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BURDEN AND QUALITY OF LIFE OF INFORMAL CAREGIVERS OF DEPENDENT ELDERLY

SOBRECARGA E QUALIDADE DE VIDA DOS CUIDADORES INFORMAIS DE IDOSOS DEPENDENTES

CARGA Y CALIDAD DE VIDA DE LOS CUIDADORES INFORMALES DE ANCIANOS DEPENDIENTES

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ABSTRACT

Introduction: The overload to which informal caregivers are subjected in their continuous care process can influence their quality of life. Some strategies and measures that prevent the exhaustion of the caregiver and that invest in their self-care can be taught and made available by health professionals.

Objective: To evaluate the overload of informal caregivers in the performance of their functions to the elderly person and to characterize their quality of life.

Methodology: Cross-sectional, descriptive study with a quantitative approach. Convenience sample, consisting of 24 caregivers of elderly people dependent in Activities of daily living. Questionnaire survey (WHOQOL-Bref) and selected scales (Zarit and Barthel), were anonymously applied to the caregiver. Statistical treatment through the Software Statistical Package for Social Sciences version 24.0.

Results: Most caregivers were women, married, aged between 41 and 50 years. 19 caregivers, out of a total sample of 24, present moderate and severe overload and assess their quality of life in 52.08%, which, according to the WHOQOL 100 (higher percentage = better perception of quality of life) means that they have a median/satisfactory perception of their quality of life.

Conclusion: With this study, it was possible to characterize the health profile of informal caregivers of elderly people with dependency, in a rural community in Alentejo, noting the urgent need to support this population in order to reduce their overload, stress, and anxiety.

Keywords: Burden; Informal Caregiver; Quality of Life; Self-care Promotion.

RESUMO

Introdução: A sobrecarga à qual os cuidadores informais estão sujeitos no seu processo contínuo de cuidar pode influenciar a sua qualidade de vida. Algumas estratégias e medidas que previnam a exaustão do cuidador e que invistam no seu autocuidado podem ser ensinadas e disponibilizadas pelos profissionais de saúde.

Objetivo: Avaliar a sobrecarga dos cuidadores informais no desempenho das suas funções à pessoa idosa e caraterizar a sua qualidade de vida.

Metodologia: Estudo transversal, descritivo, de abordagem quantitativa. Amostra por conveniência, constituída por 24 cuidadores de pessoas idosas dependentes nas Atividades de Vida Diárias (AVD). Inquérito por questionário (WHOQOL-Bref) e escalas selecionadas

(Zarit e Barthel), aplicadas ao cuidador em anonimato. Tratamento estatístico através do *Software Statistical Package for Social Sciences* versão 24.0.

Resultados: A maioria dos cuidadores são mulheres, casadas, com idades entre os 41 e 50 anos. 19 cuidadores, de uma amostra total de 24, apresentam sobrecarga moderada e severa e avaliam a sua qualidade de vida em 52,08%, o que pelo WHOQOL 100 (maior percentagem = melhor perceção da qualidade de vida) se conclui terem uma perceção mediana/satisfatória da sua qualidade de vida.

Conclusão: Com este estudo foi possível caraterizar o perfil de saúde dos cuidadores informais de pessoas idosas com dependência, de uma comunidade rural do Alentejo constatando-se a necessidade, urgente, de apoio a esta população com o objetivo da redução da sua sobrecarga, stress e ansiedade.

Palavras-chave: Cuidador Informal; Promoção do Autocuidado; Qualidade Vida; Sobrecarga.

RESUMEN

Introducción: La sobrecarga a la que están sujetos los cuidadores informales en su proceso de cuidado continuo puede influir en su calidad de vida. Algunas estrategias y medidas que previenen el agotamiento del cuidador e invierten en su autocuidado pueden ser enseñadas y puestas a disposición por los profesionales de la salud.

Objetivo: Evaluar la sobrecarga de los cuidadores informales en el desempeño de sus funciones por los ancianos y caracterizar su calidad de vida.

