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CHARACTERIZATION OF INFORMAL CAREGIVERS OF PEOPLE IN CANCER PALLIATIVE CARE

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ABSTRACT

Objective: This study aimed to identify the sociodemographic characterization, life and work habits and activities developed by informal caregivers. **Method:** A quantitative, transversal and descriptive study developed with 45 informal caregivers of people with stage IV of cancer and palliative care, attended at a High Complexity Unit in Oncology of Minas Gerais. Data collection was performed through interviews in home visits with the application of a characterization tool developed by the researchers. Data presented absolute values and descriptive statistics. **Results:** There was a predominance of women, daughters or wives, with a high school education, with a mean age of 50 years-old, married or with partners, who reported having Hypertension, were not smokers or alcoholics, and did not practice physical activities and leisure activities. They had been in care for more than a year, and most of them have not worked, corresponded with the person under their care, and carried out daily care between five and ten hours, without care assistance, and haven't had caregiver courses. **Conclusion:** Identifying the informal caregiver profile contributes to the advancement of science and to improving the support of health professionals to caregivers.

Keywords: Cancer. Palliative care. Family Caregivers. Nursing.

INTRODUCTION

Cancer is considered a public health problem worldwide, according to the National Cancer Institute (INCA). It is estimated that in 2030 there will be about 27 million new cases of the disease worldwide. In Brazil, in 2013, 189,454 cancer deaths were recorded and for the 2018-2019 biennium, 600,000 new cases of cancer were reported for each year(1).

Due to their magnitude and the complexity of the disease, some patients are unable to respond to treatment further, despite the advancement of medicine, making palliative care necessary (1).

The concept of palliative care was sanctioned by the World Health Organization (WHO) in 2002 as an approach that improves the quality of life of patients and their families in a biopsychosocial and spiritual way(2).

Under this view, significant changes in the care process are necessary, since it is essential to guide it in the principles of palliative care, which are symptom control, spiritual, psychological and social support, and the involvement of family and patient(3).

In this perspective, the informal caregiver appears in the process of changes of roles within the family and the choice often does not occur spontaneously. He is usually a member of the family who does not receive remuneration for care and may not have specific knowledge of care and dedicates part of his time to the sick person(4).

Many caregivers become ill for lack of support to develop care, as they are stressed by not knowing how to deal with the other's suffering and also his suffering, and by the closeness of the death of the care. Many caregivers feel that their personal lives were directly or indirectly negatively affected, with the presence of stress and high overload, and that this interferes with the care given to the patient(5).

Identifying the characterization of the informal caregivers of people in cancer palliative care can allow healthcare professionals to know the context of life and thus offer support to help them in this

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process, improving the quality of life of the caregiver and the person cared. It can also contribute to the advancement of science in relation to the proposed theme.

The present study aimed to identify the sociodemographic characterization, life and work habits and activities developed as informal caregiver.

METHOD

This is a cross-sectional quantitative study conducted with informal caregivers of people with stage IV of cancer and palliative care enrolled in a High Complexity in Oncology Unit of a municipality in the South of Minas Gerais, from 2014 to 2017. In order to select the participants, the following inclusion criteria were adopted: male and female caregivers aged 18 years-old and over, people with stage IV of cancer, in a palliative care condition, and who lived in the urban area of the municipality under study. From the total of 63 possible participants, 18 were excluded, four of whom died, four had an incorrect address, four had their records duplicated, one had a formal caregiver and five were enrolled in the pilot study and were excluded. Thus, 45 informal caregivers participated in this study.

Data collection was performed in the second semester of 2017 by the researcher on a pre-scheduled home visit, through interview and application of a semi-structured questionnaire, prepared by the researchers, containing 24 questions to identify the sociodemographic characterization, life habits, labor activities, and activities developed as informal caregivers of people in cancer palliative care, as well as the data of the person under care. The instrument was submitted to the pilot study with the objective of ascertaining the pertinence of the variables and the comprehension, without the need for alterations. The objective and the relevance of the research to the caregivers were explained and, through its acceptance, the researcher submitted the Free and Informed Consent Term in two ways, one to the participant, and the other to the researcher. The study was approved by the Research Ethics Committee of the Federal University of Alfenas (UNIFAL-MG), with an opinion number 064258/2017 (CAAE: 69684417.2.0000.5142), following the principles of Resolution 466/2012.

The data collected were typed in an MS-Excel spreadsheet, version 2010, for database design, in double typing. The *Statistical Package for Social Science* (SPSS) software version 17.0 was used for data analysis.

Data were presented by means of tables, consisting of absolute and percentage values, and numerical variables with descriptive statistics (mean, median, standard deviation, minimum and maximum).

RESULTS

It was verified the predominance of female subjects (80.0%), age group of 36 to 50 years-old (35.6%), married (62.2%), Catholic (75%), with one to two children (44.4%), monthly family income from R$ 1,851 to R$ 2,700 (42.2%) and who had a high school education (35.6%), as presented in the table 1.

