The Caregiver's Burden of Alzheimer Patients: Differences Between Live-In and Non-Live-In

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The objective of our study was to describe the burden of a sample of 208 live-in/non-live-in caregivers of patients with Alzheimer's disease (AD). We analyzed the statistical correlation between Caregiver Burden Inventory (CBI) and the live-in/non-live-in caregiver status, and between the "objective burden," the cognitive deterioration, functional ability, and psychic and behavioral disorders. Using analysis of variance (ANOVA), the live-in groups of caregivers were compared to each subscale and to the total CBI. Living with a patient causes a bigger burden associated to the

Introduction

Alzheimer's disease (AD) is a degenerative pathology of the central nervous system showing a prevalent and initial loss of memory associated over time to a diffuse cognitive deterioration and loss of independence together with the presence of psychic and behavioral disorders. The course of the disease creates many complex caring issues to the point that dementia becomes a disorder affecting the dynamic and life of the whole family.

The caregiver's psychological and physical balance is affected by the complexity of the care, the constant commitment, personal relationships and emotions, and the direct and indirect costs.

The progressive nature of the disease causes an increase in dependency and therefore the constant commitment with the high number of hours used "developmental and physical burden," which is affected more by the functional impairment than by the cognitive-behavioral aspect. Understanding the aspects of this burden in the initial-intermediate phase of the disease and being able to monitor it over time could contribute to improving the interventions already in place, which affect burden, stress, and quality of life of caregivers and their sick family members.

Keywords: Alzheimer's disease; Caregiver Burden Inventory; live-in caregivers; non-live-in caregivers

to care for the person¹ results in a reduction of free time and high level of stress.²⁻⁴ In addition, the patient's psychic and behavioral disorders affect the caregiver's burden⁵ and are the main causes of anxiety and depression.⁶⁻⁹ The symptoms of anxiety and depression in caregivers of patients with AD correlate to the hours of assistance but not to the severity of the disease.^{10,11} Some studies show that anxiety is a very common symptom in these caregivers and when it is present with other disorders, the perception of their burden increases.¹²

The caregivers tend to overestimate the severity of the patients' symptoms when compared to the clinicians' objective evaluation.^{13,14} Among all caregivers, the spouses are the ones who get more stressed physically and psychologically. They experience difficulty in caring for their loved ones because of the decrease in effective communication and of the increased dependency of the sick spouse. These factors often lead to a deterioration of the marital relationship. Characteristics of burden of coresident spouse carers have been already studied.¹⁵ However, no attention has been put on the difference between coresident and non-coresident caregivers.

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The objective of this research was to evaluate the burden of primary live-in and non-live-in caregivers, based on their social and demographic characteristics, and on the functional, cognitive, and behavioral aspects of the patients.

A better understanding of the burden of caregivers of patients with AD may contribute to modify the existing interventions to decrease the stress level,¹⁶ and consequently improve the caregivers' quality of life.^{17,18}

Methods

Participants

The research was conducted on a sample of 208 caregivers, including 92 live-in and 116 non-live-in, of patients diagnosed with AD according to the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Associaion (NINCDS-ADRDA) criteria, referred to the U.V.A. of the Unità Operativa di Neurologia (Operative Neurology Unit) of the Istituto Nazionale di Ricerca e Cura dell'Anziano (National Institute for Geriatric Research and Care), Ancona, Italy. Caregivers of patients with Mini-Mental State Examination (MMSE) <10 and those hospitalized in residential institutions were not included. Furthermore, caregivers must be in their role for at least 6 months prior to enrollment.

The socio-demographic characteristics of the caregivers were gathered through the administration of a questionnaire which gathered information about age, sex, live-in or non-live-in status, relationship with the patient, job, time spent caring for the patient, and presence of other care support.

Assessment

The Italian version of the 30-point MMSE,¹⁹ a tool for a global cognitive evaluation, was administered to the patients. Row scores were corrected for both age and education according to Magni et al.²⁰ Scores greater than 20 indicate mild impairment, scores between 20 and 10 indicate moderate impairment.

The following tests regarding functional independence and noncognitive disorders relative to the sick loved ones were administered to the caregivers:

 Activities of Daily Living (ADL)²¹ assesses the ability of carrying out independently the basic tasks of everyday life, such as taking a shower, getting dressed, going to the bathroom, transferring, being continent, and eating (range 0 to 6, with higher scores indicating greater ADL impairment).