Metodología: Estudio descriptivo transversal con enfoque cuantitativo. Muestra por conveniencia, constituida por 24 cuidadores de ancianos dependientes de Actividades de la Vida Diaria (AVD). Encuesta cuestionario (WHOQOL-Bref) y escalas seleccionadas (Zarit y Barthel), aplicadas al cuidador de forma anónima. Tratamiento estadístico a través del Paquete de Software Estadístico para Ciencias Sociales versión 24.0.

Resultados: La mayoría de los cuidadores son mujeres, casadas entre 41 y 50 años. 19 cuidadores, de una muestra total de 24, presentan sobrecarga moderada y severa y evalúan su calidad de vida en un 52,08%, que según el WHOQOL 100 (mayor porcentaje = mejor percepción de la calidad de vida) se concluye que tienen una mediana percepción/calidad de vida satisfactoria.

Conclusión: Con este estudio, fue posible caracterizar el perfil de salud de los cuidadores informales de ancianos con dependencia, en una comunidad rural del Alentejo, constatando la urgente necesidad de apoyar a esta población para reducir su carga, estrés y ansiedad.

Descriptores: Calidad de Vida; Cuidador Informal; Promoción del Autocuidado Sobrecarga.

INTRODUCTION

The world population is aging and in every country in the world there is an increase in the number and proportion of elderly people. Population aging has become one of the most significant social transformations of the 21st century, with cross-cutting implications for all sectors of society(1). Portugal follows this global trend, facing a progressive aging of its population, with inevitable consequences both at a socioeconomic level and in terms of health and quality of life. In this sequence, the Alentejo is also making great strides towards progressive aging, registering aging rates in the order of 207 elderly people for every 100 young people(2). According to the Ministry of Health(3), this demographic context is reflected in the state of health, with emphasis on the significant increase in chronic diseases and a high number of people with multiple pathologies that require an unquestionable complexity of care. For Canhestro(4) aging and the awareness of a longer life pose challenges to health systems and society in general, as well as to individuals, families and communities, involving greater individual and collective investment so that greater longevity implies more health and quality of life.

Elderly people in a situation of dependence and fragility essentially need care and attention from those who are close to them, namely a close family member who assumes the role of informal caregiver. The informal caregiver, also sometimes referred to as a family caregiver, is the person closest to the recipient of care and is increasingly essential to continue the provision of care, starting to perform tasks with the guidance and training of health professionals. The role of caregiver is usually assumed by the closest family member, usually the spouse or a daughter, with a predominance of females in this role. The Statute of the Informal Caregiver(5), considers the main informal caregiver the spouse or common-law partner, relative or similar up to the 4th degree of the straight line or collateral line of the person cared for, who accompanies and cares for this person permanently, who lives with her in a common house and who does not receive any remuneration for her professional activity or for the care she provides to the person being cared for.

For Teixeira *et al*(6), informal caregivers are all citizens who have taken upon themselves the duty of caring for another person. Analyzing it from the perspective of involvement with the person being cared for, the caregiver is, therefore, a co-participant, since the caregiver must be seen as active in this partnership(7). Also for these authors, caring is an inter-relational and contextual process that requires involvement of caregiver's personal, social, moral and spiritual commitment and commitment to self and others. Family care has been conceptualized as a complex and multidimensional experience, primarily explained in terms of stress or overload(7). The term caregiver burden has been extensively studied lately and refers mainly to the negative effects that caring for another person can have on the caregiver. The role of informal caregiver entails great responsibility, and the continuous exposure to physical, psychological and social efforts causes an overload that may have repercussions on the caregiver's physical and mental health. In order to reverse this trend, it is extremely important to develop strategies that prevent caregiver overload and increase their self-esteem, self-care and, consequently, their quality of life. The research developed aimed to identify the factors that influence the quality of life and the perception of the objective and subjective overload of the informal caregiver, providing care for dependent elderly in a rural community in Alentejo. In general terms, it was intended to characterize the way in which the informal caregiver, who provides care to dependent elderly people, sees the provision of that same care and what is their degree of exhaustion, as well as their quality of life.

