

Emotions and Caregiver's Needs in Patients with Alzheimer's Disease: The Caregiver Burden

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Abstract

The burden on the caregiver patients with Alzheimer disease need assistance and supervision in their daily activities. In literature, the term "burden" has been used to indicate the overload of work experienced by the caregiver. In our country, the patient's domiciliary "take-care system" is based firstly on the family support together with the supply of health care providers and home care professionals provided by the National Health System.

Caregivers of Alzheimer's Disease (AD) patients are usually subjected to enormous physical and mental stress, as well as emotional, which may have repercussions on personal, familiar and social contest and, consequently, on life's quality [1].

The aim of our study was to investigate caregiver's burden "predicting factors" and evaluates to improve the quality of their caregivers.

Introduction

Dementia is the most common term that indicates the neurological distinction of major neurocognitive disorder in DSM5, the fifth edition of the Diagnostic and Statistical Manual [2].

With the term 'dementia', it is possible to refer to a number of symptoms that can be found in some diseases, where there is deterioration or loss of brain cells. Among the natural processes of aging is the loss of brain cells, but in diseases that lead to dementia this happens very quickly, to prevent the brain from its normal function. Mental functions such as memory, attention, and concentration, speech, thought are affected by brain damage [3].

In addition to cognitive symptoms, there are also non-cognitive symptoms that may concern the sphere of personality, behaviour, affectivity, ideation, perception, vegetative functions [4].

Our society grow old and the number of people that living with dementia worldwide will increase to 55 million in the 2019 to 139 million in the 2050 according to the WHO [5]. Among

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the most common diseases of the elderly, dementia represent a crisis that health care systems will be facing in the coming years, age is a risk factor and the number of people that will be affected by this disease, will increase, progressively [4]. The most frequent form of dementia in Europe, the United States and Canada is Alzheimer's disease, which accounts for 50 to 80% of cases [4].

The number of sick people has reached 50 million worldwide, and every 3 seconds a new case of dementia is diagnosed [6]. From both the social and the economic point of view, our health systems are not prepared to deal with this disease [7].

The World Alzheimer's Report 2023 analysed the economic cost of dementia by observing the doubling from \$1.3 trillion a year in 2019 to \$2.8 trillion by 2030 [8].

The main costs are social and informal assistance, because many people who take care of a relative lose work or must start part-time working [8].

The impairment of the functional abilities of everyday life has a dramatic impact on the quality of life of both patients and their caregivers [9,10].

Dementia is a disease that changes constantly, not only from patient to patient, but also and above all over time, and this leads, necessarily, to adapting goals and methods of rehabilitation, depending on both the clinical stage and the history of the person. It is a "social" disease, in which an entire family becomes ill more than a single person, and the supporting role of the caregiver is almost as important as that of the patient. The aim of this paper is to examine the predictive factors of the caregiver's burden.

Inclusion criteria were: Age >50 years, diagnosis of probable AD according to the NINCS-ADRDA criteria (Mc Khann et al., 1984); on the other hand, we considered as exclusion criteria a previous stroke and/or brain trauma, co-morbidity with neurological or psychiatric diseases, co-existence of severe internal diseases, history of alcohol and/or drug abuse.

All patients underwent an extensive anamnestic, neuro-radiological, neurological and cognitive screening. The caregivers were submitted to an extensive evaluation using MMSE, Clinical Dementia Rating Scale, Caregiver Burden Inventory, Hdrs, Iadl, Iadl.

Materials and methods

Inclusion criteria: Age more than 55 years Diagnosis of probable AD in accordance with NINCDS-ADRDA criteria or diagnosis of MCI in accordance with criteria proposed by Petersen et al. (1999).

Exclusion criteria

Positive anamnesis of stroke or precedent head traumas.

Other neurological pathologies in comorbidity.

Severe internal diseases, comorbidity with psychiatric disturbances (schizophrenia).

Positive anamnesis of alcohol or psychotropic drug abuse.

Insurgence probable period was supposed after the anamnestic investigation provided by the main caregiver.