It was found that 26.7% of informal caregivers are smokers, 80.0% said they are not alcoholic, 82.2% have not practiced physical activity, 77.8% said they don’t have leisure activity, 57.8% work, with a weekly workload above 20 hours (57.9%), 60.0% reported having no chronic disease, however, 77.8% reported having arterial hypertension (Table 2).

From the data presented in table 3, it can be observed that 35.6% of the participants performed care from 1.01 to 2 years, 35.6% were the patient's child or spouse, 33.4% up to 5 hours of care a day, 86.7% lived with the person cared, 93.3% did not have a caregiver course and the totality did not receive help to perform care (Table 3).

Table 1 -Distribution of informal caregivers of persons in palliative care according to sociodemographic data. Poços de Caldas, MG, 2018. (n=45).

Variables	f	%
Gender		
Male	9	20,0
Female	36	80,0
Age group		
Up to 35 years-old	7	15,6
36 to 50 years-old	16	35,6
51 to 65 years-old	13	28,8
Older than 65 years-old	9	20,0
(mean = 51.18, median = 49.00, standard deviation = 15.22, minimum = 21, maximum = 88)		
Marital status		
Single	9	20,0
Married/ with partner	28	62,2
Separated/divorced	6	13,4
Widowed	2	4,4
Religion		
Catholic	34	75,6
Protestant	10	22,2
Spiritist	1	2,2
Number of children		
No one	11	24,4
1 to 2	20	44,4
More than 2	14	31,2
(mean = 1.80, median = 2.00, standard deviation = 1.44, minimum = 0, maximum = 6)		
Family Income		
Up to 1000 reals	8	17,8
1001 to 1850 reals	5	11,1
1851 to 2700 reals	19	42,2
More than 2700 reals	13	28,9
(média = 2251,40; mediana = 2000,00; desvio padrão = 1253,18; mínimo = 954,00; máximo = 8000,00)		
Scholarship		
Illiterate	1	2,2
Incomplete elementary school	4	8,9
Complete elementary school	13	28,9
Incomplete high school	5	11,1
Complete high school	16	35,6
Incomplete graduation	1	2,2
Complete gratuation	3	6,7
Post-graduation	2	4,4

Source: Created by the author.

Table 2 -Distribution of informal caregivers of persons in palliative care according to variables related to living habits and labor activities. Poços de Caldas, MG, 2018. (n=45).

Variables	f	%
Smoking		
No	33	73,3
Yes	12	26,7
Alcoholism		
No	36	80,0
Yes	9	20,0
Physical activities practice		
No	37	82,2
Yes	8	17,8
Leisure activities		
No	35	77,8
Yes	10	22,2
Labor activities		
No	26	57,8
Yes	19	42,2
Weekly workload **		
Up to 20 hours	8	42,1
More than 20 hours	11	57,9
(mean = 29.26, median = 30.00, standard deviation = 11.69, minimum = 12, maximum = 44)		
Presence of chronic disease in the caregiver		
No	27	60,0
Yes	18	40,0
Chronic disease**		
Systemic Arterial Hypertension	14	77,8
Diabetes Mellitus	5	27,8
Schizophrenia	1	5,6
Rheumatoid arthritis	1	5,6
Skin cancer	1	5,6
Rhinitis	1	5,6

Source: Created by the author.

*Only caregivers who have a labor activity (n=19).

**Only informal caregivers who have chronic illness. There was more than one response per interviewee (n=18).

Table 3 -Distribution of informal caregivers of people in palliative care according to the variables related to informal caregiver activities. Poços de Caldas, MG, 2018. (n=45).

Variables	f	%
Time of care		
Up to 1 year	14	31,1
1,01 to 2 years	16	35,6
2,01 to 3 years	6	13,3
More than 3 years	9	20,0
(mean = 2.69, median = 1.60, standard deviation = 2.82, minimum = 0.4, maximum = 15)		
Degree of kinship		
Child	16	35,6
Husband/wife	16	35,6
Sibling	5	11,1
Grandchild	2	4,4
Daughter-in-law/ son-in-law	3	6,7
Niece/nephew	1	2,2
Brother-in-law/ sister-in-law	1	2,2
Friend	1	2,2
Daily hours of care		
Uo to 5 hours	15	33,4
From 6 to 10 hours	14	31,1
From 11 to 15 hours	11	24,4
More than 15 hours	5	11,1
(mean = 8.82, median = 8.00, standard deviation = 4.49, minimum = 3, maximum = 18)		
Live with the person		
No	6	13,3
Yes	39	86,7
Receive assistance in the care		
No	45	100,0

Source: created by the author

DISCUSSION

In this investigation, the predominance of female caregivers in the age group 36-50 years-old, married or living with a partner, findings corroborating other studies(6,7). Because they are married women and with partners, it is inferred that such condition associated to the care activity with increasing demands can lead to biopsychosocial overload and compromise the conjugal relationship.

The predominance of women as caregivers reflects the condition associated with gender, that is, the woman was always responsible for maintaining the functioning of the home and care for the children, while the role of the man was to ensure the financial provision of the family. Even with the changes related to the insertion of women in the labor market, it is still common for women to play the role of caregiver(8,9).

