

Burnout in a sample of Alzheimer's disease caregivers in Brazil

Annibal Truzzi*
Wanderson Souza**
Erika Bucasio**
William Berger**
Ivan Figueira**
Elias Engelhardt*
Jerson Laks*

* Center for Alzheimer's disease and
Related Disorders, Institute of Psychiatry,
Federal University of Rio de Janeiro

** Institute of Psychiatry, Federal University
of Rio de Janeiro

BRAZIL

ABSTRACT – Background and Objectives: Caregiver burden has been associated to both caregiver and patient factors, but little is known about their relationship to burnout. We aimed at investigating burnout correlations to the sociodemographic and clinical variables of a sample of caregivers of Alzheimer's disease (AD) outpatients.

Methods: AD patients (n=69) and their caregivers completed a sociodemographic questionnaire, Maslach Burnout Inventory, Beck Depression and Anxiety Inventories. Patients were administered the Mini Mental State Examination, the Neuropsychiatric Inventory, Clinical Dementia Rating and the Functional Activities Questionnaire. Burnout and each dimension (emotional exhaustion, depersonalization, and reduced personal accomplishment) were correlated to caregivers' sociodemographic characteristics, burden of care, anxious and depressive symptoms as well as to the patients' behavioral, functional and cognitive profile.

Results: Burden of care was the only variable that associated to caregiver burnout. Emotional exhaustion was the most prevalent dimension and associated to all caregivers' and patients' clinical variables.

Conclusions: Caregiver burden associated to burnout, and emotional exhaustion is the dimension mostly associated to dementia severity and psychiatric morbidity in caregivers.

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Introduction

Caregiving of dependent aged individuals is a major public health issue worldwide. Since the eighties the elderly population in developing countries is growing fast, with approximately 14.5 million subjects aged 65 years or more living in Brazil nowadays. Consequently, the Brazilian society is facing the burden of chronic and degenerative disorders including Alzheimer's disease (AD) which prevalence rate has been estimated as 7.1%^{1,2}.

Burden of care in dementia represents a chief source of chronic stress to caregivers^{3,4}. A recent Brazilian study on the issue found high levels of psychological distress, exhaustion stress, anxiety, depression, and hopelessness in dementia caregivers although the dementia subtype of the patients was not assessed⁵.

The combination of chronic stress and loss of social contacts leads to an increase in caregiver risk of mental and physical diseases. Depression and anxiety are frequently seen in AD caregivers, with a depression prevalence ranging from 30% to 55%^{6,7}. Furthermore, the chronic stress involved in constantly strenuous tasks make caregivers especially vulnerable to burnout.

Burnout is a psychological syndrome in response to chronic interpersonal stressors at the work environment. Burnout is usually viewed as having three dimensions, namely emotional exhaustion, depersonalization or cynicism, and reduced personal accomplishment. Emotional exhaustion is the feeling of being overextended and being depleted of one's resources. Depersonalization represents a detached response towards work, whereas reduced personal accomplishment refers to feelings of incompe-

tence and lack of achievement at work. It is worth mentioning that burnout research began in caregiving and human services occupations in which work involved the presence of a care recipient and a provider⁸.

There is little information correlating burnout to the burden of care, the anxious and depressive symptoms, as well as to the cognitive, functional, and neuropsychiatric status of AD patients. The purpose of this study is to correlate burnout, including each dimension individually, to the sociodemographic and clinical characteristics of AD patients and their caregivers.

Methods

Sample

A convenience outpatient sample of 69 caregiver and AD patient dyads were consecutively included in this cross-sectional study. Patients were diagnosed as possible or probable Alzheimer's disease according to the National Institute of Neurological and Communicative Disorders and Stroke – Alzheimer's Disease and Related Disorders Association⁹ and the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition¹⁰ criterias. Caregivers were older than 18-years-old and both formal and informal caregivers were accepted. Informal caregiver is defined as the one who provides care without pay and whose relationship to the care recipient is due to personal ties, whereas formal caregiver refers to a professional, paraprofessional, or volunteer associated with a service system who provides care at home, in community agencies, institutions, or residential facilities^{11,12}.

