



Coping Strategies and Distress in Patients and Caregivers Dealing with Neurocognitive Disorders

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Abstract

Background and Aims: Quality of life (QoL) is described as the individual's perception of life in relation to the cultural context and value system in which they live, and their objectives, expectations and interests. The aim of the present study is to investigate the perceptions of QoL on the part of patients with Mild Cognitive Impairment (MCI) or mild dementia and on the part of their caregivers, by examining how they are influenced by factors such as anosognosia, coping strategies, perceived stress and caregiver burden.

Methods: QoL was assessed in a sample of 30 patients with MCI or mild dementia and their caregivers using the QoL-AD. Other variables were measured with the AQ-D, PSS-10, COPE-NVI-25 and CBI instruments. We also assessed patients' levels of cognitive impairment with the MMSE.

Results: Patients' QoL ratings were significantly higher than those of their respective caregivers. Patients' perceptions of QoL were predicted by their caregiver's avoidance coping strategy ($\beta = -0.591, p < 0.01$), whereas the caregivers' perceptions of QoL were predicted by their perceived stress levels ($\beta = -0.567, p < 0.01$), the patient's transcendent orientation ($\beta = -0.369, p < 0.05$) and the caregiver's positive attitude coping strategy ($\beta = 0.312, p < 0.05$).

Conclusions: This study shows that perception of QoL is mostly influenced by coping strategies and perceived stress, and that caregivers' dysfunctional coping strategies can affect patients' perceptions of QoL. Our data also highlight the crucial role of the caregiver in the treatment of neurocognitive disorders.

Keywords: Quality of Life; Neurocognitive Disorders; Coping Strategies; Perceived Stress; Caregiver Burden

Introduction

The World Health Organization defines Quality of Life (QoL) as "the individual's perception of their position in life in the context of the culture and the value system in which they live and in relation to their goals, expectations, standards and concerns" [1].

Different medical conditions can negatively impact on QoL, and these certainly include neurocognitive disorders, which profoundly change the lives of the people who are affected and their families.

Individuals with Mild Cognitive Impairment (MCI) or with mild or moderate dementia were found to be able to properly

evaluate their QoL [2]. There is also evidence showing a significant difference between patients' and caregivers' perceptions of QoL [3,4]. Patients' tend to rate their QoL higher than their caregivers do [5, 6], in accord with the "disability paradox" [7]: despite their serious physical or cognitive impairments, patients' perceptions of their QoL are higher than would be expected.

The literature shows that perception of QoL can be negatively influenced by several factors, with lack of autonomy in daily activities, and behavioral and mood disorders (such as depression) the main negative predictors of QoL [8], especially for caregivers and their overall caregiving burden [8-10]. On the other hand, anosognosia (i.e., a lack of awareness) appears to be the factor that most impacts on both patients' and caregivers' perceptions of QoL. Higher anosognosia is usually associated with a better evaluation by the patient and a worse evaluation by the caregiver [3]. Along with anosognosia, caregiver burden is also a factor associated with caregivers' lower perceptions of QoL [6,11-13]. On the other hand, cognitive impairment does not adversely affect the perceptions of QoL of either patients with neurocognitive disorders nor their caregivers [14,15].

Several studies suggest that the ability of patients with neurocognitive disorders to adapt, and the ways they deal with problematic situations may predict and modify their QoL [16]. The use of functional coping strategies would therefore improve adaptation to daily life situations, which in turn would improve perceptions of QoL.

The use of problem-focused coping strategies by caregivers is associated with a slower decline in patients' cognitive functions [17]. On the other hand, dysfunctional strategies, especially avoidance strategies, are closely associated with greater anxiety or depressive symptoms, and higher levels of stress and burden in the caregiver, which inevitably influence their patients' QoL [18]. Notwithstanding this important evidence, only a few studies have so far investigated the potential impact of the coping strategies adopted by people with dementia and caregivers on the perception of patients' QoL.