The study followed the ethical standards of the 1964 Helsinki declaration and written informed consent was obtained from all participants before the survey. They were assured that the transcript of the interview would remain strictly confidential and that patients would not be named in the final description and analysis.

Diagnostic iter: In the study were inserted patients from our Centre that gave authorization to a clinical research participation. We enrolled familiar caregiver no-professional assistants.

Patients and caregivers: We enrolled 289 patients' caregivers of (61.2% F) (38.8% M), mean age 74.46 years, mean M.M.S.E: 14.96, mean ADL 3.02, mean IADL 3.33, that practised a regular follow up at our Dementia Centre. We considered one caregiver for patient, with no sex difference (women 74.7%, men 25.3%). As regards the familiar role, they were mainly sons (60.2%) and spouses (32.5%). Mean age was 56.8±13.5 and the educational years level was very low (mean 9.3±3.9).

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Clinical evaluation: We also investigated activities of daily living (with ADL and IADL scales) as well as cognitive level (with MMSE). Activity Daily Living Scale (ADL) [11] is the most appropriate instrument to assess functional status as a measurement of the client's ability to perform activities of daily living independently. Clinicians typically use the tool to detect problems in performing activities of daily living and to plan care accordingly. The Index ranks adequacy of performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding. Clients are scored yes/no for independence in each of the six functions. A score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment Instrumental Activities of Daily Living Scale (IADL) [12].

IADL is an appropriate instrument to assess independent living skills. These skills are considered more complex than the basic activities of daily living as measured by the Katz. The instrument is most useful for identifying how a person is functioning at the present time. There are eight domains of function measured with the Lawton IADL scale. Clients are scored according to their highest level of functioning in that category. A summary score ranges from 0 (low function, dependent) to 8 (high function, independent) for women, and 0 through 5 for men.

Cognitive assessment: The MMSE consists of thirty items that assess orientation, short and long-term memory, language, attention, visuospatial skills, and the ability to follow simple verbal and written commands. This easy-to-use and relatively quick neuropsychological test is often employed to assess the overall cognitive status we referred to norms for the Italian population considering age and education corrections [13].

HAM-D investigates different areas for assessing the depressive state of a subject. It cannot be used as a diagnostic tool for depression, but it allows to quantitatively assess the severity of the subject's conditions and to document the modifications of these conditions, for example during a psychotherapeutic treatment. The HAM-D consists of 21 items. The severity cut-off is ≥25 severe depression, 18-24 moderate depression, 8-17 mild depression, ≤7 absence of depression [14].

CBI [16] is a rapidly compiling scale that measures the care burden created for caregivers of patients with AD and related dementias. It is a self-report tool, which must be completed by the main caregiver. It is structured according to a multidimensional perspective. The CBI is divided into 5 sections that measure the different aspects of the care burden: Objective, psychological, physical, social, and emotional. The burden depending on the Time required for assistance (T) (items 1-5) describes the load associated with the restriction of time for the caregiver. The evolutionary burden (S) (item 6-10) is the isolation perception of the caregiver, also considering the expectations and opportunities of their peers. The physical burden (F) (item 11-14) describes the feeling of chronic fatigue and somatic health

problems while the social burden (D) examines the perception of a role's conflict. The emotional burden (E) (items 20-24) describes the feelings towards the patient, which can be induced by behavioural disorders of the latter. Each section consists of 5 items and the score for each individual item goes from 0 (factor with minimum value) to 4 (factor with maximum value), for a total ranging from 0 to 20 for each dimension, except for the physical burden which is composed of 4 items. A correction factor of 1.25 is then applied to the total score. The range of the total score varies from 0 to 100. The scores for each section increase proportionally to the perceived severity of the burden for each area; therefore, with the same total score, the burden profiles may be very different. These so defined profiles will be the evaluation basis on which to build ad-hoc psycho-social interventions.

