

Exploring the association between optimism and quality of life among informal caregivers of persons with dementia

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ABSTRACT

Objective: We aimed to analyze the relationship between optimism and quality of life (QoL) among informal caregivers of patients with dementia (PWD).

Design: In this cross-sectional study, a hierarchical multiple linear regression analysis was used to determine the association between optimism and caregiver's QoL after controlling the effect of different covariates, including burden.

Participants: A sample of 130 PWD and their informal caregivers underwent a comprehensive protocol of assessment.

Measurements: Caregivers completed the Battery of Generalized Expectancies of Control Scales, the Zarit Burden Interview, and the World Health Organization Quality of Life-Brief as measure of QoL. Optimism was estimated based on the combination of three expectancies of control, namely, self-efficacy, contingency, and success.

Results: QoL correlated positively with optimism and negatively with burden. Optimism predicted each dimension of QoL, even after controlling for the effect of sociodemographic, care-recipients' clinical covariates, and burden in all models.

Conclusion: Optimism consistently predicted well-being and QoL in informal caregivers of PWD.

Key words: quality of life, optimism, informal caregivers, dementia

Introduction

Approximately, 47 million people worldwide were living with dementia in 2015, and the figure is likely to double in 20 years (Prince *et al.*, 2016). In this context, numerous studies have found a robust relationship between caring for patients with dementia (PWD) and negative health outcomes (Etters *et al.*, 2008). Caring for PWD involves important demands that may lead to exhaustion, frustration, and other adverse reactions among informal caregivers when the situation is maintained over time. In the case of caring for patients with Alzheimer's disease, the degree of

dependence on the caregiver increases progressively and irreversibly, creating a perfect context for the occurrence of stress-related health problems. Not surprisingly, caring for a PWD has been considered even more stressful than caring for a person with a physical disability (Ory *et al.*, 1990).

It is well known that exposure to stress is associated with different health problems through the immune dysfunction (Glaser and Kiecolt-Glaser, 2005; Kemeny and Schedlowski, 2007), although coping strategies can help ameliorate the negative effect of stress on health and well-being (Raggi *et al.*, 2015; Snyder *et al.*, 2015). In the context of caregiving, Pearlin *et al.*'s (1990) stress model underlines the importance of the subjective appraisal of resources to deal with the situation of caring, compared with the objective burden, such as degree of dependency or behavioral disturbances. Therefore, it seems that optimistic people use more problem-focused and adaptive coping strategies (Carver and Scheier, 2014). In

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this study, we adopted a perspective of optimism (also referred as “grounded” optimism) based on an integrated and multidimensional approach of generalized expectancies of control (GEC; Palenzuela *et al.*, 1997; Palenzuela, 2008). From this point of view, optimism may be defined as the conviction of being able to exercise control (self-efficacy component) in an environment perceived as controllable (contingency component), which supports expectancies of goal achievement (success or outcome component). Previous research has found that a higher level of optimism in caregivers predicted less burnout (Contador *et al.*, 2012) and reduced demands of institutional care (Contador *et al.*, 2015). Despite these observations, the relationship between optimism and quality of life (QoL) among informal caregivers remains elusive.

QoL is defined as individuals’ perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectancies, standards, and concerns (The WHOQOL Group, 2008). Previous studies have provided evidence supporting the case for control-related psychological resources and positive emotions (Roepke *et al.*, 2008; Carver and Scheier, 2014) for the management of the adverse effects of caregivers’ role stress. Therefore, strategies to improve optimism or perception of control may improve the psychological adjustment. In this context, optimism may act as a mediator or moderator between known stress-related health risk factors and QoL (Márquez-González *et al.*, 2009; Mausbach *et al.*, 2012). In fact, a protective relationship between optimism and all-cause mortality in old age has already been described (Giltay *et al.*, 2004). However, as far as we know, the role of optimism as a psychological construct in QoL of informal caregivers of PWD remains unknown.

The objective of this study is to analyze the predictive value of optimism on perceived QoL among informal caregivers of PWD. To our knowledge, this is the first study attempting to evaluate this relationship considering the effect of different covariables, such as sociodemographic characteristics, patient’s attributes, care situation, and burden. This research will potentially contribute to the development of interventions aimed at improving the well-being of caregivers of PWD.

