Depression and burden level in the natural caregiver of the demented patient : A Tunisian experience

Latifa Ghanmi (1)
Sonia Hammami (2)
Salem Bouomrani (3)
Amine Jabri (4)
Mouna Abbes (1)
Khalifa Zitoun (1)
Lobna Zouari (5)
Mohamed Maalej (5)

(1) Psychiatry department, Regional Hospital, Gabes. 6000 Tunisia
(2) Internal Medicine Department, Geriatric Unit, CHU Fattouma Bourguiba, Monastir. Tunisia
(3) Internal Medicine Department. Military Hospital, Gabes, Tunisia
(4) Medical Inspection of Labor, Gabes, Tunisia
(5) Psychiatry C department, Hedi Chaker University Hospital, Sfax, Tunisia

Corresponding author:
Dr Latifa Ghanmi
Psychiatry department, Regional Hospital, Gabes. 6000,
Tunisia
Tel : +2169724350; Fax : +21675292530
Email : ghanmi_latifa@yahoo.fr

Abstract

Background : Home care for the patient with Alzheimer's disease is often tiring and can lead to exhaustion of caregivers.

Aims: Assessment of the level of burden and frequency of depression among caregivers in Alzheimer's disease, and identification of the main factors associated with the burden and depression in these caregivers.

Methods: We conducted a cross-sectional, descriptive and analytical study. This survey took place at the psychiatric department of the Regional Hospital of Gabes. All caregivers who accompanied their relatives with Alzheimer's disease to their appointments from 01 November 2016 to 15 January 2017 were invited to take part. We used a questionnaire containing the patient's and the caregiver's socio-demographic and medical data, as well as the characteristics of the care relationship. The autonomy of the patient was assessed by Katz's autonomy scale (ADL). The Zarit Burden Interview and the Beck Depression inventory were the Instruments used to measure burden and depression in the caregiver.

Results: The caregivers were women in 74% of cases with a mean age of 46 and cohabiting with the patient in 68% of the cases. The mean Zarit Burden Interview score for the caregivers surveyed was 43. The burden was perceived as high by 48% of caregivers. A high caregiver burden was significantly associated with the absence of recreational activity (57% vs 83%, p = 0.04), being the primary caregiver of the patient (50% vs 83%, p = 0.01) and cohabiting with him/her (53% vs 83%, p = 0.02). Regarding patient variables, only the level of dependence of the patient correlated with a high level of caregiver burden (38% vs. 79%, p = 0.004). The mean score of the Beck scale was 8.18 (± 6.3). Depression was moderate to severe in 44% of caregivers. Caregiver depression was significantly associated with the absence of caregiver activity (50% vs 86%, p = 0.007), being the spouse of the caregiver (0% vs. 31%, P = 0.02) and cohabiting with him/her (53 vs 86, p = 0.01).

Conclusion: The level of burden and depression in caregivers caring for a patient with Alzheimer's disease is high. This rate can be reduced by all members of the family sharing in the care of the patient, and by resorting to institutional care in the advanced stages of the disease.

Key words: Alzheimer's disease, caregivers, stress, depression

Introduction

Alzheimer's disease is a dementia that is characterized by impaired cognitive function and psycho-behavioral disorders. It particularly affects people over 60 years old (1). In Tunisia, the prevalence of Alzheimer's disease among the Tunisian population aged 65 and over was 3.2% in 2012 (Alzheimer's disease affected more than 24,371 people) (1).

At an advanced stage, patients have a total and irreversible dependence. They require ongoing care and careful monitoring 24 hours a day, 365 days a year. The family is the main source of support for the patient with Alzheimer's disease and plays a key role in their care. This care is often demanding and requires much time and willingness, which can lead to the exhaustion of the caregivers. It is within this framework that our work has been carried out, in order to study the psychological health of the caregivers of the patient suffering from Alzheimer's disease.

The objectives of this study were firstly, to develop the socio-demographic profile of the natural caregiver of the patient, secondly to assess the level of burden and frequency of depression among caregivers and finally to identify the factors associated with the burden and depression of these caregivers.