The purpose of this study is to investigate the perceptions of patients' QoL by caregivers and by individuals with MCI or mild dementia by looking at the role played by various factors, namely awareness of the disease, coping strategies, stress levels,

and caregiver burden. Our hypothesis is that problem-oriented coping strategies are associated with lower levels of stress and less negative perceptions of QoL. In line with the literature, we expect the discrepancy between the perceptions of the caregiver and that of the family member being cared for to be greater when the patient's degree of anosognosia is higher.

Materials and Methods

Participants with MCI or mild dementia ($n = 30$, 16 women and 14 men, mean age 81.8 ± 3.01 years) and their respective caregivers ($n = 30$, 23 women and 7 men, mean age 64 ± 13.6 years) were recruited by the Cognitive Impairment and Dementia Center (CDCD), Department of Medicine, University of Padua. Inclusion criteria were: a diagnosis of MCI or neurocognitive disorder according to standard clinical criteria (NINCDS-ADRDA), a Mini Mental State Examination (MMSE) score between 18 and 26, and care provided by a close relative, such as a spouse, child or sibling. Exclusion criteria were: a history of alcoholism or drug abuse, the presence of a psychiatric disorder (as informed by the caregiver during a preliminary clinical interview), serious communication problems preventing them from giving adequate responses to questions, and other diseases that could compromise inclusion.

After an initial geriatric visit during which the MMSE was administered, all participants were contacted by phone to arrange an appointment. The questionnaires were handed out during a single meeting that patients attended accompanied by their respective caregivers, but were completed individually by patients during an experimental session lasting about 30 minutes. While waiting, caregivers were given a brief explanation then asked to fill in their own questionnaires. The various assessments made are described briefly below.

Cognitive functions

The cognitive functions of participants with neurocognitive disorders were assessed with the MMSE [19], a 30-point screening tool that assesses spatial and temporal orientation, coding and recall of words, attention and calculation, visuospatial skills and language to give an overall cognitive profile. Total scores range from 0 to a maximum of 30, with a score of less than 24 indicating cognitive impairment.

Perception of quality of life

Patients' and caregivers' perceptions of QoL were assessed with the Italian version of the Quality of Life in Alzheimer's Disease instrument QoL-AD [20], a 13-item questionnaire on various aspects of the patient's life. Questionnaires (with the same questions) were administered separately to the caregiver and to the patient. The items are rated on a 4-point Likert scale from 1 "Poor" to 4 "Excellent" with total scores ranging from 13 to 52: the lower the score the poorer the quality of life.

Anosognosia

Patient's anosognosia was measured with the Italian version of the Anosognosia Questionnaire - Dementia AQ-D [21], a 30-item measure of the patient's awareness of his/her deficits in two domains: intellectual functioning (AQ-D A) and behavioral functioning (AQ-D B). Questionnaire (with the same questions) were administered separately to the caregiver and to the patient. The items are rated on a 4-point Likert scale from 1 "Never" to 4 "Always". The level of anosognosia is determined by final differential scores obtained by subtracting the patient's score from the caregiver's score: differential scores equal to or greater than 2 in at least 4 items indicate an anosognosic patient.

Perceived stress

Perceived stress was measured in both patients and their caregivers using the Perceived Stress Scale PSS-10 [22], a self-report 10-item questionnaire that asks the subject how often s/he has felt or thought in a particular way in the last month. The items are rated on a 5-point Likert scale from 0 "Never" to 4 "Very often".

Coping strategies

Participants' coping strategies were measured with the short Italian version of the Coping Orientation to Problems Experienced COPE-NVI-25 [23], a 25-item self-report questionnaire that measures how often the subject uses various coping strategies in difficult or stressful situations. The items are rated on a 6-point Likert scale from 1 "I usually don't" to 6 "I almost always do". Five coping strategies are measured:

- Problem orientation: Use of active planning strategies aimed at solving the problem;
- Transcendent orientation: Religion;

- Positive attitude: Attitude of acceptance and positive reinterpretation of events;
- Social support: Seeking understanding, support and information from others;
- Avoidance strategies: Denial of events, behavioral and mental detachment.

