Article

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Health self-perception by dementia family caregivers

Sociodemographic and clinical factors

Letice Ericeira Valente[1], Annibal Truzzi[1], Wanderson F. Souza[2], Gilberto Sousa Alves[1], Carlos Eduardo de Oliveira Alves[1], Felipe Kenji Sudo[1], Maria Elisa O. Lanna[2], Denise Madeira Moreira[3,4], Eliasz Engelhardt[1,3], Jerson Laks[1,5]

ABSTRACT

Caring for a demented family member has been associated with burden. Studies concerning health self-perception of family caregivers are still scarce. **Objective:** To investigate caregivers perceived health and to look into relationships with patients and caregivers' sociodemographic and clinical data. **Method:** Dyads of dementia outpatients and family caregivers (n=137) were assessed with Mini Mental State Examination, Functional Activities Questionnaire, Neuropsychiatric Inventory and Clinical Dementia Rating. Caregivers answered Sociodemographic Questionnaire, Beck Depression and Anxiety Inventories, Zarit Burden Interview and Maslach Burnout Inventory. **Results:** Caregivers poor perceived health was associated with emotional exhaustion, burden, depression and anxiety. Logistic regression analyses revealed caregivers' age, anxiety and physical problem as the main predictors of health self-perception. **Conclusion:** Aged family caregivers with anxiety who also report physical problem characterize a group at risk for poor self-perceived health. Evaluation of health self-perception may be useful for designing interventions to improve anxiety and physical health.

Key words: dementia family caregiver, dementia, health self-perception, age, anxiety.

Autopercepção de saúde em cuidadores familiares de pacientes com demência: fatores sociodemográficos e clínicos

RESUMO

Cuidar de familiar com demência tem sido associado a sobrecarga. Estudos sobre autopercepção de saúde em cuidadores ainda são escassos. **Objetivo:** Investigar autopercepção de saúde em cuidadores e relação entre dados sociodemográficos e clínicos de cuidadores e pacientes. **Método:** Díades de pacientes demenciados e cuidadores familiares (n=137) foram avaliados pelo Mini Exame do Estado Mental, Questionário de Atividades Funcionais, Inventário Neuropsiquiátrico e Escala de Avaliação Clínica da Demência. Cuidadores responderam ao Questionário Sociodemográfico, Inventários Beck de Depressão e Ansiedade, de Sobrecarga Zarit e de Burnout Maslach. **Resultados:** Pior percepção de saúde associou-se a exaustão emocional, sobrecarga, depressão e ansiedade. Análise de regressão logística revelou idade, ansiedade e problema físico como principais preditores da percepção de saúde. **Conclusão:** Cuidadores familiares idosos, com ansiedade e problema físico, constituem grupo de risco para pior percepção de saúde. Avaliação da percepção de saúde pode ser útil em intervenções para melhorar ansiedade e saúde física.

Palavras-Chave: cuidador familiar de demenciado, demência, autopercepção de saúde, idade, ansiedade.

Correspondence
Letice Ericeira Valente
Rua Bulhões de Carvalho, 599 / 701
22081-000 Rio de Janeiro RJ - Brasil
E-mail: leticevalente@hotmail.com

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[1] Center for Alzheimer's Disease and Related Disorders, Psychiatry Institute, Federal University Rio de Janeiro, Rio de Janeiro RJ, Brazil; [2] Department of Epidemiology, National School of Public Health, Rio de Janeiro RJ, Brazil; [3] Neurology Institute Deolindo Couto, Federal University Rio de Janeiro, Rio de Janeiro RJ, Brazil; [4] Pró-Cardíaco Hospital, Radiology Service, Rio de Janeiro RJ, Brazil; [5] Researcher 2/National Council of Research (CNPq), Rio de Janeiro RJ, Brazil.

With the increasing life expectancy worldwide, dementia is becoming a major public health challenge, especially in developing countries like Brazil[1]. Due to the progressive loss of mental and physical capacity, persons with dementia require a growing need of supervision and caring over time. In Latin American countries, the majority of patients receive assistance at home[2] and this fact imposes important extra burden on the family constellation.

An important but yet not well explored topic is how familial dementia caregivers perceive their own health. Few studies on this issue have established the poor self-perceived health of family caregivers when compared with caregiver groups for non-demented patients[3]. Also, the worse quality of perceived health profile has been correlated with high levels of burden and burnout in dementia family caregivers[4].