Instruments

Clinical, functional, and behavioral data of AD patients were assessed using the following instruments.

Clinical Dementia Rating (CDR)

CDR ranges from 0 for healthy people, 0.5 for questionable dementia and 1, 2 and 3 for mild, moderate and severe dementia as defined in the scale. The total rating is made from the sum of boxes which represents an aggregate score of each individual's area¹³. We employed the validated Brazilian Portuguese version of the CDR¹⁴.

Functional Activities Questionnaire (FAQ)

The FAQ is a 10-item scale that assesses instrumental and basic functional capacities in older people, each rated on a four-point scale (0 being normal and 3 incapable) and the maximum score is 30 points (severely disabled)¹⁵. The FAQ has been recommended as an useful instrument to assess functional abilities in the elderly Brazilian population¹⁶.

Mini Mental State Examination (MMSE)

The MMSE is probably the most widely used measure of cognitive function. The MMSE has a maximum score of 30 points, with different domains assessed: orientation to time and place (10 points), registration of 3 words (3 points), attention and calculation (5 points), recall of 3 words (3 points) and language (8 points)¹⁷. The MMSE version used in the study has been translated and validated to Brazilian portuguese¹⁸.

Neuropsychiatric Inventory -10 (NPI)

The NPI is a brief interview assessing 10 behavioral disturbances: delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy and aberrant motor

behavior. Severity and frequency are independently assessed. It is scored from 1 to 120¹⁹. Recently, the Brazilian Portuguese version of the NPI was proved to be a reliable instrument for the evaluation of neuropsychiatric symptoms in AD Brazilian patients²⁰.

The socio-demographic and clinical status of caregivers were assessed by means of the tests described below.

Sociodemographic Questionnaire

A brief self-administered sociodemographic questionnaire was developed by the authors in order to collect general sociodemographic data (age, gender, marital status, family relationship, scholarship and time as caregiver) from the caregivers.

Beck Depression Inventory (BDI)

The BDI is a 21-item self-rating scale that covers a variety of depressive symptoms including feelings of sadness, concerns about the future, suicidal ideation, tearfulness, sleep, fatigue, interests, worries about health, sexual interest, appetite, weight loss and general enjoyment. Each item is rated 0, 1, 2 and 3 denoting increasing severity of symptoms²¹. The Brazilian version of the BDI validated by Gorestein and Andrade²² were employed.

Beck Anxiety Inventory (BAI)

It consists on a self-administered instrument with 21 items that covers the most frequently anxiety symptoms seen in clinical practice. Each item is scored 0, 1, 2 and 3 denoting increasing severity of symptoms²³. The Brazilian Portuguese validated version of the BAI was administered²⁴.

Maslach Burnout Inventory (MBI)

The MBI consists of a 22-item self-rating scale concerning the 3 dimensions of burnout:

emotional exhaustion (9 items), depersonalization (5 items) and personal accomplishment (8 items). Frequency on each item is scored from 0 (never) to 6 (every day)²⁵. Burnout is defined as the presence of high scores in both emotional exhaustion and depersonalization subscales, and low score in the personal accomplishment subscale. A cut-off score of 26 or more indicates the presence of high emotional exhaustion, 9 or more of high depersonalization and 33 or less of diminished personal accomplishment. The Brazilian Portuguese version of MBI, as well as the cut-off scores, adapted by a previous study performed in Brazil were employed²⁶. Recently the MBI was proved useful in studies with caregivers of old people with dementia²⁷.

Burden Interview (BI)

This is an interview developed for the assessment of burden of caregivers in caring for individuals with dementia. It is a 22-item instrument rated by self-report and scored according to frequency²⁸. The Brazilian version validated by Taub *et al.*²⁹ was administered.

Approval for the study was granted by the Ethics Committee of the Federal University of Rio de Janeiro and all the participants signed the informed consent forms prior to any procedure.