- Instrumental Activities of Daily Living (IADL)²² assesses the ability of carrying out instrumental activities of daily life, such as, using a telephone, going shopping, cooking, taking care of the house, doing laundry, driving or using public transportation, taking medicines, and managing money (range 0 to 8, with higher scores indicating greater IADL impairment).
- Neuropsychiatric Inventory (NPI)²³ is a scale to assess the frequency and severity of 12 psychic and behavioral symptoms, such as, delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, lability, aimless and/or aberrant motor activity, dysrhythmia of the sleep-wake cycles, and eating disorders (score range from 1 to 144, with higher scores indicating greater behavioral disturbance).

In addition, the caregivers completed a questionnaire to measure their burden:

Caregiver Burden Inventorv (CBI)²⁴ is a self-administered questionnaire to assess the perceived burden by caregivers of patients with dementia; it is made of 24 items divided in 5 subgroups: (1) objective burden, associated to the restrictions of the family member's time; (2) developmental burden, relative to feeling "out of sync" with respect to their peers' expectations and opportunities; (3) physical burden, relative to tiredness and problems of somatic health; (4) social burden, relative to role's conflicts with job and with the other family members; (5) emotional burden, associated to feelings of shame and embarrassment toward the patient.

Statistical Analysis

A descriptive analysis was done of sample characteristics for the patients and for their caregivers. Using Student t test the live-in and non-live-in caregivers were compared in relation to their social and demographic characteristics, to the cognitive, functional, and behavioral status of the patient and to the scores obtained with the CBI total scale and subscales. Using Pearson's correlation coefficient (r) the level of correlation between the "objective burden" (CBI-1) and the cognitive (MMSE), functional (ADL; IADL), and behavioral (NPI) status was analyzed. Using analysis of variance (ANOVA) the 3 groups of live-in caregivers (spouses, children, other) were compared in relation to each CBI subscale and the total scale.

The software SPSS/WIN V.12.0 was used for all statistical analyses.

	Average	±	SD	Range	Р
Age	77.93	±	6.15	(58-93)	
Live-in	77.40	±	7.26	(58-93)	
Non-live-in	78.35	\pm	5.10	(61-90)	NS
Education (years)	5.47	±	3.31	(0-17)	
Live-in	5.77	±	3.51	(0-17)	NS
Non-live-in	5.22	\pm	3.13	(0-17)	
MMSE	17.24	\pm	4.00	(10-27.4)	
Live-in	17.36	\pm	4.30	(10.7-25.9)	
Non-live-in	17.15	\pm	3.76	(10-27.4)	NS
IADL	2.48	\pm	2.13	(0-8)	
Live-in	2.10	\pm	1.79	(0-8)	
Non-live -in	2.78	\pm	2.33	(0-8)	NS
ADL	4.66	\pm	1.55	(1-6)	
Live-in	4.55	\pm	1.56	(1-6)	
Non-live-in	4.75	±	1.54	(1-6)	NS
NPI (Frequency x severity)	20.00	±	15.96	(0-77)	
Live-in	21.90	±	16.59	(0-77)	
Non-live-in	18.49	±	15.35	(0-75)	NS

Table 1.Socio-Demographic and Clinical
Characteristics of Patients

Abbreviations: ADL, activities of daily living; IADL, instrumental activities of daily living; MMSE, Mini-Mental State Examination; NPI, Neuropsychiatric Inventory; NS, not significant; SD, standard deviation.

Results

Patients were homogeneous as regards to age, education, cognitive deterioration, functional abilities, and psychic and behavioral symptoms (Table 1).

Sixty-nine percent of the caregiver sample were women; among the live-in, 55% were spouses and 33% were children. Seventy-four percent of nonlive-in was made of children (Table 2).

The comparison between the 2 groups of caregivers with regards to the burden (Table 3) showed significant differences in the total score of the CBI scale (28.63 \pm 17.93 live-in; 23.10 \pm 17.19 nonlive-in; P < .05) and in the subscales relative to the "developmental burden" (CBI-2: 8.12 ± 5.83 livein; 5.81 \pm 5.33 non-live-in; P < .01) and to the "physical burden" (CBI-3: 5.01 \pm 4.07 live-in; 3.81 ± 5.33 non-live-in; *P* < .01). In addition, considering the total sample, the relation between the "objective burden" (CBI-1) and MMSE, ADL, IADL, and NPI obtained with the Pearson correlation coefficient (r), was lower (r = -0.41; P < .05) with the MMSE than with the ADL (= -.68) and IADL (r = -.69). Among the live-in caregivers, the relation was higher with the ADL (r = -.74), while among the non-live-in the higher relation was with the IADL (r = -.70). The relationship between the "objective burden" subscale (CBI-1) and the NPI was

