL

Spirituality was a significant moderator in the relationship between family communication and QoL ($\beta = .020, t = 2.407, p = .018$). The positive relationship between family communication and QoL was stronger when spirituality was higher ($\beta = .440, t = 5.225, p < .001$) (Figure 1). The Johnson-Neyman technique showed that the relationship between family communication and QoL was significant when spirituality was -4.07 standard deviations above the mean ($\beta = .1786, p = 0.05$), but was not significant with lower values. However, spirituality was not a significant moderator in the relationship between family satisfaction and QoL ($\beta = .007, t = .782, p = .436$).

Moderating Role of Social Support between Family Communication/Family Satisfaction and QoL

Satisfaction with social support was not a significant moderator in the relationship between family communication and QoL ($\beta = -.0004, t = -.070, p = .944$) nor between family satisfaction and QoL ($\beta = -.002, t = -.452, p = .653$).

Discussion

Results regarding the differences in QoL according to context-caregiving variables revealed that employed caregivers, who chose to care and received help in caregiving showed better QoL. These results are in accordance with those suggested by the literature (Pereira & Soares, 2015). Caregivers with a job reported better QoL, which is in accordance with studies that found that caregivers who spent more time away from the patient, regardless of the activity in which they were involved, reported better QoL (Farina et al., 2017).

Table 2. Relationship between all variables with QoL.

Measures	1	2	3	4	5	6	7	8	9	10	11	12
1. Caregivers' QoL	–	–.324***	–.303***	–.408***	–.464***	–.439***	–.495***	–.498***	.417***	.517***	–.176	.591***
2. Caregivers' Age		–	.376***	.048	.170	.125	.152	.159	.096	.005	.280**	–.339***
3. Duration of daily care			–	.018	.128	.099	.120	.123	.123	.070	.048	–.262***
4. Patient's Memory and behavioral problems				–	.319***	.336***	.232*	.322***	–.113	–.108	.114	–.374***
5. Depression symptoms					–	.855***	.767***	.942***	–.163	–.270**	.281**	–.465***
6. Anxiety symptoms						–	.769***	.949***	–.145	–.251*	.303**	–.347***
7. Stress symptoms							–	.898***	–.130	–.246*	.200*	–.399***
8. Psychological distress (Total)								–	–.158	–.275**	.285**	–.431***
9. Family communication									–	.864***	–.020	.333***
10. Family satisfaction										–	–.104	.396***
11. Spirituality											–	–.162
12. Satisfaction social support												–
M	34.01	53.14		2.23	5.98	7.70	4.70	18.37	40.14	33.71	36.25	49.43
SD	6.17	13.33		.770	3.98	4.46	3.51	11.13	7.95	8.15	10.09	10.62

Note: QoL = Quality of Life; M = Mean; SD = Standard deviation; *p < .05, ** p < .01, *** p ≤ .001.

Table 3. Variables that contribute to caregiver’s QoL.

Model	R	R ²	Adjusted R ²	Standardized error of the estimate	Change Statistics				
					R ² change	F change	df1	df2	Sig. F change
1	.378	.143	.126	5.766	.143	8.258	2	99	.000
2	.774	.599	.574	4.024	.457	27.070	4	95	.000
			B	Error	β	t	p		
1	(Constant)		41.624	2.363		17.615	.000		
	Age		-.113	.046	-.244	-2.431	.017		
	Daily Caregiving Hours		-2.655	1.262	-.211	-2.103	.038		
2	(Constant)		30.931	4.016		7.703	.000		
	Age caregiver		-.071	.034	-.152	-2.076	.041		
	Duration of daily care		-2.542	.906	-.202	-2.807	.006		
	Patient’s Memory/Behavior Problems		-1.850	.578	-.231	-3.200	.002		
	Psychological Distress		-.110	.041	-.199	-2.674	.009		
	Satisfaction with social support		.093	.050	.160	1.855	.067		
	Family Satisfaction		.294	.056	.389	5.285	.000		

