ORIGINAL

Assessment of the burden placed on caregivers of patients with dementia using the ZARIT-MOR scale in Morocco

Evaluación de la carga de los cuidadores de pacientes con demencia mediante la escala ZARIT-MOR en Marruecos

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Abstract

Introduction: Family carers play an essential role in dementia care. This noble role is a significant burden that requires special support from family members and society in general.

Objective: Describe and analyse the characteristics of the dementia patients and the experiences of their primary caregivers according to the ZARIT-MOR scale (Moroccan dialect version) in the prefecture of Marrakech.

Methods and materials: An analytical and quantitative study of 110 care-givers in the district of Marrakech contacted through pharmacists, the private neurologists' offices, and the diagnostic centers of the Mohamed VI University Hospital, and also through the contact of care-givers directly via family and friends.

Results: The mean age of the patients was 77.3 ± 6.58 years, while the mean age of the caregivers was 44.7 ± 8.9 years. The gender of the patients is 69% female, whereas 83% of the caregivers are also female. In the relationship between the caregiver and the patient, 48% are the child and fraternity with 20%. The Zarit score shows a moderate to severe burden (56.8 ± 14.3). This study also found that the burden on the male caregivers (63.1 ±10.5) is high as compared with the female ones (55.4 ±14.6) (p= 0.013). Altogether, the study population presented a positive correlation between total Zarit score and the hours that the caregiver had spent caring for the patient per day (Spearman's correlation = 0.29, p<0.01).

Conclusion: The findings showed a high caregiver burden in dementia patients, requiring focused intervention to reduce primary caregivers' burdens and to improve their quality of care and their quality of life.

Key words: Dementia, family caregivers, burdens, Zarit-MOR.

Resumen

Introducción: Los cuidadores familiares desempeñan un papel esencial en el cuidado de la demencia. Este noble papel es una carga importante que requiere un apoyo especial de los familiares y de la sociedad en general.

Objetivo: Describir y analizar las características de los pacientes con demencia y las experiencias de sus cuidadores principales según la escala ZARIT-MOR (versión dialectal marroquí) en la prefectura de Marrakech.

Materiales y métodos: Estudio analítico y cuantitativo de 110 cuidadores del distrito de Marrakech contactados a través de farmacéuticos, las consultas de neurólogos privados y los centros de diagnóstico del Hospital Universitario Mohamed VI, y también a través del contacto de los cuidadores directamente o mediante familiares y amigos.

Resultados: La edad media de los pacientes fue de 77,3 ± 6,58 años, mientras que la edad media de los cuidadores fue de 44,7 ± 8,9 años. El género de los pacientes es 69% femenino, mientras que el 83% de los cuidadores son también mujeres. En la relación entre el cuidador y el paciente, el 48% son hijos y hermanos el 20%. La puntuación Zarit muestra una carga de moderada a severa (56,8 ± 14,3). Este estudio también encontró que la carga de los cuidadores masculinos (63,1 ± 10,5) es alta en comparación con los femeninos (55,4 ± 14,6) (p= 0,013). En conjunto, la población de estudio presentó una correlación positiva entre la puntuación total de Zarit y las horas que el cuidador había dedicado a atender al paciente por día (correlación de Spearman = 0,29, p<0,01).

Conclusiones: Los hallazgos mostraron una elevada carga de los cuidadores en los pacientes con demencia, que requiere una intervención focalizada para reducir la carga de los cuidadores primarios y mejorar su calidad de atención y su calidad de vida.

Palabras clave: Demencia, cuidadores familiares, cargas, Zarit-MOR.

Introduction

Over the past decade, a great deal of research has been conducted on the phenomenon of caregiver's burden. Although the concept is relatively new in the literature, the responsibility and potential consequences of caring for a loved one have existed for centuries. An experience that has many benefits, including personal fulfilment; however, it is also associated with physical, psychological and financial burdens[1].

This term came to the fore in Canada in 1980[2] is legally recognized for the first time in the French law n 2005-102 of 11 February for the equality of rights the rights of caregivers. In the literature and in the collective imagination, there are several terminologies referring to the same general idea (caregiver, natural caregiver, main caregiver, informal caregiver, accompanying caregiver, family caregiver[3].

While the exact definition is elaborated by the Confederation of Family Organizations in the European Union (CFOFEU) and the Collective departmental Inter Associative for help caregiver's Family in France which defined "The family caregiver or de facto carer is the person who provides non-professional assistance, in part or in full, to a dependent person in his or her family circle, for the activities of daily life[2]. A definition that reflects the range of activities of family caregiver's and its complexity[2].