METHODOLOGY

This is a cross-sectional, descriptive and observational study of a quantitative nature, which took place in one of the parishes in the area covered by a Community Care Unit (UCC) of the Agrupamento de Centros de Saúde (ACES) in Central Alentejo. The study population consisted of informal caregivers of dependent elderly people, enrolled in the area covered by the UCC, namely in one of the parishes in the municipality, who voluntarily agreed to participate in the study and who met the following inclusion criteria: being over 18 years-old, be the main caregiver, the person cared is 65 or older and is dependent on one of the ADLs, signing the Informed, Free and Informed Consent (CILE). The sample consisted of 24 participants, thus representing a convenience sampling and also a snowball sampling, as some caregivers indicated others.

Taking into account the intended objective of carrying out the study and the theoretical anchoring taken as a premise, the use of anonymous scales and questionnaires was used as data collection instruments. Thus, the Barthel Scales were used to characterize the degree of functional dependence of the elderly in activities of daily living and the Zarit Scale to assess the objective and subjective burden of the informal caregiver, which includes information on: health, social life, personal life, financial situation, emotional situation and type of relationship. The World Health Organization's quality of life questionnaire, the WHOQOL-Bref, was also applied. This is a questionnaire with 26 questions of a multidimensional and multicultural nature, for a subjective evaluation of the quality of life and integrates four domains, the physical, the psychological, social relations and the environment, and also allows the calculation of a global indicator, namely the general facet of quality of life. Three questions will have to be reversed at the end (3, 4 and 26) and the final result will be transformed into a scale from 0 to 100, with a higher score corresponding to a better perception of quality of life(9).

Data were processed using the software SPSS – Statistical Package for the Social Sciences for Windows, version 24.0. The presentation of descriptive statistics is done through tables, charts and graphs.

All ethical requirements were fulfilled in accordance with the Helsinki Declaration of Ethics in research involving human beings, and all necessary authorizations were also obtained. The study obtained a favorable opinion from the Ethics Committee for Scientific Research in the areas of Human Health and Welfare of the University of Évora and from the Ethics Committee for Health of the Regional Health Administration of Alentejo.

RESULTS

Of the 24 caregivers surveyed, 20 are female and 4 are male, with different ages, with the age group between 41-50 years-old being the one with the highest frequency, and it can be said that most caregivers are under 50 years-old.

Regarding marital status, most caregivers (n = 17) are married or living in a de facto relationship. Also with regard to employment status, 10 caregivers are active in terms of employment, 7 are retired, 4 are unemployed and 3 are housewives or have never worked. Educational qualifications are also dispersed, but the one with the highest number of responses was the 7th-9th grade, with 8 caregivers, 1 caregiver cannot read or write, just sign his/her name. The degree of kinship that unites the caregiver to the elderly person in their care is, in most cases, "child" (n = 17) and then spouse (n = 5). As for the time of dependence of the elderly person, the highest frequency was registered in the variable of "more than 5 years", with 10 responses. Most informal caregivers live in the same home as the elderly person being cared for (n = 17), however 6 live in another home and 1 occasionally lives with the elderly person. Regarding the question about whether they receive help to provide care, 13 caregivers answered yes, usually from siblings or children and 11 answered that they are the only ones caring. Of the 24 caregivers, only 2 receive formal support from the National Network for Continuing Integrated Care and Palliative Care. Some of the elderly people have support of a particular nature, regarding hygiene care and food supply, as there is no social support in the parish in question. Dependent elderly people are mostly female (n = 15) and the rest are male. They are between 66 and 100 years-old.

Although 4 elderly people were totally bedridden, with the application of the Barthel Scale we found that: 8 had moderate dependence, 6 had total dependence and severe and mild dependence was manifested in 5 elderly people (Graph 1↗).

When we applied the Zarit scale to the informal caregiver, to assess the caregiver's degree of overload and exhaustion, we verified, through the descriptive analysis, that most caregivers are in a moderate and severe level of overload, with only 4 caregivers mentioning the absence of overload (Table 1↗).

When assessing whether the caregiver perceives being overloaded, we found that 17 caregivers regularly recognize this overload, identifying it on a scale that ranges from "sometimes" to "almost always" as shown in Table 2↗.