Patients and Methods

This is a descriptive and analytical cross-sectional study. This investigation took place at the psychiatric consultation of the regional hospital of Gabes (South-Eastern Tunisia). All caregivers who accompanied their loved ones with Alzheimer's disease to their appointments, from November 1, 2016 to January 15, 2017 were invited to take part in the study. Caregivers who were unable to answer questions (n=4) or refused to participate in the study (n=11) were not included. All included patients gave their oral and written consent to take part in the survey and to answer the questions put to them.

Investigative methods included:
- A semi-structured questionnaire administered to the caregiver, which included socio-demographic data, lifestyle, past medical history as well as the caring relationship (relationship with the patient, primary caregiver or not, the period of care)
- The autonomy scale of Katz with 6 items. This is the "Activity of Daily Living" scale (ADL) (2).
- Zarit's burden inventory of 22 items (3).
- The abbreviated Beck inventory of depression of 13 items (7).

Course of the study
We conducted a pre-survey of 5 families to ensure the feasibility, clarity and relevance of our questionnaire. The objectives and modalities of this study were presented to families. Each caregiver was interviewed alone. The survey was conducted by the same investigator.

Statistic study
Descriptive analyzes (mean, standard deviation, frequency) were used to present the socio-demographic and clinical characteristics of our sample. We used the comparative analysis of the two groups of caregivers according to their levels of burden and depression. We chose parametric comparison statistics.

For each crossing performed, a Pearson Chi-squared statistical test was performed when the objective was to test the link between two qualitative variables, a T-test for independent samples was performed when the objective was to test the link between two qualitative and quantitative variables. The result of this test will confirm or refute our hypotheses. This is a statistical test used in the analysis of categorical responses. It provides a "p" value, which, if it is less than "0,05", leads us to accept the hypothesis that we can conclude that there is a link between the variables involved in the analysis.

All these descriptive and comparative analyzes were done by SPSS software (version 21).

Results

We were able to recruit 50 caregivers. The mean age of the patients was 77 years, with a standard deviation of 10 years, 54% were women (sex ratio H / F of 0.35) and 68% were illiterate. The average duration of disease progression was 4 years with a standard deviation of 2 years, and 58% were dependent.

The socio-demographic characteristics of caregivers are summarized in Table 1.

The average age of caregivers was 46 years old. Of those surveyed, 74% were women and 76% were married. One third of these caregivers had organic disease. The characteristics of the care relationship are summarized in Table 2.

The caregivers surveyed were the main caregivers in 66% of the cases, the children of the patients in 60% of the cases and living with them in 68% of the cases. The mean duration of care was 4 ± 2 years with an average of 6 hours care per day.

The average Beck score in our sample was 8,18 ± 6,3 ranging from 1 to 26.. Forty four percent (44%) Of the caregivers had a score above 8 and therefore a moderate to severe depressive state. Perceived burden as identified by Zzarit score averaged 43, ranging from 16 to 68. The score high than 43 points was categorized as high overloadconsidering as an approximate value for the threshold of a high burden, the level of 43. Thus, 24 caregivers (48%) had a high burden and 26 (52%) had a low burden. A high burden level was significantly correlated with the presence of depression (33% vs 67%, P = 0.002).

Table 1: Sociodemographics characteristics of natural caregivers

	N=50 Number (%)
Age of respondent (mean±SD)	46 ± 13
Gender	
Female	37 (74)
Male	13 (26)
Level of education	
Illiterate	8 (16)
Primary school	19 (36)
Secondary school	11 (22)
High school	12 (24)
Employment status	
Not employed	30 (60)
Retired	3 (6)
Liberal profession	8 (16)
Employee	9 (18)
Marital status	
Married/living with partner	38 (76)
Single/widowed	12 (24)
Children	3 ± 2
Socioeconomic status	
Low	5 (10)
Middle	41 (82)
High	4 (8)
Leisure practice	
No	35 (70)
Yes	15 (30)

SD : Standard Deviation.

Caregivers were defined as those currently caring for an adult relative with Alzheimer's disease or dementia,

- -

We found a significant correlation between depression and the following factors: the lack of employment activity in the caregiver (p = 0,007), being the child of the patient (p = 0,025) and living with him (p = 0,014). A high burden level was significantly correlated with the presence of depression (33% vs 67%, P = 0.002).