Methods

Participants

A convenient sample of 130 informal caregivers (mean age = 58.62 ± 12.45 ; 36 males and 94 females) and their respective patients (mean age

= 77.97 ± 6.02 ; 48 males and 82 females) was recruited through consecutive referrals to the local Association of Family Members of Patients with Alzheimer’s (AFA) in Salamanca (semi-rural area, north western Spain). Informal caregivers who visited the AFA (from January to December 2009) because they were interested in specific adult day-care programs were invited to participate in the study. All caregivers volunteered to participate in the study. Their role was that of primary caregiver, taking on responsibility for any decisions and for the patient’s well-being for at least 6 months. None of the caregivers were receiving specialized psychological support at the time of assessment, and they were living at home with the PWD. All care recipients met the DSM-IV-TR criteria for the diagnosis of dementia, which was corroborated by the general practitioner, and they were susceptible to receiving assistance in the AFA day-care center of Salamanca. A written informed consent was obtained from all the participants. This study was approved by the institutional review board of the AFA (Salamanca), conforming to the provisions of the Declaration of Helsinki.

Measures

Information obtained about PWD included age, gender, education, type of dementia, and time since diagnosis. All patients underwent a standard assessment protocol including the Clinical Dementia Rating (CDR) scale (Hughes *et al.*, 1982) to assess the severity of the syndrome. In addition, the Mini-Mental State Examination (MMSE) (Folstein *et al.*, 1975), the Barthel index (Mahoney and Barthel, 1965), and the Neuropsychiatric Inventory- Brief Questionnaire Form (NPI-Q) (Kaufert *et al.*, 2000) were used to assess the patients’ cognitive status, functional impairment, and psychopathological symptoms, respectively.

All caregivers were also interviewed in one session divided into two parts: a sociodemographic questionnaire and a psychological protocol using instruments developed and/or validated into Spanish. The caregivers’ questionnaire provided sociodemographics (age, sex, and education) and data about context of care (relationship with the patients and duration of caregiving). In addition, the following standardized measures were included in this survey: the Zarit Burden Interview (Zarit *et al.*, 1986), the Goldberg Anxiety and Depression Scale (Goldberg *et al.*, 1988), the Battery of Generalized Expectancies of Control Scales (BEEGC, acronym in Spanish; Palenzuela *et al.*, 1997), and the World Health Organization Quality of Life-Brief (WHOQOL-BRIEF; The WHOQOL Group, 1998; Lucas-Carrasco, 2012).

Assessment of optimism and quality of life

The BEEGC is based on Palenzuela's approach to personal control (Palenzuela *et al.*, 1997). The questionnaire includes 20 items distributed in five GEC-related scales (contingency, self-efficacy, success, helplessness, and luck). Respondents rate their degree of agreement with each statement on a nine-point Likert-type scale ranging from 1 (totally disagree) to 9 (totally agree). Independent scores are obtained by adding the items contained in each scale, which are positively formulated (e.g. high scores on each dimension represent higher levels of this construct). Although each dimension measures different theoretical concepts, we combined the scores to study the targeted psychological construct of optimism (self-efficacy, contingency, and success; range: 3–27), based on the confirmatory factor analysis of Palenzuela *et al.* (1997). Therefore, the scales assess different theoretical constructs, but higher order constructs related to positive control expectancies (e.g. optimism) were obtained by calculating composite scores.

The WHOQOL-BRIEF version (The WHOQOL Group, 1998; Lucas-Carrasco, 2012) intended to produce a profile with four domain scores: physical health (seven items), psychological health (six items), social relationships (four items), and environment (eight items), plus two unscored questions about overall QoL and satisfaction with health. Participants rate how they felt in the domains over the last two weeks on a five-point scale. Domain scores are calculated by multiplying the mean of all the items included within the domain by four. Potential scores for each domain score, therefore, range from 4 to 20. Higher scores indicate higher QoL.