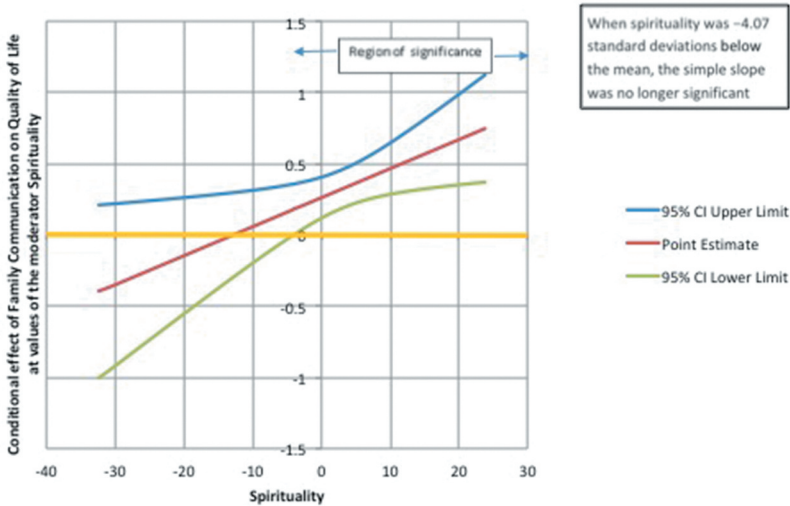


Figure 1. Spirituality as a moderator in the relationship between family communication and QoL.

Caregivers who spent less time in caregiving and received help in the caregiving tasks, as expected, reported better QoL, as other studies have found (Pereira & Soares, 2015). The decision to become a caregiver plays an important role in the caregiver’s adaptation to the patient’s illness and, therefore, caregivers by choice reported better QoL. One may hypothesize that caregivers by choice would experience positive feelings as a result of the caregiving

role, which may attenuate the impact of caregiving stress, promoting caregivers' QoL (Tarlow et al., 2004). Also, choosing the caregiving role may also give the caregiver more time to think and process the demands of the new role they are about to engage and, as a result, being better able to adapt to caregiving tasks.

The patient's AD stage had no impact on caregivers' QoL, which may be explained by the fact that AD patients, in this sample, were all in a moderate/severe disease stage, with significant functional impairment and dependency. One may hypothesize that if the AD's mild stage was included, more variance would have been added to the statistical model that could result in a different outcome. Future studies should confirm this hypothesis. Also, as expected, caregivers who had no experience in caregiving showed more negative outcomes (Koca et al., 2017). Future studies should analyze and compare caregivers of AD patients with more and less experience controlling also AD symptoms.

Regarding the variables that contributed to caregivers' QoL, results are corroborated by the literature revealing that younger caregivers (Raivio et al., 2015; Serrano-Aguilar et al., 2006) that report a lower duration of daily care (Farina et al., 2017), higher family satisfaction (Raivio et al., 2015), and lower distress and perceive less memory and behavioral problems in patients (Kim & Lee, 2014) were associated with better QoL. Also, in the Portuguese context, lower caregivers' distress and patients' neuropsychiatric symptoms were associated with better QoL (Bárrios et al., 2013). The present study showed that the perception of less behavioral problems was associated with better QoL, like other studies have proposed (Bergvall et al., 2011). Sequeira (2013) showed that caregivers of patients with psychological/behavioral problems reported significantly higher levels of burden and lower levels of satisfaction, compared to caregivers of patients with physical dependence. Spousal caregivers of AD patients that are dissatisfied with the marital relationship reported lower psychological well-being (Raivio et al., 2015) and, therefore, impaired QoL.