Statistical analysis: Categorical variables are expressed as frequency and percentage, numerical variables as average and standard deviation. The non-parametric approach was applied for the statistical analysis, because most of the analysed variables were not normally distributed, as occurred from the Kolmogorov-Smirnov test. Spearman correlation test was applied in order to find out the interdependence between the HDRS of Hamilton and the CBI (time loading, development loading, physical load, social load and emotional load). The same test was applied to verify the correlation between MMSE and ADL, IADL, hours of treatment and also, between, clinical dementia and ADL, IADL and treatment hours. In order to perform statistical comparison between who lives in a house and who doesn't, in relation to numerical variable such as the HDRM of Hamilton, service hours, emotional and social load, ecc, the Mann Whitney test was applied. SPSS for Windows software, 22.0 version was adopted for all statistical analyses. A p-value lower than 0,050 was considered statistically significant.

Results

Caregiver's examinations showed a high perception of the care load, in particular: load time (11.35 ± 6.94), evolutionary load (11.51 ± 5.56), physical load (9.32 ± 5.07), social load (5.86 ± 5.43), and emotional load (2.89 ± 3.26).

Looking at the results obtained from the correlation between HDRS and time loading, we find the existence of a significant and negative correlations between the HDRS scores and all individual time load factors (TD1: $r_s = -0.267$, $p < 0.001$; TD2: $r_s = -0.172$, $p = 0.003$; TD3: $r_s = -0.203$, $p = 0.001$; TD4: $r_s = -0.275$, $p < 0.001$; TD5: $r_s = -0.224$, $p < 0.001$); there are significant and negative correlations between HDRS scores and all dimensions of development burden (S6: $r_s = -0.192$, $p = 0.001$; S7: $r_s = -0.231$, $p < 0.001$; S8: $r_s = -0.210$, $p < 0.001$; S9: $r_s = -0.176$, $p = 0.003$; S10: $r_s = -0.144$, $p > 0.001$); there are significant and negative correlations between HDRS scores and only two physical load sizes (F12: $r_s = -0.149$, $p = 0.010$; F1=0, and, therefore, only two dimensions of social load (D15: $r_s = -0.146$, $p < 0.001$; D16: $r_s = -0.121$, $p = 0.039$) and, finally, three dimensions of emotional load, of which one negative (E20: $r_s = -0.255$, $p < 0.001$) and one positive (E23: $r_s = 0.146$, $p = 0.013$). When the depression HDRS index goes up drops the indicator of sociability. As HDRS depression increases, the E20 (emotional burden) index decreases, while E23 increases.

In addition, we found that MMSE and clinical dementia were significantly and negatively related ($r_s = -0.847$, $p < 0.001$) while there is a positive correlation between MMSE and Hamilton HDRS ($r_s = 0.261$, $p < 0.001$), ADL ($r_s = 0.800$, $p < 0.001$), IADL ($r_s =$

Table 1: Absolute frequencies and percentages for categorical variables.

	Gender	
	Frequency	Percentage
Female	177	61,2
Male	112	38,8
Totale	289	100,0
Family relationship		
Sister-in law	1	,3
daughter	130	45,0
son	36	12,5
husband	33	11,4
wife	61	21,1
nephew	15	5,2
Daughter- in law	8	2,8
sister	5	1,7
Caregiver gender		
Female	216	74,7
Male	73	25,3
Profession of caregiver		
housewife	153	52,9
executive	13	4,5
employed	57	19,7
entrepreneur	1	,3
freelancer	5	1,7
worker	2	,6
pensioner	55	19,0
student	3	1,0
Marital status caregiver		
celibate	12	4,2
married	203	70,2
divorzia	9	3,1
maiden	62	21,5
widow	3	1,0
Live in the house		
No	65	22,5
Yes	224	77,5

Table 2: Descriptive statistics for numerical variables.