Statistical analyses

Statistical analyses were performed using the Statistical Package for Social Sciences application, version 21.0 for Mac. Sociodemographic and clinical characteristics of groups were expressed as means (*M*) and standard deviation (*SD*). Caregivers with scores above the median (*Mdn* = 78) in the sum of the perceived personal control subscales (self-efficacy, contingency, and success) were categorized as optimistic caregivers (50.8% of the sample), whereas those with scores below the median value in perceived personal control (49.2% of the sample) were considered as non-optimistic. Pearson's correlation was used to analyze the association between quantitative variables. Analysis of variance (ANOVA) and Student's *t*-test (independent samples) were used to determine significant group differences for

quantitative variables. Levene's tests were used to assess the homogeneity of variances for all variables. Only depression and burden scales did not satisfy with this assumption, so corrected *p*-values (equal variances not assumed) for *t*-contrast were considered for these factors. Moreover, Mann–Whitney U tests were also conducted to confirm the statistical significance of the parametric approach for these variables. Then, independent multiple regression models were conducted including optimism (main predictive variable) and QoL dimensions as the outcome variables. The inclusion of covariates (enter method) on each model was based on correlation analysis between the target variables and each QoL dimension. Therefore, the characteristics of attributes of caregivers and patients including optimism, age, education (years), and caring time (months), cognitive status (MMSE scores), functional impairment (the Barthel index), time from diagnosis (months), psychopathological symptoms (NPI-Q score), severity of dementia (CDR score), and burden were included as covariates. The significance adopted in the analysis was $p < 0.05$.

Results

Table 1 shows the characteristics of the sample as a function of caregivers' level of optimism (optimistic vs. non-optimistic).

The groups of caregivers (optimistic vs. non-optimistic) did not differ in age, sex, or years of schooling. However, the percentage of caregivers who were first-degree relatives (spouses or children) was higher (92.03% vs. 69.69%) in the non-optimistic group than in the optimistic one. Second, there were no differences in the characteristics of patients cared for by optimistic versus non-optimistic caregivers, except for the type of dementia. In the optimistic group, 56.06% of the patients had Alzheimer's disease, whereas in the non-optimistic group, this percentage was only 25%. Finally, the optimistic group scored significantly higher than the non-optimistic group in physical, psychological, social, and environmental QoL, and lower in depression, anxiety, and burden. Statistical contrast for depression and burden remained significant using the Mann–Whitney test.

Association between optimism and QoL dimensions

Optimism scores positively correlated with all the QoL dimensions: physical health ($r = 0.424$, $p < 0.001$), psychological health ($r = 0.554$, $p < 0.001$), social relationships ($r = 0.389$, $p < 0.001$), and environment ($r = 0.383$, $p < 0.001$).

Table 1. Characteristics of patients and caregivers as a function of caregivers' level of optimism ($n = 130$)

	OPTIMISTIC CAREGIVERS, $N = 66, M (SD); M/F$	NON-OPTIMISTIC CAREGIVER, $N = 64, M (SD); M/F$	T/χ^2	P
Caregivers				
Age (years)	56.80 (12.73)	60.50 (11.98)	1.70	0.092
Sex (M/F) ^a	21/45	15/49	1.14	0.291
Education (years)	10.42 (4.20)	9.43 (4.05)	-1.36	0.183
Relationship with patient (S/C/O) ^b	14/32/20	23/35/6	9.83	<0.01*
Burden	26.71 (10.35)	34.95 (15.25)	3.59	<0.001**
Depression	0.50 (1.00)	4.94 (3.08)	10.98	<0.001**
Anxiety	3.16 (2.13)	5.13 (2.45)	4.90	<0.001**
Quality of life				
Physical	3.82 (0.39)	3.53 (0.44)	-3.94	<0.001**
Psychological	3.61 (0.38)	3.17 (0.55)	-5.26	<0.001**
Social	3.48 (0.64)	3.15 (0.64)	-2.94	<0.01*
Environmental	3.27 (0.47)	2.98 (0.57)	-3.10	<0.01*
Patients				
Age	77.73 (6.40)	78.22 (5.66)	0.46	0.645
Sex (M/F)	22/44	26/38	0.74	0.397
Education (years)	7.51 (3.58)	8.03 (3.33)	0.85	0.401
Diagnosis (months)	41.20 (25.88)	43.88 (25.29)	0.60	0.550
Caring time (months)	41.46 (22.41)	38.96 (22.16)	-0.64	0.524
Subtype (AD/OD) ^c	37/2	16/48	16.42	<0.001**
Mini-Mental State Examination	17.62 (5.12)	16.96 (5.83)	-0.69	0.492
Barthel index	67.52 (29.90)	60.03 (32.49)	-1.36	0.171
Clinical Dementia Rating (CDR) scale (1/2/3) ^d	25/23/18	22/21/21	0.48	0.793
Neuropsychiatric Inventory (NPI-Q)	9.67 (4.66)	9.02 (4.88)	-0.78	0.440