Another question addressed in the Zarit Scale is whether the health of informal caregivers can be affected due to the provision of care to dependent family members. Among the 24 caregivers, the majority (n = 11) answered that "never" or "almost never" considers this care for the elderly family member as an influencing factor for their health (Table 3↗).

In the application of the questionnaire WHOQOL-Bref, the participants are asked to consider the last 15 days of their lives, their expectations, joys and concerns. Thus, the 24 caregivers answered the general question "How do you evaluate your quality of life?", obtaining an overall result of 52.08%, which, according to the WHOQOL 100, reveals a quality of life, in general, median/satisfactory (in this instrument, the higher the best final score is the perception of quality of life).

The other question, related to satisfaction with their own health, 8 caregivers responded that they are satisfied, 5 are neither satisfied nor dissatisfied, 7 are dissatisfied and we have 2 very dissatisfied caregivers and 2 very satisfied. In short, 9 caregivers are dissatisfied or very dissatisfied with their health status.

When we analyze in detail the different domains of the WHOQOL-Bref., we found that in the physical dimension of the caregivers, an average score of 58.32% is obtained, which indicates that there is some repercussion of the care provided to the elderly family member, on the physical health of the caregivers. In the psychological domain, we obtained an average of 63.01% and in social relationships, also evaluated in this instrument, a very similar value of 63.19%, which shows that most caregivers are satisfied with their intimate and social relationships and with the support you get from your friends. Finally, the last domain evaluated implies the environment in which the caregiver is inserted, and for which we obtained an average response of 58.98% (Graph 2↗).

DISCUSSION OF RESULTS

After analyzing the results, we found that most of the informal caregivers who participated in this study are women, married and with a degree of kinship with daughters or spouses in relation to the person cared for. Most of them live with the elderly relative in the same house, have educational qualifications between the 7th and 9th grade and 10 of these caregivers are still exercising their profession. The results obtained regarding the characterization of the caregivers in this sample are in line with what was mentioned by Sequeira(10) when he states that "the most consensual data suggest that the caregiver is essentially performed by women and by close relatives of the elderly, who usually live in co-residence". The same author also reveals that caregivers are essentially adults over 40 years-old, an aspect also evidenced by the results of this study. Another investigation(11) showed that, in general, the caregiver is a woman, a daughter and does not have knowledge or experience about serious diseases. In the Journal of Nursing, a study was published in 2017(12), which aimed to describe the characteristics of the elderly people and their family caregivers at home. The authors used, among others, the Zarit scale and the WHOQOL-Bref questionnaire, in 71 elderly people and their caregivers, having obtained the following results about the caregivers: predominance of women, with advanced age, low education, unfavorable economic conditions and cohabiting with the elderly person, facts that are corroborated by the results of the present study. Another study(13), in which the objective was to assess the quality of life and burden of female caregivers, concluded that they had an average age of 51.8 years-old and were mostly married, with low incomes and low education, with a degree of close kinship, they provided care for between one and five years and already had some pathology.

In view of the above, we can say that the profile of informal caregivers in the present study is similar to that of previous studies.

Regarding the characterization of elderly people with dependence, we found that most of them have moderate to severe dependence, aged between 66 and 100. In a society where the elderly population has been growing exponentially, the assessment of the degree of autonomy of this population group is extremely important in assessing the population's health status and care needs(14). The increase in average life expectancy has led to an aging population and a higher prevalence of chronic diseases, so informal caregivers are essential in caring for dependent family members.

Caring for a dependent family member can have a negative impact on the health, emotionality and professional life of the caregiver(15). The performance of this role can lead to overload and exhaustion, as described in a study that included 164 informal caregivers of people dependent on self-care, which concludes, like the present study, that most caregivers are women (82.9%), living with the person cared for (70.1%) and more than half have intense overload (57.7%), related to preparation for care, areas and time of dependence(16). The objective of our study was to evaluate the burden of informal caregivers of elderly people with dependence, having concluded that most caregivers have a level of burden that ranges from moderate to severe. Overload is a concept that refers to exhaustion due to fatigue, translating the caregiver's exposure to significant stress factors in a relatively short period of time(10). Some of the studies(10,16) consulted on the problems of informal caregivers refer that the burden has two levels: objective and subjective burden. The objective burden is related to practical and physical aspects, while the subjective burden is aimed at the caregiver's perception of care, namely their emotions and feelings. The burden is related to the decrease in the caregiver's quality of life and to the increase in morbidity, both for the caregiver and for the elderly person being cared for.