The notion of burden began in 1960 with Grad and Sainsbury[4] who measured burden as a significant family cost. Furthermore, family giver's often accept the multiple and complex tasks involved in caring for another family member[5]. In relation to dementia, studies by Irvin and Acton[6] concluded that caregiving for Alzheimer's patients was more stressful because of the many behavioural problems that this population presents. According to these burdens, nearly 40% of caregivers[7] feel depressed and almost nine out of 10 caregivers feel a high burden and moral fatigue. And to assess this burden, several studies have tried to make it objective through scales that are essentially based on active listening and participant observation[8].

Finally, Steven H. Zarit conducted pioneering research on caregiver burden and stress. This led to the development of the Zarit scale, which provides an objective measure of burden based on several factors (emotional, physical and financial). With its 22 items, this scale has been translated into several languages, making it possible to assess the difficulties felt by caregivers. This test can be carried out with a social worker, the attending physician or the geriatrician in consultation[9]. On the other hand, in Morocco, despite the absence of a statute for natural caregivers, a Moroccan dialect version was created in 2022, which will make it possible to reveal the experiences of caregivers in a more objective way[10].

Materials and methods

Data collection: realised in the city of Marrakech, which is the third most populous city in Morocco with 45,205,569 inhabitants[11], of which the population aged over 65 years constitutes 9%. Contact with caregivers was made through several sites, pharmacies, private neurology practices, the diagnostic centre affiliated with the University Hospital Centre, health centres and also through direct contact with caregivers through friends and family.

Population and sample size: The sample is calculated on the basis of patients living in the city with an age above 65 years, as well as the target population was represented by the primary caregivers of demented patients living in the Marrakech and its regions (n=110).

Tool for data collection: Data collection was conducted by using the adapted and the translated version of the Zarit score. This was the Zarit Moroccan version (Zarit-MOR)[10]. Each item is scored from 0 to 4 according to its importance; 0=never, 1=rarely, 2=sometimes, 3=fairly often and 4=almost always. The sum of the scores obtained for each of the 22 items will vary from 0 to 88. Interpretation is done according to the number of points: Score lower than 20 (slight), score between 20 and 40 (mild to moderate), score between 40 and 60 (moderate to severe), score between 61 and 88 (severe).

Data analysis methods: performed by Microsoft Office Excel, SPSS21, Pvalue.io. The comparisons between groups were made on percentage numbers, using Student (T) and Chi-square tests. The Spearman correlation coefficient was used to quantify the strength of the linear association between two continuous variables. Due to the unequal sample size, the premise of equality of variances was checked systematically. If the test is significant (unequal variances), the Welch test was used.

Ethical considerations: this study took place after the authorisation of those in charge of the health care institutions following the agreement of the Bioethics Advisory Commission of the Faculty of Sciences of Agadir (N°: FCR-CS-09/2021-0001). Also, the investigators explained the purpose of the study with respect to the anonymity and confidentiality of the persons.

Results

The present study revealed that the mean Zarit score is 56.8 ± 14.3. Concerning the patients' characteristics, table 1 illustrates the predominance of the female gender (69%) and the urban origin is also dominant with 67%. for the level of education, it is observed that the illiterate present 51% against only 31% for the secondary level and 13% for the primary. In relation to marital status, 54% of the patients were married, 28% were divorced

and 12% were single. The statistical analysis of these variables did not show any significant relationship with the Zarit score (see **table I**).

Table II reveals that the mean age of the patients is 77.3 ± 6.58 years with no significant relationship with the Zarit score (p=0.39). The mean duration of the disease is 6.05 ±2.14 years which significantly increases the burden on caregivers (p<0.001).

For the characteristics of the principal caregivers, table 3 shows that the female gender represents 83% with a significant relationship with the Zarit score (p=0.011). The data from this study also shows that the mean age of the caregivers is 44.7 ± 8. 90 years but this time with no significant relationship with Zarit burden (p=0.51) (see **Table II**). Looking at the marital status of the caregivers we find that married caregivers constitute 65% followed by single caregivers with 21% but with no significant statistical relationship with the Zarit score (p=0.88) (**Table III**).

Daughters and sons predominate in the caregiver-patient relationship with 48%, followed by spouses with 20%, but no relationship with burden was found (p=0.24). In relation to education level, the results show that secondary and primary education are in first place with 36% and 33% respectively (**Table III**).

In relation to socio-economic level, caregivers working in the private sector represent 52% followed by 40% who do not have a fixed profession; this component is statistically related to the Zarit score (p=0.045). as for the data relating to caregivers' salaries, 55% have a monthly salary of less than 1,000 Moroccan dirhams and only 8.1% have a salary of between 4,000 and 10,000 dirhams. despite this, the relationship is not significant with the burden (see **table III**). Caregivers often need other people for assistance, this study shows that 25% take care of patients alone and 61% are replaced from time to time by one person and only 15% declare to be assisted by two other people. but without any significant relationship with the Zarit score (p=0.12).