Variables	Mean	SD
Age	74,4671	5,99245
schooling	7,4913	3,94151
MMSE	14,9635	5,21714
Adl	3,0242	1,87531
IADL	3,3322	2,39800
Caregiver age	56,8304	13,50986
scolar_caregiver	9,3841	3,92568
Hours of assistance for day	11,6055	6,31880
Time burden	11,3542	6,94425
Evolutionary burden	11,5174	5,56680
Physical burden	9,3261	5,07045
Social buden	5,8685	5,43107
Emotional burden	2,9481	3,02663

0.792, $p < 0.001$) and hours of care ($r_s = 0.783$, $p < 0.001$). Clinical dementia has been negatively correlated with HDRS Hamilton (-0.272 , $p < 0.001$) ADL ($r_s = -0.748$, $p < 0.001$) and IADL ($r_s = -0.724$, $p < 0.001$) and positively correlated with hours of care ($r_s = 0.733$, $p < 0.001$) and positively correlated with ADL ($r_s = -0.706$, $p < 0.001$) IADL ($r_s = -0.711$, $p < 0.001$) and Hamilton HDRS ($r_s = -0.262$, $p < 0.001$). The Mann Whitney test (Table 1) allows us to highlight that there are statistically significant differences between those living at home and those not living, with reference to some variables: in particular, those living at home show significantly higher scores with respect to service hours, time load, development load and physical load. There were no significant differences between the two groups regarding HDRS, social burden and emotional burden.

Table 3: Comparison between caregivers living at home vs not living at home.

	Living at home	Not living at home	p-value
HDRS	21.37±7.04	22.92±5.88	0.119
Hours of assistance	13.23±6.16	5.98±2.43	<0.001
Time burden	12.69±6.68	6.75±5.76	<0.001
Evolutionary burden	12.35±5.34	8.64±5.33	<0.001
Physical burden	10.43±4.82	5.49±3.93	<0.001
Social burden	5.75±5.44	6.24±5.39	0.525
Emotional burden	2.98±2.95	2.83±3.28	0.375

Table 4: Spearman's correlation between MMSE and CBI (partial and total scores).

TEMP		MMSE	EVOL	MMSE	FIS	MMSE	SOC	MMSE	EMOT	MMSE
TD1	Coeff	-.766**	S6	-.644**	F11	-.606**	D15	-.419**	E20	-.458**
	Sig.	<.001		<.001		<.001		<.001		<.001
TD2	Coeff	-.746**	S7	-.610**	F12	-.590**	D16	-.337**	E21	-.043
	Sig.	<.001		<.001		<.001		<.001		.470
TD3	Coeff	-.766**	S8	-.577**	F13	-.475**	D17	-.216**	E22	.010
	Sig.	<.001		<.001		<.001		<.001		.861
TD4	Coeff	-.755**	S9	-.569**	F14	-.576**	D18	-.100	E23	-.054
	Sig.	<.001		<.001		<.001		.089		.357
TD5	Coeff	-.664**	S10	-.541**			D19	-.320**	E24	-.098
	Sig.	<.001		<.001				<.001		.097
TOT	Coeff	-.781**	TOT	-.698**		-.631**	TOT	-.355**	TOTi	-.370**
	Sig.	<.001		<.001	TOT	<.001		<.001		<.001

As highlighted from the results of Spearman's correlation, reported in (Table 4), all of dimension of time, evolutionary and physical are significantly and negatively related with MMSE ($p < 0.001$).

All of dimension on social burden (except for D18) are significantly and negatively related with MMSE.

Finally, only one of the dimension related to emotional burden, the E20, turns out significantly and negatively related with MMSE, and also the total emotional burden ($p < 0.001$ for both). Other dimensions are not statistically significant ($p > 0.050$).

Discussion

To take care of the patient are mainly sons (60.2%) and the partner (32.5%), middle-aged 56.8 ± 13.5 years, little educated (9.4 ± 3.9 anni). The 76.8% of the interviewed live with sick family member, of those 65% is conjugated. While the 74.7% women are the highest percentage of caregivers, significantly younger than men ($p < 0.01$), mainly house wives ($p < 0.05$), able to devote more hours of the day to the care of their family members than men ($p < 0.001$). However, the average stress load, measured by the CBI score, in the two sexes was not significantly different.

The patients are 177 women (61.3%) and 112 men (38.7%) of average age 74.4 ± 6 and schooling 7.5 ± 3.9 . Classifying patients according to their MMSE scores, according to the cut-off of the neuropsychological scale, we see that 56.4% of the sample has moderate to severe impairment, and 15.9% mild impairment. Regarding the scales that measure independence in carrying out daily activities, we have that the average score of ADL is 3.0

1.9, while that of IADL is 3.3. No statistically significant difference between the two sexes, for any clinical scale, was found.