These caregivers, when asked if they want to entrust their family member to the care of other people, mostly respond (n = 16) that “never or almost never” equate it, also denying feelings of irritation or damage to their social life, with the friends, because they are caregivers. It is the bonds of love and affection that unite them to their dependent family members, which prevail, even in a situation of stress and overload resulting from the provision of care.

Regarding the quality of life of the participants in this study, it was perceived as reasonable (with a metric of 52.08%), however, for 9 of the caregivers, when asked about their health status, they revealed to be dissatisfied or very dissatisfied. with the same.

Quality of life and psychological well-being include dimensions such as: personal satisfaction, emotions, sensitivity, feelings and desires, according to each person's subjectivity(10). In the applied questionnaire (WOQOL Bref.) four domains were evaluated: physical, psychological, environmental and social relationships. The evaluation obtained very similar results in all domains, with the physical domain having the lowest rating (58.32%), followed by the environmental domain (58.98%), the psychological domain (63.01%) and finally the best evaluated, the domain of social relations (63.19%). The areas that presented the highest results were the taste for life and the physical environment of the healthy home. The facets that present the lowest results are satisfaction with sleep and rest, leisure activities and also negative feelings, such as sadness, despair, anxiety or depression. These data are corroborated by another study(17), where more than half (61.8%) of caregivers experienced at least mild symptoms of depression, the overall quality of life was lower compared to care non-providers, with a lower score in the physical domain (51.9%) and higher in the environmental domain (64.9%).

To improve the quality of life of care providers and the quality of care provided to patients, health professionals must be well informed about the difficulties and needs of care providers(18). The same authors recommend, in their work, that the inclusion of care providers, in a holistic approach, represents a basic principle in health care(18).

A study(19) on self-care in informal caregivers of patients in palliative home care, corroborates the results obtained with the application of this questionnaire. It found that caregivers' self-care needs are linked to inadequate sleep and rest, ineffective nutrition and hydration, impaired social interaction, health risk, socioeconomic vulnerabilities, and lack of education and experience in caring. In Portugal, the Caring for Informal Caregivers Movement(20), carried out a national study, by telephone survey, in which it obtained similar results, as many of the caregivers responded regarding family reorganization, that they no longer had time for themselves and to be with family (38.8%), for vacations or weekends and social life (24.7%), who had lost income (5.1%) and some had emotional disturbances (2.2%) .

Despite the limitations of the present study, inherent to its descriptive and case typology, which make it impossible to generalize the results, some important conclusions can be drawn regarding the characterization of informal caregivers.

Thus, based on this diagnosis of the situation, based on the Health Planning Methodology, it was proposed the elaboration and implementation of a community intervention project with the purpose of contributing to the promotion of self-care of informal caregivers of elderly people with dependence, in a rural community in Alentejo.

CONCLUSION

With this study, it was possible to characterize the informal caregivers of elderly people with dependency, in a parish of Alentejo Central. It was proven that there is a prevalence of female caregivers, usually daughters or spouses; the elderly people cared for are mostly dependent on ADL and have had this condition of dependence for more than 5 years. Through the diagnosis carried out, it was verified that the self-care of informal caregivers was compromised, whether in terms of sleep and rest, or in terms of recreational and leisure activities. Burden is present, as well as a lower perception of quality of life, aggravated in the physical and environmental aspects. This study presents itself as an asset to understand the needs of informal caregivers and guide activities that meet their specificities, namely in support and information about care for the elderly person.