Caregiver burden

The Caregiver Burden Inventory CBI [24] is a 24-item self-report questionnaire for assessing the burden of caregivers caring for people with chronic disease. The items are rated on a 5-point Likert scale from 0 "Never" to 4 "Nearly always". The questions cover 5 dimensions of caregiver burden: objective burden; time-dependence, referring to time demands for assistance; psychological burden, understood as the caregiver's feelings of exclusion from expectations and opportunities; physical burden, which describes the caregiver's feelings of fatigue and health problems; social burden, which describes the caregiver's feelings of role conflict; and emotional burden, which describes the caregiver's feelings of shame or embarrassment caused by the patient.

Statistical analyses

The Kolmogorov-Smirnov test was used to verify the normal distribution of the variables under study. Cronbach's α coefficient was calculated to assess the internal consistency of the patients' and caregivers' responses to the QoL-AD, AQ-D, COPE-NVI-25, and PSS-10, and caregivers' responses to the CBI. The paired sample t-test was performed on the QoL-AD, COPE-NVI-25 and PSS-10 total scores to identify possible differences between the patients' and caregivers' in their perceptions of QoL, and in their coping strategies and perceived stress levels. The Pearson's correlation coefficient r was used to explore the correlations among all the variables of interest. Four stepwise regression analyses were performed to determine the factors associated with the patients' and caregivers' QoL ratings. Two regressions were performed using the patients' QoL-AD scores as the dependent variable: in one model, MMSE score, degree of anosognosia, patient's and caregivers' perceived stress levels and coping strategies, and caregiver burden were included as predictors; in the other model, only MMSE score, degree of anosognosia, patients' perceived stress levels and coping strategies were included as predictors. Another

two regressions were performed using the caregivers' QoL-AD scores as the dependent variable: in one model, MMSE score, degree of anosognosia, patient's and caregivers' perceived stress levels and coping strategies, and caregiver burden were included as predictors; in the other model, only caregivers' perceived stress levels, coping strategies and burden were included as predictors.

Statistical analyses were carried out using SPSS - Statistical Package for the Social Sciences (IBM SPSS Statistics for Windows, version 22.0, 2013).

Results

Internal consistency reliability

Internal consistency was good for all the instruments, except the behavioral functioning domain of the AQ-D (AQ-D B) administered to patients. Cronbach's α coefficient was 0.84 for QoL reported by patients, and 0.89 reported by caregivers. See Table 1 for the other Cronbach's α coefficients.

	Patient	Caregiver
Quality of life in Alzheimer's Disease (QoL-AD)	0.84	0.89
Anosognosia Questionnaire - Dementia (AQ-D)	0.81	0.93
AQ-D A	0.79	0.92
AQ-D B	0.50	0.83
Perceived Stress Scale (PSS-10)	0.85	0.89
Coping Orientation to Problems Experienced	0.81	0.87
Social support	0.81	0.84
Avoidance	0.61	0.73
Positive attitude	0.56	0.74
Problem orientation	0.43	0.77
Transcendent orientation	0.95	0.93
Caregiver Burden Inventory (CBI)		0.95
Objective burden		0.91
Psychological burden		0.92
Physical burden		0.79
Social burden		0.63
Emotional burden		0.76

Table 1: Cronbach's α coefficient for the variables measured.

Table 2 shows the descriptive statistics for the sample. The Kolmogorov-Smirnov test indicated that all the variables measured had a substantially normal distribution ($p > .05$).

	MCI/mild AD (n = 30)	Caregiver (n = 30)
Age, m \pm sd	81.83 \pm 3.018	64.53 \pm 13.6
Education, m \pm sd	8.43 \pm 5.28	11.97 \pm 4.12
MMSE, m \pm sd	23.13 \pm 2.047	
Quality of Life in Alzheimer's Disease (QoL-AD)		
QoL-AD total score, m \pm sd	37.97 \pm 5.97***	28.83 \pm 7.37***
Coping Orientation to Problems Experienced (COPE-NVI-25)		
COPE_social support, m \pm sd	3.93 \pm 1.31	3.36 \pm 1.34
COPE_avoidance, m \pm sd	2.83 \pm 0.81**	2.08 \pm 1.02**
COPE_positive attitude, m \pm sd	4.69 \pm 0.61	4.37 \pm 0.99
COPE_problem orientation, m \pm sd	4.03 \pm 0.69**	4.75 \pm 0.85**
COPE_transcendent orientation, m \pm sd	4.26 \pm 1.65***	2.67 \pm 1.64***
Perceived Stress Scale-10 (PSS-10)		
PSS-10, m \pm sd	8.8 \pm 7.3**	16.13 \pm 8.66**
Caregiver Burden Inventory (CBI)		
CBI_objective burden, m \pm sd		6.33 \pm 4.72
CBI_psychological burden, m \pm sd		5.03 \pm 5.44
CBI_physical burden, m \pm sd		3.92 \pm 4.13
CBI_social burden, m \pm sd		2.1 \pm 2.99
CBI_emotional burden, m \pm sd		2.23 \pm 2.82
CBI_total score, m \pm sd		19.62 \pm 17.87