The results show strong correlations between CBI scores and clinical patient scales (MMSE, ADL, IADL). Going to look in more detail we see that the highest correlations are with the first 3 load dimensions (objective, evolutionary, physical), while the other two dimensions correlate slightly.

The stress of the family members is influenced by all 5 dimensions of the CBI, but it seems that the objective load is that of greater weight. The age (of the caregiver) and, in particular, the hours of daily care are also significant predictors.

Moreover, Kim et al. (2011) reported that compromise in ADL and IADL tests represent the most difficult part in the burden of caregivers with general dementia. In this study, IADL was the third most important variable to explain the variance in the load of the caregiver, while ADL did not show a significant change in variance. Difficulty with IADLs management seems to be very common in patients with AD, as these tasks include complex tasks and tasks such as cleaning and managing medications [18].

In this study women tend to experience a major support burden than males; the marital relationship and the hours of assistance, contribute to the perception of burden of care.

Studies in the literature report a four times greater risk of depression in the caregivers of the spouse than the controls [19,20]. In their studies focus on how with the evolution of the

disease, require a greater need for care that leads to an outward relational closure and a stronger emotional attachment to the patient, with consequent burden of care for the caregiver. These studies agree with the results of our research. In this analysis, time spent on caregiving activities was significantly associated with the level of caregiver burden.

When the time spent, caregiving increased to more than 8 hours, the burden score increased significantly and is greater in caregivers living at home with the patient.

Studies have shown that the total number of hours of care is strongly correlated to the level the lack of self-sufficiency of the patient; the functional decline of the patient can increase the hours of care and the stress of the caregiver [21,22].

In this study, caregiver's age is an indirect determinant of burden as older adult caregivers experience physical vulnerability in terms of an increasing number of diseases.

[23,24] have found that the age of the caregiver can be a nondirect factor of the burden as older adults who are also caregivers experience a physical vulnerability in terms of even more diseases. Health has been reported as an important variable in previous studies on loading and has been shown to significantly increase the psychological discomfort of the caregiver.

Conclusion

The experience of caregivers is in connection with the evolution of the disease and has a strong incidence in their choices and in their personal lives. Due to the characteristics of the degenerative course of the disease, caregivers experience a daily psychophysical decline in their loved one [25].

The care that the caregiver provides to patients with Alzheimer's disease undermines their physical health and psychological well-being; this leads to the development of negative effects on quality of life [26,27].

Many studies have highlighted the so-called caregiver burden, a condition that is characterized by psychophysical manifestations that can lead to a deterioration in physical health resulting in a decrease in immune defenses, emotional exhaustion, development of anxiety. With the progression of the disease the weight of the situation management increases, as the evolution of cognitive disorders, the decrease in daily life and the non-cognitive symptoms of the patient with Alzheimer's feed the discomfort, anxiety, depression of the caregiver [28,29].

The scientific literature confirms that supporting interventions are important to reduce anxiety-depressive symptoms and stress in the caregiver, but they are also effective for increasing general well-being. These interventions have positive consequences for the quality of life of the family member with dementia [30,31].

Scientific literature has shown that individual interventions are more effective in reducing perceived stress, because they are adapted to the specific needs of the caregiver; instead, group interventions diminish the perception of social isolation that caregivers feel. Psycho-educational, psychotherapeutic and multidimensional interventions show positive effects on depression and anxiety in the short term, managing to maintain these benefits up to seven months after the end of the surgery [32].

In addition to supporting interventions aimed directly at the caregiver, it is important to report services on the national territory whose purpose is to provide relief from the high burden of care that is required. These include 'Relief Centres', day care centres and home care [33,34].

Another very important aspect in the support of caregivers is given by the Associations that give information at national and local level, emotional support, practical advice, support groups and training programs to help people with dementia and their families. It is good that the caregiver participates in these types of interventions not only in situations of burden, but also as a form of prevention already when you become aware of the diagnosis of dementia of your family member [35-37].