^aM/F = frequency for males/females.

^bS = spouse; C = child; O = other.

^cAD = Alzheimer-type dementia; OD = other dementias.

^dMild dementia = 1; moderate dementia = 2; severe dementia = 3.

* = < 0.01; ** = < 0.001

Patients' and caregivers' variables associated with QoL dimensions

Caregivers' burden showed negative correlations with all the QoL dimensions: physical ($r = -0.469$, $p = 0.001$), psychological ($r = -0.505$, $p < 0.001$), social ($r = -0.472$, $p < 0.001$), and environmental ($r = -0.494$, $p < 0.001$). Caregiver's age ($r = -0.191$, $p = 0.029$) correlated with physical QoL negatively, whereas caring time showed a positive association with psychological QoL ($r = 0.182$, $p = 0.038$). Patients' educational level was positively associated with caregivers' social ($r = 0.195$, $p = 0.026$) and environmental QoL ($r = 0.187$, $p = 0.033$). Finally, greater dependence ($r = 0.213$, $p = 0.015$) and a longer period of time from diagnostic ($r = -0.023$, $p = 0.023$) were also associated with caregivers' lower scores in environmental QoL.

Prediction of QoL dimensions

Table 2 includes multiple regression models using each dimension of QoL as outcome, and optimism as main predictor. Caregivers' age, years of

education, time of care, burden, and PWD's characteristics (independence, cognitive status, functional impairment, psychological and behavioral symptoms, time from diagnosis, and severity of dementia) were considered as covariates in all models. Optimism remained the best predictor of every dimension of QoL, even after controlling for the effect of all covariates.

Discussion

In this study, we showed that optimism is a significant predictor of QoL among informal caregivers, after controlling for the effect of different covariates. This prediction remained significant for all dimensions, even when burden was considered in all models. Therefore, optimism, defined by the combination of three GECs (contingency, self-efficacy, and success), is a relevant construct for predicting QoL dimensions among informal caregivers. This finding is consistent with previous studies that show the importance of psychological resources for caring of PWD (Márquez-González

Table 2. Regression models for quality of life domains as outcome measures ($n = 130$)

PHYSICAL	B	T	P	95% INTERVAL	ADJUSTED R ²	F	P
Model					0.27	16.81	0.001
Optimism	0.21	2.38	0.019	(0.01/0.012)			
Caregivers' age	-0.14	-1.84	0.067	(-0.010/0.000)			
Burden	-0.35	-4.08	0.001	(-0.017/0.006)			
Psychological							
Model					0.37	26.31	0.001
Optimism	0.36	4.28	0.001	(0.007/0.020)			
Caring time	0.10	1.48	0.141	(-0.001/0.006)			
Burden	-0.32	-3.92	0.001	(-0.019/-0.006)			
Social							
Model					0.24	14.95	0.001
Optimism	0.22	2.45	0.016	(0.02/0.019)			
Patient' education	0.10	1.26	0.207	(-0.011/0.051)			
Burden	-0.33	-3.52	0.001	(-0.025/-0.007)			
Environmental							
Model					0.26	10.18	0.001
Optimism	0.19	0.03	0.030	(0.001/0.015)			
Patient's education	0.03	0.73	0.735	(-0.022/0.032)			
Time from diagnosis	0.01	0.88	0.881	(-0.005/0.005)			
Barthel index	0.15	0.20	0.205	(-0.001/0.007)			
Burden	-0.36	-3.76	0.001	(-0.022/-0.007)			

et al., 2009; Mausbach *et al.*, 2012; Carver and Scheier, 2014). Therefore, optimism may protect caregivers from the effects of anger on their physical health (López *et al.*, 2013), burden (Contador *et al.*, 2012), or even suicide ideation (O'Dwyer *et al.*, 2013).