We found a significant correlation between depression and the following factors: the lack of employment activity in the caregiver (p = 0,007), being the child of the patient (p = 0,025) and living with him (p = 0,014). A high burden level was significantly associated with being the primary caregiver (p = 0.013) and living with the patient (p = 0,026) (Table 3 and 4).

Table 2: Distribution of caregivers by characteristics of the helping relationship

	Mean ± SD/ Number (%)
Relationship	
Child	30 (60)
Husband/Wife	7 (14)
Daughter-in-law	7 (14)
Others	6 (12)
Residence	
With patient	34 (68)
Not with patient	16 (32)
Main caregiver	
No	17 (34)
Yes	33 (66)
Number of years of assistance	4 ± 2
Duration of assistance per day (hour / day)	6 ± 3

Table 3: Correlations of socio-demographic and medical characteristics of caregivers with level of burden and depression

	Burden			Depression		
	Low burden (N=26)	High burden (N=24)	P	Not Depressed caregiver (N=28)	Depressed caregiver (N=22)	P
	Mean ± SD/ Number (%)	Mean ± SD/ Number (%)		Mean ± SD/ Number (%)	Mean ± SD/ Number (%)	
Age of caregiver (years)	42 ± 12	50 ± 12	NS	42 ± 12	50 ± 12	NS
Gender						
Female	17 (65)	20 (83)		19 (68)	18 (81)	
Male	9 (35)	4 (17)	NS	9 (32)	4 (19)	NS
Level of education						
Illiterate	4 (16)	4 (17)	NS	5 (18)	3 (14)	NS
Educated	22 (84)	20 (83)		23 (82)	19 (86)	
Employment status						
Not employed or retired	14 (54)	19 (79)	NS	14 (50)	19 (86)	0,007
Liberal profession/Employee	12 (46)	5 (21)		14 (50)	3 (14)	
Marital status						
Married	19 (73)	19 (79)	NS	21 (75)	17 (77)	NS
Single or widowed	7 (27)	5 (21)		7 (25)	5 (23)	
Children	2 ± 2	3 ± 2	NS	2 ± 2	3 ± 2	NS
Socioeconomic status						
Low	2 (8)	3 (13)	NS	3 (11)	2 (9)	NS
Middle/ High	24 (92)	21 (87)		25 (89)	20 (91)	
Leisure practice						
No	15 (57)	20 (83)	,048	19 (68)	16 (72)	NS
Yes	11 (43)	4 (17)		9 (32)	6 (28)	
Diagnosed comorbidities						
No	20 (78)	17 (71)	NS	21 (75)	16 (72)	NS
Yes	6 (22)	7 (29)		7 (25)	6 (28)	

Table 4: Correlations of socio-demographic and medical characteristics of caregivers with level of burden and depression

	Burden			Depression		
	Low burden (N=26)	High burden (N=24)	P	Not Depressed caregiver (N=28)	Depressed caregiver (N=22)	P
	Mean ± SD/ Number (%)	Mean ± SD/ Number (%)		Mean ± SD/ Number (%)	Mean ± SD/ Number (%)	
Relationship						
Son/ Daughter	17 (66)	13 (54)		20 (72)	10 (46)	
Husband/wife	1 (4)	6 (25)	NS	0 (0)	7 (31)	0,025
Daughter-in-law	3 (11)	4 (17)		4 (14)	3 (14)	
Others	5 (19)	1 (4)		4 (14)	2 (9)	
Residence						
With patient	14 (53)	20 (83)		15 (53)	19 (86)	
Not with patient	12 (47)	4 (17)	0,026	13 (47)	3 (14)	0,014
Main caregiver						
No	13 (50)	4 (17)		12 (43)	5 (23)	
Yes	13 (50)	20 (83)	0,013	16 (57)	17 (77)	NS
Number of years of assistance	4 ± 2	4 ± 2	NS	4 ± 2	4 ± 2	NS
Duration of assistance per day (hour / day)	5 ± 3	7 ± 3	NS	5 ± 2	7 ± 3	NS

Discussion

In our study, the socio-demographic description of our caregivers replicates some classic data (8,9). The younger age of caregivers and the predominance of female are also reported by other studies from Aarab countries (9). In this population, scores in Zarit Burden scale tend to be Higher than older caregivers (10), . In our study, the average burden was 43. Of the caregivers, 48% had a high level of burden. Similar results were reported by the Sfax study: the average burden in this region was 42 (8). In the literature, the burden level appears to be lower (5, 6, 10-12). These differences can be explained by a long duration of help in our study: 4 ± 2 years, and the younger age of our population. The high level of the Zarit Burden score may be related to the high prevalence of dependent Alzheimer's patients (58 %).