Psychotherapists must be aware of their intrusion in a system which balance is threatened by the disease-driven change. This involves a painful anticipation of the loss both in the patient and in the caregiver with a wide range of intense emotions and complex interactions [38].

"If, on the one hand, without memory there is no self, on the other, whoever is not recognised by their beloved after a life together, runs the risk of feeling deprived of their relationship and of their emotional background". Professionals therefore have an ethical duty towards patients and their families.

The analysis of the real needs allows us to deal with the several ethical questions arising in the course of the illness, in compliance with the principles of: Independence-self-determination, charity and social justice. Nowadays it seems that a person affected from dementia has no dignity. A human being, as a "person", possess an original dignity in any phase of his/her existence. A person is not only a "cognitive" being and a patient with dementia is still a "person", therefore in any kind of relationship with him/her we have to acknowledge this dignity [38].

References

1. Ryu SH, Ha JH, Park DH, Yu J, Livingston G. (2011). Persistence of neuropsychiatric symptoms over six months in mild cognitive impairment in community-dwelling Korean elderly. *International Journal of Psychogeriatrics*. 2011; 23: 214-220.
2. Cloak N, Al Khalilli Y. Behavioral and Psychological Symptoms in Dementia. StatPearls. Treasure Island (FL): Stat Pearls. 2023.
3. Alzheimer Europe, Alzheimer Italia. Manuale per prendersi cura del malato di Alzheimer. Milano. 1999.
4. Trabucchi M, Le demenze. Ares (MI). 1998.
5. World Health Organization. Geneva, Switzerland: World Health Organization. Fact sheets of dementia. 2021.
6. Patterson C. Alzheimer's Disease International; London. World Alzheimer report. 2018.
7. Wortmann M Dementia: A global health priority-highlights from ad ADI and World Health Organization report. 2012.
8. Long S, Benoist C, Weidner W. World Alzheimer Report: Reducing dementia, risk, never too early, never too late. London, England: Alzheimer's Disease International, September. 2023.
9. Andersen CK, Wittrup-Jensen KU, Lolk A, Andersen K, Kragh-Sørensen P. Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia. *Health Qual Life Outcomes*. 2004; 2: 52.
10. Graff MJ, Adang EM, Vernooij-Dassen MJ, Dekker J, Jönsson L, et al. Community occupational therapy for older patients with