In this research, optimism predicted QoL in informal caregivers beyond burden and other clinical and sociodemographic variables, such as neuropsychiatric and behavioral symptoms or level of daily functioning, which traditionally have drawn more attention from researchers (Shin *et al.*, 2005; Pinquart and Sörensen, 2007). Optimistic expectancies, such as internal control, self-efficacy, and success, may encourage caregivers to engage in more effective coping skills. Thus, optimism may explain differences in the adaptation to this stressful situation by mitigating the negative consequences of caring for a PWD (Menezes de Lucena *et al.*, 2006).

It seems that non-first-degree relatives were more prevalent in the optimistic group. Potentially, caring for PWD under this condition may be assumed more voluntary, whereas first-degree relatives experience more sense of responsibility or feel trapped by a family caregiving role (Pearlin *et al.*, 1997; Archbold, 1983). Moreover, the influence of sociocultural factors (e.g. cohabitation arrangements or rotation) should also be taken into account to explain this relationship (Rivera *et al.*, 2009). Regarding differences in type of dementia, most optimistic caregivers deal with AD patients

compared to less optimistic ones. More information and resources on AD, currently the most prevalent and researched type of dementia, are probably available compared to other dementias, which implies more control to deal with the caring situation (National Institute on Aging, 2018).

This study may contribute to understanding the positive role of optimism in QoL of informal caregivers, who have been reported to project part of their own QoL onto PWD (Arons *et al.*, 2013). This result supports the need to shift from a patient-focused approach to a combined patient- and caregiver-focused approach for interventions in dementia care. Interventions aiming to improve the QoL of informal caregivers of PWD should consider maximizing caregiver's psychological resources, such as optimism, fostering a subjective appraisal of control over one's life, especially in the presence of chronic conditions that involve dealing with stressors like fatigue or pain (Kurtz *et al.*, 2008). The ability of the informal caregiver to recognize the importance of caring for oneself is essential for themselves and quality of caring received by the PWD.

Our findings highlight the importance of optimism for QoL in family caregivers of PWD beyond subjective (burden) and objective stressors (behavioral disturbances). Hence, Pearlin *et al.* (1990) emphasized the effect of intrapsychic variables (e.g. sense of competence) as mediators on the relationship between the stressors (objective and subjective) and negative outcomes related

to physical or psychological health of caregiving. Considering that optimism prevents subjective overload of family caregivers (Contador *et al.*, 2012), this research suggests that optimism has a moderator effect on the inverse relationship between burden and QoL of family caregivers. The small sample size and sociocultural differences should be considered as potential limitations before generalizing these findings to the whole caregivers' population.

Finally, these results encourage the use of non-pharmacological interventions approaches based on GEC to improve the QoL of PWD caregivers. In fact, this research may help to understand the needs of informal caregivers and contribute to improve their QoL, supporting new intervention strategies based on GEC. Although prevention and reduction of burden is a key element of some interventions programs aimed to support family caregivers of PWD (Parker *et al.*, 2008), the importance of GEC and related coping strategies to prevent the negative effect of stress on family caregivers has been ignored (Chien *et al.*, 2011). Therefore, interventions that foster optimism in caregivers of PWD would improve their QoL. Future research should further explore the relationship between optimism and health outcomes in order to optimize the care and management of PWD. Positive appraisals of the challenges of dementia-caregiving emerge as powerful psychological resources to enhance greater mental and physical health in informal caregivers.

Conflict of interest

None.

Description of authors' roles

P. Ruisoto was responsible for the statistical design of the study, carrying out the statistical analysis, and writing the paper. I. Contador designed the study, collected the data, and wrote the paper. B. Fernández-Calvo formulated the research questions and designed the study. Finally, D. Palenzuela and F. Ramos supervised the data collection, statistical analysis, and writing the final draft of the manuscript.

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