Among the caregivers in our study, Beck's mean score (8,18 ± 6,3) was higher than that of the general population (7 ± 7,05) (13), but lower than that found in a sample of Spanish carers (28 ± 8) (11). The rate of moderate to severe depression among caregivers in our study (44%) was higher than that observed in the Kerhervé study (22,8%) (5). These caregivers were referred to the psychiatric outpatient clinic.

The Zarit and Beck burden inventory scores were strongly correlated in our study (p = 0,002). Our results are consistent with several studies concluding that depression is significantly involved in the subjective experience of burden (5, 11, 14).

The Zarit and Beck burden inventory scores were strongly correlated in our study (p = 0,002). Our results are consistent with several studies concluding that depression is significantly involved in the subjective experience of burden (5, 11, 14).

In our study, the sociodemographic factors of patients do not seem to influence the level of burden and depression among caregivers. This result is consistent with the literature (6, 11, 14).

We also noted that 58% of the patients were dependent. The caregivers who reported the greatest burden and distress were those who reported the greatest loss of autonomy in their loved ones. Several studies are consistent with our results: the decrease in the basic activities of daily living of demented patients reflects a dependence on caregivers, which is undoubtedly an emotional, physical and financial burden for the caregiver (8, 10-12 , 15). Despite the literature, we did not find a correlation between the level of burden and depression in caregivers and the aggressiveness of patients towards caregivers (6, 8).

Since the caring relationship usually extends over a long period of time, the question of the influence of the number of years as a caregiver is important. The increase in the number of years spent in this status increases depression in the caregiver (16). This result was not found in our study: the mean duration of disease progression was 4 years (± 2) with no correlation with the level of burden and depression among caregivers.

Comparing the level of burden with that of not having a leisure activity gives a significant relationship. This could be explained as follows: The greater the burden felt by the caregiver, the more exhausted he is and the less time he can find for his leisure time.

In our study, there was a statistically significant relationship between depression and lack of employment activity of the caregiver. Work would play a moderating role in the onset of depression in our caregiving population.

In our study, there was no correlation between age, gender, educational level, socio-economic level, and past medical history of caregivers with level of burden and depression. The data in the literature differ on this finding. Indeed, some authors highlight the lack of relationship between the age, gender and educational level of the caregiver on the one hand and the level of the burden on the other hand (10, 11). However, Andrieu S. shows that women report a higher level of burden than men (6). Cinar E. finds that only a low level of caregiver education is associated with a high level of burden (14). Ben Thabet J. in his study of depression and burden of family caregivers of demented subjects in Sfax found that a high level of caregiver burden is correlated with the medium to high socio-economic level of caregivers (8). Ozlem E. shows that depression among caregivers is associated with female sex (17).

One of the factors that is recognized as a predictor of the burden for caregivers is the isolation of caregivers. Being

the main, if not the only person on whom the patient's care is based, increases the feeling of burden. Conversely, perceiving the environment as available and providing adequate support decreases the burden felt by caregivers (5).

In our study, 66% said they were the sole caregivers of the patient and 68% of caregivers lived with the patient. Both factors were associated with the burden. Several studies on the assessment of the level of burden among caregivers of demented patients are consistent with our findings in concluding that being the principal caregiver and living with the patient may be a predictor of the burden on caregivers (5, 8). , 10).

We did not find a statistically significant relationship between the level of burden, the duration of care, and the number of hours of care per day. These results are consistent with the literature (6, 10).

In our study, spouses had significantly more depression. On the other hand, for the principal caregiver, the duration of care and the number of hours of care per day do not present factors of depression. In his study José Maria Garcia (11) did not find a significant correlation between the relationship with the patient, the hours of care per day and depression among caregivers.

The value of the care provided by the family for a person with Alzheimer's disease is recognized. But this care has a negative impact on the health of the caregivers, in particular their mental health.