Previous investigations have recognized the poor perceived health as an independent predictor of health related outcomes, such as the increased risk of suicidal ideation and mortality[5,6]. In addition, both the poor perceived health and the presence of chronic diseases have been documented as risk factors for depression among the elderly[7]. On the other hand, a positive health perception has been strongly correlated with healthy conducts, promotion of physical and emotional well-being, earlier improvement from diseases and better longevity[8]. Moreover, some authors have distinguished the influence of personality characteristics on the health perception[9].

The purpose of the present study was to identify which sociodemographic and clinical characteristics (of both patients and caregivers) could influence the caregivers' profile of health self-perception. We hypothesized that the perceived health may differ according to sociodemographic characteristics of the caregiver family members such as educational level, marital status and age, as well as to the presence of physical and emotional problems.

METHOD

A convenience outpatient sample (n=137) of caregivers and demented patients dyads were consecutively examined in a cross-sectional design from January 2008 to March 2010. A multiprofessional group of geriatric psychiatrists, neurologists, one radiologist and one neuropsychologist took part in this evaluation. Dyads composed by patients aged 60 years or more with clinical diagnosis of Alzheimer's disease (AD), vascular dementia (VaD) and mixed dementia (MD) established according to Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV)[10], National Institute of Neurological and Communicative Disorders and Stroke-Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA)[11] and National Institute of Neurological Disorders and Stroke and Association Internationale pour la Recherché et l'Enseignement en Neurosciences (NINDS-AIREN)[12] criteria; and main family care providers over 21-years-old who had the major responsibility for providing care (for at least 10 hours a week) were selected for the present study.

The project was approved by the Ethics Committee of IPUB-UFRJ and all participants provided voluntary written consent after receiving complete information about the purpose of the present research.

Clinical and functional assessment of demented patients

In order to screen for cognitive impairment, we employed the Mini Mental State Examination (MMSE). It is a 30-item scale that addresses five cognitive domains: orientation, registration, attention and calculation, recall and language[13]. The level of autonomy for activities of daily living (ADLs) and the behavioral disorders were measured by the Functional Activities Questionnaire (FAQ) and the Neuropsychiatric Inventory (NPI), respectively. FAQ is comprised by 10 items and ranges from 0-30, with upper scores representing higher severity of dependency[14]. NPI comprises 10 behavior items, each of them scoring from 0-10: delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, loss of inhibition and aberrant motor behavior[15]. Finally, the Clinical Dementia Rating (CDR) was used to rate the severity of dementia[16]. Only patients with CDR equal or greater than 1 (which corresponds to mild dementia) were included in the sample. All clinical and functional instruments administered are already validated in Brazil.

Caregiver evaluation

Self-assessment questionnaires were used to examine the sample of caregivers. Initially, a Sociodemographic Questionnaire produced by the authors was employed to investigate both sociodemographic data (age, gender, marital status, family relationship, scholarship) and questions regarding subjective health status (current physical and emotional complaints). Depressive and anxious symptoms were assessed by using the Brazilian validated version of Beck Depression Inventory (BDI)[17] and Beck Anxiety Inventory (BAI)[18], respectively. Both BDI and BAI are 21-item instruments, scored from 0-3. Burden of care feelings (physical, psychological, social and financial status) were scored using the Brazilian validated version of Zarit Burden Interview (ZBI)[19]. It is a 22-question instrument, scored from 0 (never) to 4 (almost always). ZBI was designed to assess burden of family in dementia care. Also, the Brazilian validated version of Maslach Burnout Inventory (MBI) was used to investigate burnout, defined as a psychological syndrome in response to chronic emotional and interpersonal stressors related to workplace. It is characterized by three dimensions: emotional exhaustion, depersonalization and personal accomplishment. MBI is comprised by 22 items, scored according to the occurrence of symptoms, from 0 (never) to 6 (every day)[20].

Data analysis

Descriptive results were presented as means and standard deviation (SD). T-test was employed to compare groups with and without self-reported physical and emotional problems. One-way Anova and Tukey's tests analyzed the relationship of subjective health status to sociodemographic and clinical variables of caregivers and patients. Chi-square was employed to analyze frequencies of dementia severity and self reported health status.