In terms of chronic diseases, this study found that 25% of the caregivers had high blood pressure and 25% had diabetes. In terms of relationship with Zarit score, statistical analysis shows that diabetes is significantly related to Zarit score (p<0.01) but not for hypertension (p=0.63) (see **table III**).

In relation to the help needs expressed by the caregivers, the need for financial help was expressed by 72% of the caregivers, followed by the need for psychosocial help with 63% and the need for information on the disease expressed by 37% of the caregivers. Statistical analysis found a significant relationship with the Zarit score for the psychosocial need (p<0.01), however, no relationship was demonstrated with the other help needs (see in **table III**).

The same table also shows that the mean duration of illness (6.05± 2.14) and duration of assistance (5.80 ±2.01) are close, which can be explained by the care of the patients by the same caregivers from the beginning of the disease. We also note that a significant relationship between the Zarit score and the duration of the disease is shown by the Pearson test (p<0.001), as well as for the duration of assistance (p=<0.001) (see **table II**).

The present study found that the mean number of hours required by the patient for his or her caregiver was 16.2 ± 5.15. Bivariate analysis of this variable with the overall burden shows a significant relationship According to Spearman's test (P=<0.01) (see **table II**).

Table I: General characteristics of patients.

Patient's characteristics		n (%)	Zarit scale: Mean (SD)	p
Patient gender	Female	76 (69%)	57.0 (13.7)	0.89¥
	Male	34 (31%)	56.1 (15.7)	
Educational level	None	56 (51%)	53.8 (11.4)	0.28†
	Secondary	34 (31%)	58.0 (11.4)	
	Primary	18 (16%)	51.7 (10.3)	
	University	2 (1.8%)	54.5 (4.95)	
Marital status	Married	59 (54%)	56.6 (14.4)	0.051†
	Widowed	31 (28%)	52.5 (15.2)	
	Single	13 (12%)	62.5 (10.6)	
	Divorced	7 (6.4%)	65.7 (7.74)	

Table II: Patient and caregiver factors that influence caregiver burden (ZBI score).

		Mean ± SD	Correlation coefficient (95% CI)	p
Patient	Patient's age (years ± SD)	77.3 ± 6.58	0.0834	0.39†
	Duration of the disease (years ± SD)	6.05 ±2.14	0.609 (0.476; 0.715)	<0.001†
Caregiver	Caregiver's age (years ± SD)	44.7 ± 8.90	0.0632 (-0.126; 0.247)	0.51¥
	Duration of assistance (years ± SD)	5.80 ± 2.01	0.583 (0.444; 0.694)	<0.001*
	Number of hours per day (hours ± SD)	16.2 ± 5.15	0.290	<0.01¥

† : Pearson. ¥ : Spearman. * Welch

Table III: General characteristics of caregivers.

		n (%)	Zarit scale: Mean (SD)	p
Caregiver's gender	Female	91 (83%)	55.4 (14.6)	0.011*
	Male	19 (17%)	63.1 (10.5)	
Relationship with the patients	Child	53 (48%)	55.6 ± 14.6	0.24 †
	Spouse	22 (20%)	62.5 (9.66)	
	Fraternity	18 (16%)	55.1 (13.6)	
	Other	17 (15%)	54.6 (17.6)	
Educational level	Secondary	40 (36%)	48.8 (11.1)	<0.001†
	Primary	36 (33%)	65.5 (7.63)	
	None	23 (21%)	67.3 (6.75)	
	University	11 (10%)	35.2 (11.4)	
Marital status	Married	72 (65%)	57.0 (14.6)	0.88†
	Single	23 (21%)	55.5 (14.0)	
	Widowed	11 (10%)	57.1 (14.5)	
	Divorced	4 (3.6%)	58.2 (12.9)	
Employment status	Private	57 (52%)	60.7 (11.3)	0.045 †
	None	44 (40%)	51.7 (16.4)	
	Public	5 (4.5%)	55.2 (18.0)	
	Retired	4 (3.6%)	57.8 (7.80)	
Caregiver's salary (dirhams)	<1000	61 (55%)	55.5 (15.3)	0.64†
	[1000-4000[	41 (37%)	58.5 (12.6)	
	[4000-10000[	9 (8.1%)	57.7 (14.4)	
Co-helpers	None	27 (25%)	61.5 (11.3)	0.12†
	One	67 (61%)	55.4 (15.0)	
	Two	16 (15%)	54.6 (14.5)	
Diabetes	Yes	27 (25%)	63.1 (11.9)	<0.01*
	No	83 (75%)	54.7 (14.4)	
High Blood Pressure	Yes	27 (25%)	55.9 (13.8)	0.63¥
	No	83 (75%)	57.0 (14.5)	
Psycho-social help	Yes	69 (63%)	60.0 (12.0)	<0.01*
	No	41 (37%)	51.2 (16.1)	
Information help	Yes	41 (37%)	59.5 (10.8)	0.09*
	No	69 (63%)	55.1 (15.8)	
Financial help	Yes	79 (72%)	57.7 (14.2)	0.27*
	No	31 (28%)	54.4 (14.3)	

* Welch. ¥ Mann-Whitney. † Kruskal-Wallis.