- dementia and their caregivers: Cost effectiveness study. *BMJ*. 2008; 336: 134-138.
11. Katz S. Assessing self-maintenance: Activities of daily living, mobility and instrumental activities of daily living. *JAGS*. 1983; 31(12): 721-726.
 12. Lawton MP, Brody EM. Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*. 1969; 9(3): 179-186.
 13. Folstein MF, Folstein SE, McHugh PR. Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975; 12(3): 189-1.
 14. HAM-D Adattata da Hamilton M. Development of a rating scale for primary depressive illness. *British Journal of Social and Clinical Psychology*. 1967; 6: 278-296.
 15. CDRS Morris JC. Clinical Dementia Rating: A reliable and valid diagnostic and staging measure for dementia of the Alzheimer type. *International Psychogeriatrics*. 1997; 9: 173176.
 16. CBI Novak M, Guest C. Application of a multidimensional caregiver burden inventory. *The Gerontologist*. 1989; 29: 798-803.
 17. Kim H, Chang M, Rose K, Kim S. Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*. 2011; 68: 846-85
 18. Farias ST, et al. (2009). Longitudinal changes in memory and executive functioning are associated with longitudinal change in instrumental activities of daily living in older adults. *The Clinical Neuropsychologist*. 2009; 23: 446-461.
 19. Joling KJ, et al. Incidence of depression and anxiety in the spouses of patients with dementia: A naturalistic cohort study of recorded morbidity with a 6-year follow-up. *American Journal of Geriatric Psychiatry*. 2010; 18: 146-153.
 20. Connell CM, Janevic MR, Gallant MP. The costs of caring: Impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology*. 2001; 14: 179-187.
 21. Cho E, Cho E, Kim SS. Effects of family relationship on burden of family caregivers of older adult with dementia. *Journal of Korea Gerontological Society*. 2010; 30: 421-437.
 22. Gallagher D, et al. Dependence and caregiver burden in Alzheimer's disease and mild cognitive impairment. *American Journal of Alzheimer's Disease & Other Dementias*. 2011; 26: 110-114.
 23. Conde-Sala JL, Garre-Olmo J, Turro-Garriga O, Vilalta-Franch J, Lopez-Pousa S. Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: An exploratory comparative design. *International Journal of Nursing Studies*. 2010; 47: 1262-1273.
 24. Van der Lee J, Bakker TJ, EM, Duivenvoorden HJ, Droes RM. Multivariate models of subjective caregiver burden in dementia: a systematic review. *Ageing Research Reviews*. 2014; 15: 76-93.
 25. Daga E, Corvo E, et al. L'esperienza dei caregiver primari che assistono a domicilio le persone affette dalla Malattia di Alzheimer Alzheimer's disease and caregivers experience in home care. *Professioni infermieristiche*. ISSN 0033-0205. Canterbury Christ Church University. 2014; 67(1): 5-14.
 26. Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *Am J Nurs*. 2008; 108(9): 23-27.
 27. Allen AP, Curran EA, Duggan A, et al. A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. *Neurosci Biobehav Rev*. 2017; 73: 123-164.
 28. Mitrani VB, Czaja SJ. Family-based therapy for dementia caregivers: Clinical observations. *Aging and Mental Health*. 2000; 4: 200-209.
 29. Schulz R, Martire LM. Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry*. 2004; 12(3): 240-249.
 30. Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychol Aging*. 2003; 18(2): 250-267.
 31. McCann TV, Songprakun W, Stephenson J. 2015. Una prova randomizzata controllata di auto-aiuto guidato per migliorare l'esperienza di prendersi cura dei caregiver di clienti con depressione. *Giornale di Infermieristica Avanzata*. 2015; 71(7): 1600-1610.
 32. Perlick DA, Jackson C, Grier S, Huntington B, Aronson A, et al. Studio randomizzato che ha confrontato il trattamento incentrato sulla famiglia solo per i caregiver con l'educazione sanitaria standard sull'esito di 6 mesi del disturbo bipolare. *Disturbi bipolari*. 2018; 20(77): 622-633.
 33. Hubbard AC A, McEvoy PM, Smith L, Kane RT. Breve psicoeducazione di gruppo per i caregiver di individui con disturbo bipolare: Uno studio randomizzato controllato. *Giornale di disturbi affettivi*. 2016; 200: 31-36.
 34. Mossello E, Caleri V, Razzi E, et al. Day Care for older dementia patients: Favourable effects on behavioural and psychological symptoms and caregiver stress. *Int J Geriatr Psychiatry*. 2008; 23: 1066-1072.
 35. Logsdon RG, Pike KC, Korte L, et al. Memory care and wellness services: Efficacy of specialized dementia care in adult day services. *Gerontologist*. 2016; 56: 318-325.
 36. Bangerter LR, Liu Y, Kim K, et al. Adult day services and dementia caregivers' daily affect: The role of distress response to behavioural and psychological symptoms of dementia. *Aging Ment Health*. 2021; 25: 46-52.
 37. Zarit SH, Stephens MA, Townsend A, et al. Stress reduction for family caregivers: Effects of adult day care use. *J Gerontol B Psychol Sci Soc Sci*. 1998; 53: S267-S277.
 38. Tretteteig S, Vatne S, Rokstad AM. The influence of day care centres designed for people with dementia on family caregivers-a qualitative study. *BMC Geriatr*. 2017; 17: 5.
 39. Tomasello L, Toscano G, Raffaele M. Dignità e sacralità della vita del paziente con Demenza di Alzheimer: La Persona al centro delle Neuroscienze e del Diritto Rivista di Bioetica, morale della persona e medical humanities Bio-ethos n.18 maggio-agosto. Istituto di Studi Bioetici "Salvatore Privitera" Palermo ISSN 1972-6341. 2013.