Finally, spirituality was a moderator between family communication and QoL, but not between family satisfaction and QoL, showing how important this coping strategy might be. In a study conducted by Hodge and Sun (2012), in family caregivers of AD patients, spirituality was associated with higher levels of positive feelings about caregiving and was proposed as a mediator of the relationship between stress and positive feelings about caregiving. Sequeira (2013) also highlighted the role of spirituality as a potential personal coping strategy for caregivers in the Portuguese context since it was found to be associated with QoL (Pereira & Soares, 2015). This finding also suggests that communication and satisfaction toward one's family may not be as similar as one might think in terms of impact on QoL, in caregivers of AD patients. Family communication may be impaired by the demands of caregiving, which requires the caregiver to manage several roles and tasks, in addition to the family tasks (Galvin, 2013). Actually, family communication appears to be problematic in caregivers of AD patients that showed higher levels of burden (Heru, Ryan, & Iqbal, 2004); and thus may result in decreased QoL. Considering that spirituality has been studied in caregivers as a coping strategy to deal with the demands of caring for a patient with AD (Samadi et al., 2015), we may hypothesize that it may be useful to deal with communication in the caregivers' family, helping to maintain QoL. Thus, future interventions to promote caregivers QoL should include family communication and spirituality as targets.

Satisfaction with social support was not a moderator between family variables and QoL in spite of its important role in caregivers of AD patients (Pereira & Soares, 2015; Zhang et al.,

2014). These results may have to do with the fact that the majority of the sample comprised patients' spouses and daughters that reported very high satisfaction with social support and were caregivers of AD patient with few memory and behavioral problems. Future studies should test the moderation hypothesis in a different sample.

Having in mind the Stress Process Model, the results showed that the caregiving-context variables (such as age, professional status, choosing the caregiver's role, receiving help in caring, and duration of daily care); role strains (such as family dissatisfaction); stressors (such as caregivers' psychological distress and patients' memory and behavioral problems) had an impact on the outcome (caregivers' QoL). Resources also influenced caregivers' QoL, although satisfaction with social support, in this sample, was not a predictor of QoL and spirituality was only a moderator between family communication and QoL. The hypothesis that internal resources (spirituality) would moderate between role strains and QoL was only partially confirmed, while the hypothesis regarding external resources (social support) moderating between strains and QoL was not confirmed at all. Thus, the Stress Process Model provided a useful background to study the QoL in caregivers of AD patients raising the possibility that social support and spirituality (coping) may be moderator conditions besides being mediators. Future studies need to pursue this line of research.

Limitations and Future Research

This study has some limitations that need to be acknowledged. The sample size was modest and included mostly women caregivers (daughters or spouses), from the Northern Portugal, with a low level of education, who decided to become caregivers, as well as the exclusive use of self-report measures. Future studies should employ longitudinal designs to assess how caregivers cope, over time, and to understand what psychological dimensions in caregivers are most impacted, as the disease progresses. It would be also important to analyze whether family functioning and family coping mediates the relationship between caregiver burden and QoL. Finally, positive dimensions of caregiving as the sense of meaningfulness and personal growth should also be included and studied as potential moderators in the relationship between caregiver burden and QoL.

Conclusions

The results revealed the importance of interventions for caregivers of AD patients to include coping strategies such as spirituality, given its moderating role, as well as family communication skills. In fact, the results highlighted the importance of including the patient and the caregiver's family, in order to help the family adapt to the caregiving tasks as well as communication skills among all family members in order to support the AD caregiver's since family satisfaction was an important predictor of QoL.

Primary health care should also include regular medical appointments to assess caregivers' psychological distress as the patient's disease progresses and provide training skills to promote caregivers' QoL, over time.

Authors Contributions

MGP was responsible for the study design, data analysis, data interpretation and manuscript review; ARA and DR were responsible for data acquisition, manuscript preparation, and data interpretation; GF and SL were responsible for data analysis, data interpretation, manuscript review. All authors read and approved the final manuscript.

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Conflicts Of Interest

The authors declare no conflict of interest.

Ethical Approval

The study was approved by the Ethical Committee of Tâmega and Sousa Hospital (Ref. number: 18/13-P.CES); Alto Ave Hospital (Ref. number: 65/CES); and S. João Hospital (Ref. number: 166/13_hsj).

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