Logistic regression models were carried out to evaluate which clinical variables were more associated to a poor perceived health status. "Very good/good" and "regular" health composed the baseline group while "very bad/bad" health was used for comparison. All variables which showed to be statistically significant during the bivariate analysis were included in a backwards modeling process. Ordinal logistic models using the three ordinal levels and the traditional logistic regression led to similar results. Only the logistic regression results are reported. Data were analyzed using SPSS statistical package 17.0 and Stata 9.0 (StataCorp, College Station, Tex.).

RESULTS

Table 1 summarizes sociodemographic data of both caregivers and patients. Gender proportions of caregivers differed considerably, the majority being females. Most were married, almost half had over 8 years of education and more than 80% were children or spouses of the patients. Caregivers' mean age was 56.8 (SD=14.0) years and the mean time of care was 3.9 (SD=2.7) years. With regard to the demented patients, most were females, almost half were married, and a greater part presented 4-8 years or over 8 years of education. Their mean age was 76 (SD=6.9) years. The majority of patients was at the CDR=1 stage (n=57; 41.6%), followed by CDR=2 (n=49; 35.8%) and CDR=3 (n=31; 22.6%).

Frequencies of clinical complaints by the caregivers are depicted in Table 2. When asked about the general health self-perception, most caregivers reported it as "very good/good" (54.74%), followed by "regular" (34.31%) and "very bad/bad" (10.95%). The presence of physical and emotional problems was emphasized by the greater part of the subjects. The most prevalent types of emotional and physical problems were anxiety and pain syndrome, respectively. Less than half referred history of psychological/psychiatric treatment, and 25% had been in use of psychiatric medication. In addition, a small proportion of caregivers had at least one clinical hospitalization (non psychiatric) in the last year.

Table 1. Sociodemographic data of caregivers and patients.

	Caregivers % (N)	Patients % (N)
Gender		
Male	19.7 (27)	34.3 (47)
Female	80.3 (110)	65.6 (90)
Marital status		
Married	55.5 (76)	47.4 (65)
Single	21.9 (30)	10.2 (14)
Divorced	18.2 (25)	1.4 (02)
Widow	4.4 (6)	40.1 (55)
Years of education		
<4	12.4 (17)	18.9 (26)
4-8	41.6 (57)	40.1 (55)
>8	46.0 (63)	37.2 (51)
Relationship with patient		
Children	48.9 (67)	
Spouse	32.1 (44)	
Brother/sister	10.2 (14)	
Others	8.8 (12)	

Table 2. Frequencies of caregivers' clinical complaints.

	Yes (%)	No (%)
Clinic medical (non psychiatric) Hospitalization in the last year	9.5	90.5
Presence of physical problem	53.3	46.7
Pain syndrome	50.68	49.32
Unexplained medical complaint	21.91	78.09
Metabolic syndrome	20.54	79.46
Others	12.32	87.68
Presence of emotional problem	78.1	21.9
Anxiety	56.2	43.8
Irritability/impatience	40.9	59.1
Sadness	34.3	65.7
Fatigue/discouragement	32.8	67.2
Death wish	8.8	91.2
History of psychological/ psychiatric treatment	33.1	66.9
Use of psychiatric medication	24.1	75.9

The "very bad/bad" health profile was reported by older caregivers who also presented higher symptoms on burden, depression, anxiety and emotional exhaus-

Table 3. Relationship of subjective health status and clinical variables[a].

	Very bad/bad (N=15)	Regular (N=47)	Very good/good (N=75)	F	p-value
Patients					
MMSE	13.5 (8.8)	15.9 (6.9)	15.4 (6.8)	0.65	0.53
NPI	23.7 (19.4)	21.9 (17.0)	21.6 (19.6)	0.08	0.93
Functional evaluation (Pfeffer)	21.7 (9.2)	20.9 (7.9)	19.4 (8.4)	0.76	0.47
Caregivers					
Age*	65.8 (12.8)^{1}	60.0 (13.7)^{2}	53.0 (13.2)^{1,2}	7.74	0
Burden (Zarit)*	43.3 (11.4)^{1}	37.3 (16.9)	32.9 (14.7)^{1}	3.46	0.03
Depression*	14.9 (9.5)^{1}	13.5 (9.0)^{2}	7.7 (7.4)^{1,2}	9.69	0
Anxiety*	14.9 (11.9)^{1}	10.9 (9.1)^{2}	8.6 (8.4)^{1,2}	11.31	0
Emotional exhaustion*	30.2 (17.9)^{1}	24.1 (14.5)	18.7 (14.3)^{1}	4.56	0.01
Personal accomplishment	34.9 (9.0)	32.7 (14.2)	37.2 (9.7)	2.25	0.11
Depersonalization	4.5 (4.7)	6.1 (6.9)	4.1 (5.0)	1.70	0.19

*Statistically significant; [a]Equal symbols represent statistical differences among groups; MMSE: Mini Mental State Examination; NPI: Neuropsychiatric Inventory.