Conclusion

Our results reflect the distress of caregivers of Alzheimer's disease patients. The factors correlated with a high level of burden and depression are, in part, unmodifiable (kinship and degree of autonomy of patients). However, they allow us to target a population at risk that may receive special attention. Some modifiable factors (lack of work activity for carers, leisure activities of caregivers, living space shared with the patient and the situation of primary caregiver) could be the subject of appropriate care, and this as soon as the first symptoms appear, to relieve caregivers.

References

1. Hajem SO, Ben Mansour N, Y Mejdoub, Hsairi M. Epidemiology of dementia in Tunisia. NPG Neurology - Psychiatry - Geriatrics. December 2014; 14 (84): 326-33.
2. Katz S DT, HR Cash, Grotz RC. Progress in Development of the Index of ADL. Gerontologist. 1970; 10 (1): 10-30.
3. Zarit SH RK, Bach-Peterson J. Relative of the odd elderly: correlates of feelings of burden. Gerontologist. 1980; 20 (6): 649-55.
4. Réjean Hébert GB, Girouard D. Fidelity of the French translation of three assessment instruments for natural caregivers of demented patients. Canadian Journal on Aging 1993; 12 (3): 324-37.

5. Kerhervé H GM-C, Vrignaud P. Psychic health and burden of caregivers of people with Alzheimer's disease or related disorders. Medico-Psychological Annals. 2008; 166 (4): 251-9.

6. Andrieu S BL, Gillette-Guyonnet S, Bocquet H, Cantet C, Albarede J L, Vellas B, Grand A. The burden felt by informal carers of patients with Alzheimer's disease in the REAL.FR study: measurement method and associated factors. The Journal of Internal Medicine . 2003; 24: 351-9.

7. Collet L. Cottraux J. Abbreviated Inventory of Beck Depression (13 items). Competitive validity study with the scales of Hamilton and Widlcher. The Brain. 1986; 12 (2): 77-9.

8. Ben Thabet J, Charfi N, Zouari L, Zouari N, Maalej M. Depression and burden level among family caregivers of demented subjects in Tunisia. The Pan African Medical Journal. 2011.

9. Verrecchia S. The burden of caregiving by the caregiver of the patient with Alzheimer's disease (qualitative study on factors promoting exhaustion) [General Medicine]: University Claude Bernard-Lyon 1- Faculty of Medicine and Medicine Lyon-South Charles Merieux; 2015

10. Raggi A, Panerai S, Neria W., Ferri R. The burden of distress and related coping processes in families of patients with Alzheimer's disease living in the community. Journal of the Neurological Sciences. 2015; 358 (1-2): 77-81.

11. García-Alberca JM, Lara JP, Garrido V, Gray E, Lara A, Castilla C. Disengagement coping partially mediated the relationship between caregiver burden and depression in caregivers of people with Alzheimer's disease. Results from the MÁLAGA-AD study. Journal of Affective Disorders. 2012; 136 (3): 848-56.

12. Durkin M, Gupta S, Freedman D, Chapnick J. The Association between Dependent Patient and Caregiver Burden in Alzheimer's Disease. The American Journal of Geriatric Psychiatry. March 2013; 21 (3): 134-5.

13. Bocquet H AS. The "burden", a specific indicator for family carers. Gerontol Soc. 1999; 89: 155-66.

14. Cınara E KM, Yesilb Y, Halilb M, Cankurtaranb M, Arıogulb S. Assessment of factors affecting caregiver burden in Alzheimer disease (AD). European Geriatric Medicine. September 2012; 3: 138.

15. Lacey L, Trigg R, Niecko T. Caregiver burden as illnesses in Alzheimer's disease (AD): Association with patient dependence on others and other factors- Results from the Dependence in Alzheimer's Disease in England (DADE) study. Alzheimer's & Dementia. July 2012; 8 (4): 248-9.

16. Loubatieres H. Factors influencing the burden of the primary caregiver of Alzheimer's patients living at home: a systematic review of the literature [General Medicine]: University Toulouse III - Paul Sabatier Faculty of Medicine of Rangueil; 2014.

17. OE Aki YK, S Isikli, S Kibaroglu, ED Ciftci, UA Can. Depression, anxiety, burden and coping mechanisms in the family caregivers of Alzheimer's dementia patients in a Turkish sample. The Am J Geriatr Psychiatry . 2014 Mar; 22 (3): 12