Table 2: Descriptive statistics of the variables under study.

m \pm sd = mean \pm standard deviation; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Differences between patients and caregivers

The paired sample t-test was used to compare the total QoL-AD scores of patients and their caregivers. Patients' scores were higher than caregivers' scores ($t_{(29)} = 6.61, p < 0.001$; Cohen's $d = 1.36$). Caregivers' perceived greater stress levels than patients did ($t_{(29)} = -3.55, p < 0.001$; Cohen's $d = 0.91$), and significant differences were

also observed between the patients' and the caregivers' coping strategies: patients had higher scores for avoidance strategies ($t_{(29)} = 3.12, p < 0.001$; Cohen's $d = 0.81$) and for transcendent orientation ($t_{(29)} = 4.16, p < 0.001$; Cohen's $d = 0.96$), while caregivers had higher scores for problem orientation ($t_{(29)} = -3.59, p < 0.001$; Cohen's $d = 0.93$). According to Cohen's conventions [25], all these differences are large. Patients and caregivers did not differ in social support strategies ($t_{(29)} = 1.79, p = 0.085$) nor in positive attitude ($t_{(29)} = 1.41, p = 0.17$).

Factors related to patients' perceptions of QoL

Significant Pearson's correlation coefficients were observed between patients' and caregivers' perceptions of QoL ($r = 0.372, p < 0.05$). In addition, patients' perceptions of QoL were negatively correlated with their perceptions of stress ($r = -0.369, p < 0.05$) and the caregiver's tendency to use avoidance strategies ($r = -0.591, p < 0.01$), so that as these last two scores increased, the patient's perception of QoL worsened. According to Cohen's conventions [25,26], the strength of these correlations is medium to high. Patients' perceptions of QoL were not significantly correlated with their coping strategies, caregivers' other coping strategies, caregivers' perceptions of stress, any of the components of caregiver burden, patients' anosognosia, patients' MMSE scores, participation in cognitive stimulation training, nor patients' and caregivers' socio-demographic variables (age, education, cohabitation with the caregiver, and the age and educational level of the caregiver).

Factors related to caregivers' perceptions of QoL

Caregivers' perceptions of QoL showed significant Pearson's correlation coefficients with caregivers' burden, patients' anosognosia, caregivers' coping strategies, caregivers' perceptions of stress, patients' MMSE scores, and patients' participation in

cognitive stimulation training (Table 3). In particular, caregivers' perceptions of QoL were positively associated with patients' MMSE scores, patients' participation in cognitive stimulation training and caregivers' positive attitude, and negatively associated with patients' anosognosia, caregiver burden, caregivers' avoidance coping strategy and perceived stress. These correlations were medium to large.

Variables correlated with caregivers' perceptions of QoL	r	p
CBI_objective burden	-0.478	< 0.01
CBI_psychological burden	-0.506	< 0.01
CBI_social burden	-0.496	< 0.01
CBI_emotional burden	-0.362	< 0.05
CBI_total score	-0.499	< 0.01
Degree of anosognosia	-0.427	< 0.05
COPE_C_avoidance	-0.424	< 0.05
COPE_C_positive attitude	0.415	< 0.05
PSS_C	-0.562	< 0.01
MMSE	0.440	< 0.05
CST	0.372	< 0.05

Table 3: Variables significantly correlated with caregivers' perceptions of QoL.