Table 4. Patients and caregivers' clinical characteristics in relation to presence of emotional and physical problems.

		Emotional problem[1]			Physical problem[1]		
	Total (N=137)	Yes (N=107)	No (N =30)	p value	Yes (N=72)	No (N=63)	p value
Patients							
MMSE	15.3 (7.1)	15.1 (7.2)	16.3 (6.6)	0.36	15.2 (7.8)	15.3 (6.2)	0.92
NPI	21.9(18.6)	22.3 (18.2)	20.5 (20.2)	0.66	22.2 (17.2)	20.3 (18.2)	0.53
Functional evaluation (Pfeffer)	20.2 (8.3)	20.7 (8.2)	18.3 (8.6)	0.18	22.2 (8.0)	18.8 (8.6)	0.08
Caregivers							
Age	56.8(14.0)	57.1(13.2)	55.4(16.7)	0.56	60.0(14.4)	53.6 (12.6)	0
Burden of care	35.6(15.4)	38.9 (15.4)	23.6 (8.0)	0.00	37.9 (14.9)	32.4 (15.5)	0.04
Anxiety (BAI)	8.6 (8.4)	10.2 (8.6)	2.8 (3.6)	0.00	11.0 (9.2)	6.0 (6.6)	0
Depression (BDI)	10.5 (8.7)	12.2 (8.9)	4.4 (4.1)	0.00	12.4 (8.7)	8.4 (8.4)	0.01
Emotional exhaustion (Burnout)	21.9(18.6)	25.3 (15.0)	9.9 (8.1)	0.00	24.5 (15.5)	18.6 (14.4)	0.03
Depersonalization (Burnout)	4.8 (5.7)	5.3 (6.2)	3.4 (3.8)	0.06	4.4 (5.0)	5.5 (6.5)	0.28
Personal accomplishment (Burnout)	35.4(11.6)	35.2 (11.7)	36.0 (11.2)	0.76	35.2 (11.6)	35.5 (11.7)	0.90

[1]Mean (Standard Deviation); MMSE: Mini Mental State Examination; NPI: Neuro Psychiatric Inventory; BAI; Beck Anxiety Inventory; BDI: Beck Depression Inventory.

tion (Table 3). The presence of physical and emotional problems was associated with the same variables mentioned above. Caregivers with physical problems were older than those without, but no significant age differences were found for those with or without emotional problem (Table 4).

Moderate dementia caregivers presented statistically significant (p value=0.02) higher burden (mean=39.7; SD=15.8) than care providers of dementia early stage (mean=31.6; SD=14.7); likewise, higher indices of emotional exhaustion were reported by moderate dementia caregivers (mean=24.9; SD=15.4) in comparison to dementia at early stage (mean=18.3; SD: 14.5). However, this difference only reached a trend of statistical significance (p value=0.07). Caregivers with "very bad/bad" health perception (n=15) were mostly referenced to the mild dementia group (n=6, n=40%). They were followed by 33.3% (n=5) who assisted severe dementia patients and 26.7% (n=4) of moderate stage. However differences in these frequencies were not statistically significant (p value=0.534, chi-square: 1.254, df =2).

A multiple logistic regression analysis was performed with all statistically significant variables during the bivariate analysis. The backwards modeling showed that anxiety (β=0.07, $p<0.05$), age (β=0.05, $p<0.05$) and presence of physical problem (β=2.13, $p<0.05$; R^2=0.22) remained the most significant characteristics associated to a poor perceived health. Presence of emotional problem (β=0.38, p=0.76), as well as burden (β=0.16, p=0.58), depression (β=0, p=0.91) and emotional exhaustion (β=0, p=0.94) were no longer associated with poor health status while controlling for presence of physical problem.