Discussion of results

The Zarit score is a scale that objectively evaluates the burden of caregivers of dementia patients. In our study, the mean Zarit score was 56.8 ± 14.3, which indicates that the natural caregivers participating in this study suffer from a moderate to high caregiving burden. This is consistent with the finding reported by Tawfik & al., of a moderate to high caregiving burden with an average Zarit score of 61±13.7 from 60 family caregiver[12]. Compared to developed countries, the Zarit score of the population studied in this study is relatively high[13-14]. This may be related to caregiver support as well as their motivation in developing countries[15].

The mean age of the patients was 77.3 ± 6.58 years. This study showed a non-significant increase in the Zarit score in caregivers of elderly patients. This is different from the results of 458 caregivers studied by Win & al[16]. The difference can be related to the sample size in each study. Also the burden of caregivers was not dependent on the patients' level of education or their marital status. This confirms Dauphintot & al result[17].

The caregiver demographic profile shows a gender ratio of 0,34 this same result is also found by Liu & al[18] and Mourgues & al[19]. The reason for this may be that women are comparatively more caring than men, and are more likely to be completely available[20]. In contrast, the present study reported a significant increased burden for male caregivers. Other studies[18-19] noted that the burden in both sexes was similar. The caregivers in this study are younger than in both studies of Dias & al (57.9 ±13.75 years)[21] and Win & al (53.1 ± 11.8 years)[22]. This discrepancy may be explained by the size of the population and the increased age expectancy in Europe in comparison to Morocco. Regarding its relationship with caregiver burden, the present research showed that the burden was not related to the caregivers' age (p=0.39). While the Win Study showed that burden was high in elderly caregivers (p<0.01), this may be due to alteration in their health state with age[16].

About the caregiver's relationship with their patients, for James & al23, only 15% of the caregivers were

spouses and 48% were descendants of the patients. In the current study, forty-eight percent are progeny while fifteen percent are partners. As per Lucijanić & al (14) reported that the spouses were 38.9% and descendants were 51%, however there was no association with Zarit score from any of these studies.

In another aspect, according with James & al (23) showed that the exercise of a profession significantly increased the level of Zarit (p=0.01). This is supported by present research (p=0.045), possibly explained by additional burdens of occupational activities. Concerning the caregivers' salaries, Thompson & al[24] reported only 4.9% of the caregivers with low salaries (0-15,000 USD), however 37% from this study with no fixed salaries. The Zarit score, on the other hand, had no significant association with salary in this study (P=0.64). The Tunisian study conducted by Thabet & al., confirms the increased burden for caregivers with lower economic status (p=0.034)[25]. This divergence may be caused by the high level of solidarity that exists amongst the Moroccan families.

In the present study, the burden was also significantly elevated for caregivers who had assisted their patient for a longer duration (p<0.001). This is in contrast to the result from the Chinese Study conducted by Liu & al[18] (p=0.34). This could be attributed to the sufficient existence of care institutions as compared to Morocco and also that most of the caregivers in Morocco have additional professional occupations. Regarding the average number of hours per day the caregiver spends with the patient. There was also a significant increase in the Zarit score for caregivers who exceeded a significant number of hours. While, Liu & al., found a daily average of 15 hours per day, but with no significant relationship with the load (p=0.65)[18].

In the analysis of the caregivers' comorbidities and their related to the burden, this research indicated that caregivers suffering of diabetes showed a significantly increase in their burden (p=0.01). Compared to the other caregivers, those with high blood pressure had a similar level of burden to healthy caregivers. This finding is consistent with that of king; study who reported that 18.4% of diabetic caregivers experienced an increased burden (p=0,04)[26]. However, the study of Zubaidi & al[22] revealed that 53 % of the caregivers had various chronic diseases with absolutely no influence on burden (p=0.21). This difference was probably related to caregivers' staging of their chronic diseases and the co-existence of several comorbidities.

The analysis of education level of the caregivers revealed a significant increase of the Zarit score according to the level of education (p<0.001). This is similar to the results reported by Chang & al (27) (p=0.02). We can conclude that a higher level of education gives caregivers more knowledge about the disease and abilities in managing their patients' disease. his is confirmed by the need for information, which was expressed by 37% of the caregivers.

Conclusion

The caregivers of dementia patients constitute the essential component in the care of people with dementia. Quality in care requires supporting and training actions to facilitate the work performed by caregivers. Additionally, the legislation will be important in ensuring that caregivers are not exposed to any risks associated with their complex work.

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