Statistical Analysis

Results were expressed as means and standard deviation (SD). Mann-Whitney analyses were performed to compare both patients and caregiver's socio-demographic, cognitive, functional, and clinical characteristics according to the presence or not of burnout and its dimensions. Spearman's rank correlation was used to assess the relationship of burden and burnout with the variables mentioned above. Differences

were considered statistically significant at $p \leq 0.05$. SPSS version 10 was used for data entry and analysis.

Results

The majority of caregivers were middle-aged married daughters, who had at least elementary scholarship and a mean time as caregivers of 3.5 (SD = 2.7) years. The mean NPI caregiver's distress was 7.5 (SD = 7.9). Most patients exhibited a CDR 2 (n = 29; 42%), which corresponds to a moderate level of the dementia. The socio-demographic characteristics of caregivers and the clinical profile of both caregivers and patients are summarized in Tables I and II.

Burnout was experienced by 6% (n = 4) out of the 67 caregivers who agreed to answer the MBI. Emotional exhaustion was the most prevalent dimension (n = 32; 47.8%), followed by depersonalization (n = 19; 28.4%), and reduced personal accomplishment (n = 19; 28.4%).

Burden of care was the only variable that independently associated to the presence of burnout in caregivers ($p < 0.02$). Patients' and caregivers' clinical data and their relations to burnout are described Table II.

Among all burnout dimensions, emotional exhaustion was highly associated to all clinical variables ($p < 0.05$). Caregivers who experienced emotional exhaustion also exhibited higher levels of depersonalization and reduced personal accomplishment ($p < 0.05$). The presence of depersonalization was associated significantly to higher scores on the NPI, the BI and the emotional exhaustion dimension ($p < 0.05$). Patients' and caregivers' clinical data and their associations to burnout dimensions are summarized in Table III.

Table I
Caregivers' sociodemographic data

	%(N)
Caregiver Gender	
Male	14.5 (10)
Female	85.5 (59)
Caregiver Marital Status	
Married	49.3 (34)
Single	26.1 (18)
Divorced	20.3 (14)
Widow	04.3 (04)
Level of Education	
Elementary School	40.6 (28)
High School	29.0 (20)
College	30.4 (21)
Relationship	
Children	43.5 (30)
Spouse	27.5 (19)
Distant relative/formal caregiver	23.2 (16)
Siblings	05.8 (04)

Table II
Patients' and caregivers' characteristics in relation to caregiver burnout

	Total (N=69) ¹	Burnout ²		p-value
		Yes (N=4)	No (N=63)	
Patients				
MMSE	12.5 (6.5)	14 (7.5)	12.4 (6.4)	0.62
NPI	20.5 (17.2)	34.5 (25.9)	19.9 (16.4)	0.19
FAQ	22.4 (8.2)	20.5 (8.4)	22.4 (8.2)	0.71
Caregivers				
Age (years)	56.9 (13.8)	54.3 (17.4)	57.1 (13.9)	0.53
Time as Caregiver (years)	3.5 (2.7)	2.5 (0.6)	3.6 (2.8)	0.4
BI	35 (16)	48.5 (7.8)	34 (15.9)	0.02
BAI	6.5 (7.9)	7.8 (7.5)	6.4 (8.1)	0.56
BDI	9 (7.8)	13 (8)	8.4 (7.3)	0.18

* $p < 0.01$

¹ Mean (Standard Deviation)

² Two participants refused to answer MBI

MMSE = Mini Mental State Examination

NPI = Neuropsychiatric Inventory

FAQ = Functional Activities Questionnaire

BI = Burden Interview

BAI = Beck Anxiety Inventory

BDI = Beck Depression Inventory

Table III
Patients' and caregivers' characteristics in relation to burnout dimensions