CBI = Caregiver Burden Inventory; PSS_C = Caregivers' perceived stress; MMSE = Patients' MMSE score; CST = Patients having participated in cognitive stimulation training.

Caregivers' perceptions of QoL were not significantly correlated with their other coping strategies or those of the patient, nor with caregivers' physical burden, and patients' perceptions of stress. There was a high significant correlation between caregivers' perceptions of stress and their avoidance strategies ($r = .522, p < 0.01$).

	Degree of anosognosia	COPE_C_avoidance	PSS_C
CBI_objective burden, r (p)	0.649 (< 0.01)	0.522 (< 0.01)	0.686 (< 0.01)
CBI_psychological burden, r (p)	0.622 (< 0.01)	0.530 (< 0.01)	0.812 (< 0.01)
CBI_physical burden, r (p)	0.623 (< 0.01)	0.608 (< 0.01)	0.769 (< 0.01)
CBI_social burden, r (p)	0.487 (< 0.01)	0.573 (< 0.01)	0.575 (< 0.01)
CBI_emotional burden, r (p)	0.518 (< 0.01)	0.504 (< 0.01)	0.702 (< 0.01)
CBI_total score, r (p)	0.668 (< 0.01)	0.615 (< 0.01)	0.814 (< 0.01)

Table 4: Variables significantly correlated with caregiver burden dimensions.

Degree of anosognosia = Patients' degree of anosognosia; COPE_C_avoidance = Caregivers' avoidance coping strategy; PSS_C = Caregivers' perceived stress; CBI = Caregiver Burden Inventory.

Table 4 summarizes the significant correlations between caregiver burden dimensions and patients’ anosognosia, caregivers’ avoidance coping strategies, and caregivers’ perceptions of stress. There were no significant correlations between caregiver burden and the caregivers’ other coping strategies.

Predictors of patients’ and caregivers’ perceptions of QoL

The stepwise linear regression analysis identified the factors associated with patients’ and caregivers’ perceptions of QoL. Perceived stress and coping strategies were found to be the main factors associated with perceptions of QoL. The regression

model showed that greater perceptions of stress on the part of both patients and caregivers were associated with more negative perceptions of QoL, and greater use of avoidance strategies by caregivers’ was associated with worse perceptions of QoL by patients. Furthermore, caregivers’ perceptions of QoL were negatively associated with patients’ transcendent orientation coping strategy and with the caregivers’ own positive attitude. Patients’ and caregivers’ perceptions of QoL were not significantly associated with anosognosia, MMSE score, caregiver burden, and other socio-demographic variables. See table 5 for the results of the regressions.

Regression model	QoL-AD patient	Patient factors		Caregiver Factors	
		β	p	β	p
1 ^a	Avoidance			- 0.591	< 0.01 **
2 ^b	Perceived stress	- 0.369	< 0.05 *		
	QoL-AD caregiver	Patient factors		Caregiver Factors	
		β	p	β	p
3 ^c	Perceived stress			- 0.567	< 0.01 **
3 ^c	Transcendent orientation	- 0.369	< 0.05 *		
3 ^c	Positive attitude			0.312	< 0.05 *
4 ^d	Perceived stress				< 0.01 **

Table 5: Significant predictors of patients’ and caregivers’ perceptions of QoL.

QoL-AD patient = patients’ QoL-AD scores; QoL-AD caregiver = Caregivers’ QoL-AD scores; * p < 0.05; ** p < 0.01. ^aR² = 0.350. Adjusted for non-significant patient and caregiver factors: coping strategies, perceived stress, patients’ anosognosia levels, patients’ MMSE scores, patients’ cognitive stimulation training, and caregiver burden. ^bR² = 0.136. Adjusted for non-significant patient factors: coping strategies, perceived stress, patients’ anosognosia levels, patients’ MMSE scores, and patients’ cognitive stimulation training. ^cR² = 0.504. Adjusted for non-significant patient and caregiver factors: coping strategies, perceived stress, patients’ anosognosia levels, patients’ MMSE scores, patients’ cognitive stimulation training, and caregiver burden. ^dR² = 0.316. Adjusted for non-significant caregiver factors: coping strategies, perceived stress, and caregiver burden.