DISCUSSION

This study has investigated the variables associated with health self-perception of dementia family caregivers. Our main finding was that caregivers' anxiety, age and also presence of physical problem were the most significant independent predictors of the poor health.

Ours results revealed that approximately 45% of caregivers rated own general health as "regular" or "very bad/bad". This prevalence is slightly higher than the found by Mannion's[21] study, which indicated nearly 40% of Alzheimer informal caregivers who reported their health as "fair" or "poor".

Anxiety was an independent variable associated to caregivers' poor health. Our result has agreement with a study on families caring for Alzheimer's disease patients. In this study, a significant correlation between anxiety disorder and poor self-reported health in caregivers was also found[22]. Other study with elderly population found similar results[23]. Anxiety in the elderly is however an issue which deserves more studies and attention.

We found that being older was strongly associated with physical health complaints, even though there was not relationship between age and presence of emotional problem. After we adjusted for the presence of physical problem, the model revealed that age along with physical problem remained independently associated to a poor health. The association of age with negative health self-perception has correspondence with previous researches on dementia family caregiving[21-24]. Likewise, our findings are supported by authors[25] that also established the connection between physical complaints and health perception among elder inpatients. In addition, the high prevalence of pain syndrome among caregivers in our sample agrees with Baumgarten's et al.[26] findings who have reported a significantly higher level of physical symptoms in dementia caregivers, especially pain complaints, when compared with non-caregivers.

It ought to be noted that even though the caregivers' emotional problem did not influence the poor health on regression analyses models, our results revealed that anxiety predicted the poor health. Moreover, anxiety was the most prevalent type of emotional problem among caregivers in the present study.

Contrary to other studies, ours has failed to find any influence of patients' clinical characteristics on the caregivers' self-rated health. The literature on this theme indicated the strong association of neuropsychiatric disorders with caregivers' health perception and stress[27]. A possible explanation for our results may be the lower prevalence of care recipients' behavioral neuropsychiatric symptoms. Furthermore, our sample was relatively heterogeneous, with possible or probable Alzheimer's disease (62.8%; n=86) being the most prevalent dementia diagnostic, whereas vascular and mixed dementia corresponded to 16.8% (n=23) and 20.4% (n=28), respectively. This heterogeneity might have favored a scattered prevalence of behavior disturbances, without any typical pattern. Additionally, the fact that subjects were recruited from a reference psychogeriatric service with an interprofessional team would be another factor to explain the mentioned low prevalence of patients' neuropsychiatric symptoms.

Few studies, particularly in Brazil, examined the health self-rated among dementia caregivers. One Brazilian study developed by Gratao[28] et al. identified higher levels of physical and emotional burden among caregivers of early and late dementia than in moderate dementia, even though this difference was not statistically significant. Contrasting to this study, ours revealed an atypical standard with higher burden and a trend to higher emotional exhaustion in moderate dementia caregivers comparing to the group of mild dementia. On the other hand, we found that the "very bad/bad" health status was more often among caregivers of mild and severe dementia than on moderate dementia, even though this difference was not significant statistically. Therefore, a better investigation regarding the relationship between severity of dementia and health perception is required.

Our study presents some limitations that should be exposed. We had a small sample size and no control groups for further comparisons, and the cross-sectional design precludes any conclusions on the causality of the associations. In addition, in our sample, the high level of education (of both caregivers and patients) was classified as over 8 years. Nevertheless, according to the Brazilian educational model, it is more appropriate to consider over 11 years as high education level. Also, caution should be taken to generalize our conclusions, since our data were drawn from an outpatient sample from a specialized university center.

Subjective health evaluation is a reliable and valid method equivalent to more complex health measures[23], so that in comparison to objective health variables, the self-rated health has more influence on the health care frequency and medical consultations[29]. Additionally, the negative health self-perception has been recognized as a risk factor for difficulties in the ability to provide care with potential negative effects on the patient[30]. Thus, further longitudinal studies are warranted for the understanding of factors contributing to health self-perception of caregivers so as to add evidence for specific therapeutic interventions and support focused on family caregivers and patients' wellbeing.

In conclusion, aged family caregivers with higher levels of anxiety who also report the presence of physical problem characterize a group at risk for poor self-perceived health. The evaluation of caregivers' health perception may be useful for designing interventions to improve their anxious symptoms and physical health. This study may serve to further develop health professionals' awareness on health problems of dementia familial caregivers.

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