	Total (N = 69) ¹	Emotional Exhaustion ^a		Burnout Dimensions ² Depersonalization ^a		Personal Accomplishment ^a	
		Yes (N = 32)	No (N = 35)	Yes (N = 19)	No (N = 48)	Yes (N = 19)	No (N = 48)
Patients							
MMSE	12.5 (6.5)	10.6 (6.0)*	14.3 (6.4)	13.7 (6.1)	12.0 (6.6)	12.4 (6.1)	12.6 (6.6)
NPI	20.5 (17.2)	25.5 (18.2)*	16.5 (15.2)	25.0 (14.7)*	19.1 (17.9)	20.6 (15.7)	20.9 (17.9)
FAQ	22.4 (8.2)	24.3 (6.7)*	20.3 (9.0)	22.9 (6.9)	22.0 (8.7)	19.9 (8.6)	23.2 (7.9)
Caregivers							
Age (years)	56.9 (13.8)	58.3 (15.2)	55.6 (12.8)	60.2 (13.9)	55.6 (13.9)	57.0 (15.0)	56.9 (13.7)
Time as Caregiver (years)	3.5 (2.7)	3.78 (2.7)	3.2 (2.7)	3.6 (1.8)	3.5 (3.0)	3.6 (2.5)	3.5 (2.9)
BI	35 (16.0)	42.8 (16.1)**	27.9 (12.2)	42.5 (20.0)*	31.8 (12.9)	38.2 (15.4)	33.7 (16.1)
BAI	6.5 (7.9)	9.3 (3.9)**	3.9 (5.5)	6.8 (5.7)	6.4 (8.8)	7.5 (10.5)	6.1 (6.9)
BDI	9.0 (7.8)	11.6 (8.6)**	5.6 (4.7)	10.5 (7.3)	7.9 (7.3)	10.4 (9.6)	7.9 (6.2)
Depersonalization ^a	6.3 (6.5)	7.8 (8.0)*	5.0 (4.5)	—	—	6.1 (5.6)	6.4 (6.9)
Emotional Exhaustion ^a	23.5 (14.9)	—	—	30.11 (14.6)*	20.9 (14.3)	27.6 (15.9)	21.9 (14.3)
Personal Accomplishment ^a	37.5 (10.5)	35.6 (8.9)*	39.3 (11.6)	36.3 (11.4)	38.0 (10.2)	—	—

* $p < 0.05$

** $p < 0.01$

¹ Mean (Standard Deviation)

² Two Participants refused to answer MBI

MMSE = Mini Mental State Examination

NPI = Neuropsychiatric Inventory

FAQ = Functional Activities Questionnaire

BI = Burden Interview

BAI = Beck Anxiety Inventory

BDI = Beck Depression Inventory

^aMBI = Maslach Burnout Inventory

Correlations among burnout dimensions and other variables showed that emotional exhaustion was highly associated to burden of care and to depressive and anxious symptoms in caregivers. Also, there was a high correlation between burden of care and anxious symptoms in caregivers. We found statistically significant but not strong associations between depressive symptoms and depersonalization, depressive symptoms and personal accomplishment, and emotional exhaustion and patients' behavioral symptoms. There was also a statistical significant but weak association of caregiver age with time as caregiver, anxiety and depersonalization. Other weak associations were found between burden of care and depressive symptoms, and the former and depersonalization. Table IV further depicts the correlations of caregivers and patients variables with the burnout dimensions.

Discussion

The present study found that burden of care was the most significant factor associated to burnout in our sample. Additionally, emotional exhaustion was the most prevalent burnout dimension and was related to the cognitive, functional, and behavioral profile of patients and to the presence of depression, anxiety and burden of care in caregivers. The presence of emotional exhaustion associated to higher levels of cynicism in caregivers. Depersonalization was associated to patients' behavioral problems and to caregiver burden.

The observed prevalence of burnout was lower than the one found in the only

Table IV
Correlations between patients' and caregivers' characteristics

	Age	Time as caregiver	BI	BDI	BAI	Deperson- alization ^a	Emotional Exhaustion ^a	Personal Accomplishment ^a	MMSE	NPI	FAQ
Age	1										
Time as caregiver	0.33**	1									
BI	0.21	0.25	1								
BDI	0.22	0.10	0.36**	1							
BAI	0.31*	0.19	0.48**	0.66**	1						
Depersonalization ^a	0.27*	0.14	0.26*	0.25*	0.20	1					
Emotional Exhaustion ^a	-0.02	0.11	0.61**	0.43*	0.44*	0.21	1				
Personal Accomplishment ^a	0.60	-0.05	-0.18	-0.21	-0.14	0.01	-0.35**	1			
MMSE	0.23	0.07	0.08	-0.04	-0.04	0.14	-0.24	-0.02	1		
NPI	-0.10	-0.09	0.18	0.06	0.02	0.23	0.31*	-0.03	-0.12	1	
FAQ	-0.07	-0.05	-0.09	0.14	0.10	-0.04	0.21	0.20	-0.66**	0.36**	1