Table 2.	Socio-Demographic Characteristics of
	Caregivers (%) ^a

	Total Sample $(n = 208)$	Live-In Caregivers (n = 92)	Non-Live-In Caregivers (n = 116)
Sex			
Male	31	29	33
Female	69	71	67
Age			
<45	15	5	23
46-60	49	29	65
61-70	18	29	9
>71	18	37	3
Kinship			
Spouses	25	55	_
Children	55	33	74
Other family members	20	12	26
Job			
Yes	50	27	67
No	50	73	33

 ${}^{\rm a}P < .01.$

significant (P < .01) but the correlation was low (r = .42) and it was confirmed in the 2 subgroups (Table 4).

In the sample of live-in caregiver, there was a significant difference (P < .05), to the "objective burden" subscale (CBI-1), between patients' children (12.07 ± 5.51) and spouses (8.04 ± 5.71 ; Table 5).

The difference in gender inside the live-in group (Table 6) showed that women experience a higher "emotional burden" (CBI-5; 3.60 ± 3.42) than men do $(1.85 \pm 1.89; P < .05)$.

Discussion

For many years, clinical interest and research in the field of AD have taken into account only the cognitive, behavioral, and functional aspects of the demented patients with little attention given to the characteristics of caregivers, the effects of the burden carried and the wider implications of care giving. To our knowledge, no studies were conducted on the difference between live-in and non-live-in caregivers.

The analyses of our results showed that the caregivers of patients with AD are generally represented by a female family member with an average age of 56 years,²⁵⁻²⁷ confirming the prominent role of females.

The live-in condition carried a higher level of caring burden when compared to the non-live-in, especially relative to the "developmental burden" (associated to the perceived feelings by the caregivers

Burden	Total Sample (n = 208)	Live-In Caregivers (n = 89)	Non-Live-In Caregivers (n = 119)	Р
Objective	8.79 ± 5.79	9.34 ± 6.01	8.39 ± 5.61	NS
Developmental	6.80 ± 5.66	8.12 ± 5.83	5.81 ± 5.33	<.05
Physical	4.18 ± 3.95	5.01 ± 4.07	3.55 ± 3.76	<.05
Social	3.04 ± 3.77	3.11 ± 3.63	2.99 ± 3.89	NS
Emotional	2.61 ± 2.99	3.04 ± 3.14	2.28 ± 2.84	NS
Total	25.47 ± 17.68	28.63 ± 17.93	23.10 ± 17.18	<.05

Table 3. Caregiver Burden Inventory (CBI) of Live-In and Non-Live-In Caregivers

Abbreviation: NS, not significant.

Table 4. Relationship Between Subscale CBI-1 and MMSE, IADL, ADL, and NPI

	Total Sample (n = 208)	Live-In Caregivers $(n = 89)$	Non-Live-In Caregivers $(n = 119)$
MMSE	$-0.41 \ (P < .01)$	$-0.55 \ (p < 0.01)$	-0.30 (<i>P</i> < .01)
IADL	$-0.68 \ (P < .01)$	-0.67 (p < 0.01)	$-0.70 \ (P < .01)$
ADL	$-0.69 \ (P < .01)$	$-0.74 \ (p < 0.01)$	$-0.64 \ (P < .01)$
NPI	$-0.42 \ (P < .01)$	-0.42 (p < 0.01)	$-0.42 \ (P < .01)$

Abbreviations: ADL, activities of daily living; CBI-1, Objective Burden; IADL, instrumental activities of daily living; MMSE, Mini-Mental State Examination; NPI, Neuropsychiatric Inventory.

 Table 5.
 Relation Between the CBI and Live-In Caregivers' Typology

Burden	Total Sample $(n = 89)$	Spouses $(n = 51)$	Children $(n = 28)$	Other Family Member $(n = 10)$	Р
Objective	9.34 ± 6.01	8.04 ± 5.72	12.07 ± 5.52	8.30 ± 6.82	< .05
Developmental	8.12 ± 5.83	7.73 ± 5.88	9.18 ± 5.94	7.20 ± 5.39	NS
Physical	5.01 ± 4.07	4.63 ± 4.24	5.54 ± 3.99	5.50 ± 3.54	NS
Social	3.11 ± 3.63	2.73 ± 3.21	3.96 ± 4.37	2.70 ± 3.33	NS
Emotional	3.04 ± 3.14	2.96 ± 2.84	2.68 ± 2.76	4.50 ± 5.10	NS
Total	28.63 ± 17.93	26.08 ± 17.91	33.43 ± 17.75	28.20 ± 17.55	NS

Abbreviations: CBI, Caregiver Burden Inventory, NS, not significant.