Currently, the informal caregiver is assumed to be essential due to the significant aging of the population and, consequently, the increase in the number of dependent people. Their importance must be recognized and efforts must be made to support them in providing care to their dependent family members, considering them as "care partners". Informal care providers have a high risk of suffering from burden and exhaustion, due to the stress they are subjected to by constant care. This stress has a direct influence on the person being assisted, mainly affecting the quality of care. Thus, it becomes relevant to support informal caregivers, namely through the implementation of interventions in the community for this population, with the objective of reducing burden, stress and anxiety. Interventions to be carried out with care providers generally focus on rest, counseling and education programs, focusing on literacy and self-care.

It is suggested that in the future, studies and scientific evidence on informal caregivers should continue to be developed, due to the impact they have on communities, families and/or society in general.

Authors' contributions
CD: Study coordination, study design, collection, storage and analysis of data, review and discussion of results.
LG: Study design, data analysis, review and discussion of results.
EC: Study design, data analysis, review and discussion of results.
AC: Study design, data analysis, review and discussion of results.
EM: Study design, data analysis, review and discussion of results.
All authors read and agreed with the published version of the manuscript.

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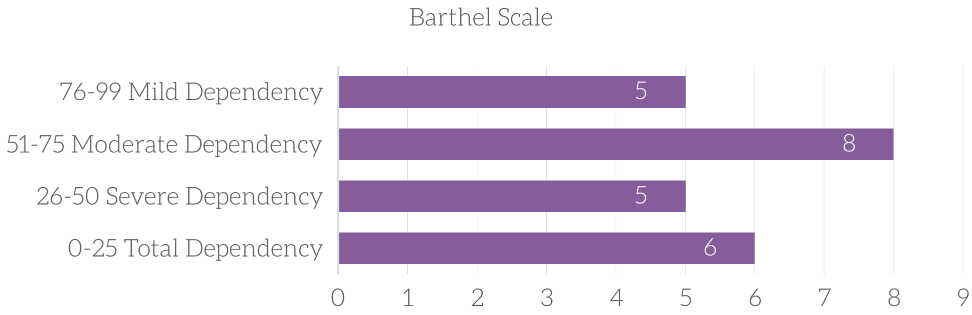


Graph 1 – Elderly people's dependency levels.

Source: Descriptive analysis of SPSS 24.0.

Table 1 – Assessment of the burden of informal caregivers.↸

		Frequency	Percentage
Valid	< 21 Absence of burden	4	16.7
	21-40 Moderate burden	11	45.8
	41-60 Moderate to severe burden	8	33.3
	> 61 Severe burden	1	4.2
	Total	24	100.0

Source: Descriptive analysis of SPSS 24.0.

Table 2 – Perception of burden by the informal caregiver.↸

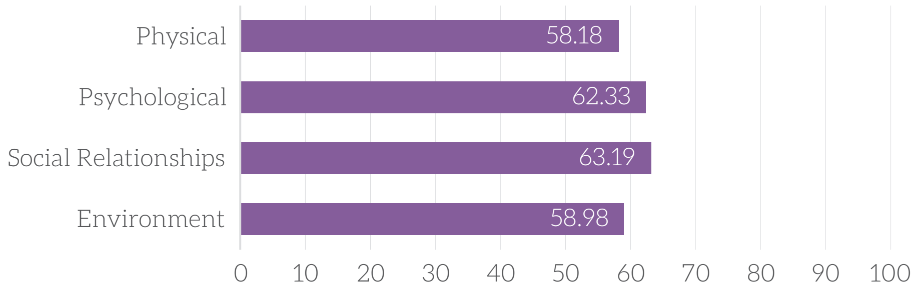
		Frequency	Percentage
Valid	Never	5	20.8
	Almost never	2	8.3
	Sometimes	8	33.3
	Usually	6	25.0
	Almost ever	3	12.5
	Total	24	100.0

Source: Descriptive analysis of SPSS 24.0.

Table 3 – Implication of care in the health of the informal caregiver.↸

		Frequency	Percentage
Valid	Never	7	29.2
	Almost never	4	16.7
	Sometimes	7	29.2
	Usually	5	20.8
	Almost ever	1	4.2
	Total	24	100.0

Source: Descriptive analysis of SPSS 24.0.



Graph 2 – Result of the WHOQOL-Bref questionnaire domains.↸