Discussion

As stated in the introduction, according to the literature individuals with mild neurocognitive disorders are able to effectively assess their quality of life [2], although their evaluations differ significantly from their caregivers’ evaluations. The aim of this study was to compare patients’ and caregivers’ perceptions

of QoL and to identify the factors that contribute to determining perceptions of QoL.

A significant difference was found between patients’ and caregivers’ perceptions of QoL: specifically, patients reported better QoL than their caregivers did, in line with the literature [6,11,27]. Patients and caregivers likely give importance to

different factors, based on their ages and lifestyles, giving rise to different perceptions of QoL, although the clinical aspects of the disease undoubtedly play an important role.

Caregivers' perceptions of QoL are correlated with clinical factors, such as patients' MMSE scores and their participation in cognitive stimulation training. The positive association with patients' MMSE scores suggests that as these decrease (i.e., the more severe the pathology) their caregivers give a more negative assessment of QoL. These data, however, conflict with what has been reported in several studies [14,15], where no significant relationship between cognitive impairment and the perception of QoL was found. This inconsistency is probably due to the fact that our group of patients had mild dementia, and the correlation is less consistent when the impairment is more severe and is associated with other symptoms of the pathology. Patients' cognitive impairment does not seem to particularly affect their self-reported perception of QoL, although caregivers may give greater importance to cognitive deficits than patients do when assessing QoL, which may also partly explain the more negative perceptions of QoL reported by caregivers.

In this study, caregivers' and patients' perceptions of stress play a crucial role in determining their perceptions of QoL. We may speculate that stress makes the situation more difficult to manage, thus worsening the perception of QoL. In addition to perceived stress, the strategies for coping with it are also important for the perception of QoL. In fact, caregivers' perceptions of QoL, as well as their perceptions of stress, are also predicted by a positive attitude and by their patients' transcendent orientation strategies. Positive attitude is a functional coping strategy for effectively reducing stress, so it may protect against stress. By taking a positive attitude, stress is reduced, and this probably improves the caregiver's perception of QoL as the patient's deficits are perceived as less invasive. Regarding the relationship between caregivers' perceptions of QoL and patients' transcendent orientation, we may speculate that caregivers interpret patients' religiosity as an index of malaise, which leads them to negatively judge their QoL.

It's interesting to note, however, that patients' perceptions of QoL are negatively associated with caregivers' avoidance coping strategy. It may be speculated that caregivers' avoidance strategies negatively affect their relationship with and behavior towards their patients, possibly increasing patients' perceptions of stress, hence negatively conditioning their perceptions of QoL.

The most important result we have obtained is undoubtedly the association between perception of QoL and perceived stress. Coping strategies imply a certain level of perceived stress, which in turn affects the perception of QoL: it is possible that the coping strategies used come into play on an intermediate level between perceived stress and perception of QoL. It is also interesting to note that caregivers' coping strategies influence patients' perceptions: this highlights the importance of taking care of the caregiver and acting on modifiable factors, such as coping strategies, to ensure the well-being of both patient and caregiver.

Limitations

We acknowledge that the present study has certain limitations. Firstly, the sample size: a larger group of individuals with neurocognitive disorders and their caregivers is required to support our results. Furthermore, we did not include participants with severe cognitive impairment nor did we have a control group, which would have allowed us to determine whether the differences between caregivers' and patients' perceptions of QoL were larger than in cases where the assisted family member is not affected by a neurocognitive disorder. Nor did we include measures of mood and behavioral disorders, factors which may influence the evaluation of QoL.

Conclusions

Our findings show that perceptions of quality of life are mostly influenced by coping strategies and perceived stress, and, in particular, that caregivers' dysfunctional coping strategies can affect patients' perceptions of QoL. Our results highlight the importance of multidimensional management that takes into account the clinical and psychological characteristics not just of patients but also of caregivers, who play a crucial role in caring for patients with neurocognitive disorders. We consider that psycho-educational interventions for caregivers would be an effective means of helping them manage stress, with beneficial effects for both caregivers and patients, and suggest they form an integral part of the care of people with neurocognitive disorders.

Conflict of Interest

The authors declare that they have no conflict of interest.

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