* $p < 0.05$
 ** $p < 0.01$
 a MBI = Maslach Burnout Inventory
 NPI = Neuropsychiatric Inventory
 FAQ = Functional Activities Questionnaire
 MMSE = Mini Mental State Examination

other study in the literature³⁰ which yielded a prevalence of 17.4% in a community sample of informal caregivers of demented patients. As shown in our study, they also observed a strong association between subjective burden, particularly limitation in social life, and burnout. It ought to be mentioned, however, that some differences in the study design and in the samples preclude the comparison between the data drawn from the two studies.

Emotional exhaustion is the core burnout dimension and is directly associated to high levels of work overload³¹. Given that AD is a degenerative, progressive condition, it is reasonable to assume that this dimension is the most commonly reported by caregivers of patients who are more cognitively and functionally impaired, whose tasks turn out to be increasingly demanding. The fact that emotional exhaustion was associated to the patients' severity of neuropsychiatric symptoms in the present study supports the relationship between high levels of caregiver stress and patient's behavioral problems³. A wide body of literature states that caregivers of AD patients are at a higher risk for depression and anxiety³²⁻³⁴. Although our study does not allow to draw causal relationships because of its cross-sectional design, we found statistically significant although moderate correlations among depression and anxiety with emotional exhaustion. Further longitudinal studies will allow to infer whether burnout or any of its dimensions is indeed a risk factor for depression and anxiety in AD caregivers.

High demands in services and consequent work overload may compromise caregivers' ability to be involved with care recipients needs, leading to an indifferent attitude as an adaptive behavior that makes their demands more manageable and less burdensome⁸. Likewise, we found that caregivers

with depersonalization showed higher levels of burden of care and emotional exhaustion. Moreover, high levels of cynicism in caregivers were also associated to the severity of behavioral symptoms in patients, meaning that they are a strong factor associated to the development of an indifference attitude from the caregivers towards AD patients.

Caregiver burden, particularly limitation in social life, has been associated to anxiety and depression in spouse caregivers³⁵. Although our sample was more heterogeneous than the one in the mentioned study, we also found a significant correlation between high levels of burden of care and anxiety, indicating that the chronic stress involved in caregiving plays a major role to impair the well-being of caregivers.

A major limitation of our study is the small size of our sample. Moreover, the fact that our sample was drawn from a psychogeriatric reference center with a multidisciplinary staff and a variety of facilities including day hospital, social service, and familial group therapy may in part explain the small prevalence of burnout in our study.

To the best of our knowledge, this is the first study conducted in Brazil that examines burnout correlations to the clinical and sociodemographic factors of AD patients and their caregivers. Alzheimer's disease caregivers represent a vulnerable group to the effects of burnout since they are exposed to high levels of burden of care, only a few receive adequate training for this occupation, and the majority receive little positive feedback³⁶. The assessment of burnout in caregivers permits not only the investigation of the emotional stress suffered by this group, as it has been largely described in the literature, but the interrelational aspects of caregiving and the caregiver's self-appraisal of care. This is an area that warrants more

information that may lead to practical measures to deliver proper services both to patients and caregivers. To sum up, burnout associated to caregivers' burden of care. Among the burnout dimensions, emotional exhaustion was highly prevalent in our sample and also associated to the AD clinical status and to the burden of care, depression, and anxiety in caregivers.

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Address for correspondence:
Jerson Laks
Av Copacabana 749/802
22050-000 Rio de Janeiro, RJ, Brazil
Phone/Fax: +55 21 2255 3454/ +55 21 2548 4510
E-mail: jlaks@centroin.com.br