Table 6. Caregiver Burden Inventory (CBI) of Gender of Live-In Caregivers

Burden	Total sample $(n = 89)$	Famale caregiver $(n = 62)$	Male caregiver $(n = 26)$	Р
Objective	9.34 ± 6.01	9.35 ± 6.22	9.04 ± 5.56	NS
Developmental	8.12 ± 5.83	8.77 ± 5.96	6.54 ± 5.42	NS
Physical	5.01 ± 4.07	5.55 ± 4.12	3.73 ± 3.81	NS
Social	3.11 ± 3.63	3.39 ± 3.93	2.58 ± 2.80	NS
Emotional	3.04 ± 3.14	3.60 ± 3.42	1.85 ± 1.89	<.05
Total	28.63 ± 17.93	30.66 ± 18.99	23.73 ± 14.71	NS

Abbreviation: NS, not significant.

of being "out of sync" with their peers' expectations and opportunities) and the "physical burden" (relative to tiredness and somatic problems).

The degree of kinship among live-in affected the caring burden, since children experienced a bigger "objective" burden with respect to spouses. This evidence can be connected to the generational trend according to which the elderly individuals consider themselves responsible for their spouses.⁵

The "objective" burden is affected by functional compromise assessed through ADL and IADL much more than cognitive and behavioral disorders. This can be explained by the fact that the loss of independence causes an increase of the caregiver's time devoted to the sick family member,²⁸ and that our sample is not affected by an advanced degree of the disease, which presents a severe cognitive and functional deterioration associated with disabling behavioral disorders.

Furthermore, live-in and non-live-in caregivers differ in their degree of correlation between "objective" burden and functional activity, insofar as live-in carers have higher correlation with ADL and non-live-in with IADL.

Our data suggest that a weak correlation exists between burden and cognitive impairment, meanwhile in the literature, the relationship is less clear, either giving a positive correlation,^{29,30} or no direct relation.^{31,32}

Gender suggests that female caregivers living with the sick person show an emotional burden (relative to feeling of shame and embarrassment toward the patient) which is bigger than the one felt by male caregivers, probably because caregivers' coping strategies influence their perceptions of burden. Almberg, Grafstrom, and Winbladd,³³ describe the relationship between burden and coping strategies. Female caregivers tended to report more emotionfocused coping, while males reported problemfocused coping strategies, and problem focused or mixed coping strategies were found to be most effective.³⁴ In the literature, it has been observed that women are more likely to experience social restrictions because of their caring role,35-37 and they experience higher levels of burden when compared with men caregivers.³⁸⁻⁴⁰ Sex differences have been reported in the ways people use to cope with the several stressors of caregiving. Women seem to have lower levels of mastery,⁴¹ and use less-effective coping strategies,⁴² while men use mostly problemsolving approaches.⁴³ Some authors explain sex differences by suggesting that men receive more informal support than women.44,45

As many factors (co-residence, gender, relationship to the patient, culture, and personal characteristics) influence the impact of the caregiving experience, interventions developed with the goal of alleviating the caregiver burden, must include a diversity of services to decrease burden, improve quality of life, and enable caregivers to provide at-home care for longer periods prior to institutionalization.

There is increasing recognition that psychoeducational interventions make an essential contribution to dementia care,⁴⁶ and may be cost effective.⁴⁷ Psychoeducational intervention may target the person with dementia, their caregiver and may cover a range of domains such as mood, well-being, and behavior.^{48,49} Gallagher-Thomson and Coon identified 3 categories of supported interventions including not only psychoeducational skill-building but also psychotherapy and multicomponent interventions.^{50,51} Notwithstanding the variety of proposed approaches, the trasferability into everyday practice settings does not meet the multiplicity of caregivers' needs.⁵²

The higher distress observed in our study in live-in caregivers, mainly as far as it concerns the "objective" burden, suggests the opportunity of a psychoeducational intervention that could be tailored to fit the different carers' needs. Non-live-in caregivers may better take advantage of multicomponent interventions.

In conclusion, understanding the different aspects of the burden between live-in and non-livein caregivers of patients with AD in the initialintermediate phase of the disease and being able to monitor it over time could be an important contribution to improve the various interventions already in place, which seem to somewhat affect burden, stress, and, therefore, quality of life of caregivers and their sick family members.

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