The fact that these women are in a mature age range may present psychological, social and biological problems, which corroborates the commitment of their health(8).

The predominant Catholic religious belief in this study was also found in the results of another investigation(6). The fact of having a belief can be considered a positive factor in the caring process(10).

It was found that caregivers reported having one to two children, a condition similar to that found in another study(11). These findings lead us to think that the caregiver's condition with children, especially among women, may increase concerns and household chores.

In this investigation, the variable monthly family income of informal caregivers resembled the results of other studies(8,9), as well as portrayed in the Brazilian population. It should be noted that the income of the informal caregiver can cause difficulties in the care given to the sick person, since it makes access to supplies, medication and other care needs difficult(12).

The predominant schooling was the complete secondary education, which corroborates with the findings of other studies(6,13). This variable influences the quality of care provided to the person, due to the complexity of palliative care, which requires care with adequate food, especially in the use of enteral feeding, as well as to medicate the patient correctly(14).

Regarding lifestyle habits, most participants denied cigarette and alcohol use, as well as physical and leisure activity, which is in line with the results of an investigation(15).

A study in other populations found that consumption of alcoholic beverages and cigarettes, as well as the failure to perform physical activities regularly and changes in systolic and diastolic pressure, has been a characteristic of the Brazilian young population, especially among men(16). Among these habits, alcohol consumption, although socially accepted, seems to occupy a common habit in the family nucleus and in the relationship between parents and children(17).

Care causes changes in the social life of the caregiver, besides imposing various responsibilities(18). In this way, the non-realization of leisure and physical activity can be attributed to complexity and responsibility in taking care, as a priority in their lives. The activities of daily living become less relevant and the caregiver turns to family care(19). On the other hand, it is possible to infer that the absence of risk behaviors, such as cigarette and alcohol consumption, can be considered a protective factor for health, since caregivers do not spare time for physical activities.

Regarding the labor activity, most of the participants did not exercise such activity, as found in the study results in which the caregivers practiced activities in an informal way, dedicating themselves to the management of their own residence and care(13).

In the face of this reality, many informal caregivers have resigned from their work activities to devote themselves to the activities of the home and care. Among those who also exercise their work activities, a greater overload and compromise of their health can be seen(19).

Although the presence of chronic disease was not self-reported by the majority of participants, it was found that among those who reported systemic arterial hypertension was predominant, as found in other studies(13,15). It is believed that the presence of a risk factor, such as sedentarism pointed out by the participants of this study, may contribute to the onset of this chronic condition.

In the present study, the time devoted to care for the sick was between one and two years, this was similar to that found in another investigation(8). It should be emphasized that the longer this time, the greater possibility of illness among caregivers, which can manifest as stress, fatigue or some physical or mental pathology(20).

The degree of kinship of the informal caregiver with the sick person was mostly child and spouse, as found in other studies(7,8). Thus, the time spent on care and the bond established between caregiver and caregiving can increase and generate in the informal caregiver a physical and emotional overload due to the complexity of care(19). It can be seen that the informal caregivers of this study are made up of family members who correspond with the person cared. When analyzing the monthly family income of these caregivers, it is possible to verify the difficulty in hiring a formal caregiver.

Regarding the daily hours of care, it was verified that it was up to five hours a day, which differs from another study, since the time for care was over 5 hours(21).

The fact that it corresponded with the person cared was predominant among the participants, which is in agreement with the literature (14). This situation is often due to the expenditure of a longer time to dedicate oneself to care, especially when the disease is an advanced stage and with compromising its multidimensionality(6).

It was found that the majority did not have a caregiver's course, which allows to infer that they learned to care in their daily practice, as found in the result of an investigation (14), in which informal caregivers revealed that they did not have the experience to care for, reinforcing the idea that there is a lack of preparation of the caregiver(7). This lack of preparation can lead to changes in their daily lives, with repercussions on their social, family and affective life and on the caregiver's illness(22).

Thus, in addition to playing a role for which they had no preparation, they did not receive help to perform care, a reality similar to the results found in the literature(19). Thus, many caregivers assumed full responsibility for care alone, and a family member's help was sporadic when requested and available. Therefore, the quality of the care provided may be compromised by the unavoidable physical and psychological exhaustion of the caregiver because he is the only one offering care to the family member(10).

When caring for the person in palliative care it is necessary that this care is permeated by feelings of love and compassion, which provides an integrative relationship and complicity(23). With this, the family is adaptedthrough the vulnerability to which they are exposed and find the power to perform this role better(24).

In this context, the support of health professionals, especially from the family health strategy team, to caregivers as responsible agents in problem solving, in the provision of care and in coherent and contextualized support to the caregiver's reality is fundamental.

FINAL CONSIDERATIONS

The characterization of informal caregivers in this study is mostly women, daughters or wives, with a high school education level, with the average age of 50, married or with partners, reported having Hypertension, are not smokers or have not practiced physical and leisure activities. They have been caregivers for more than a year and have not worked, corresponded with the person under their care and performed daily care between five and ten hours without receiving help or training caregivers.

The study in question had some limitations, given the small number of participants, the difficulty in identifying people in palliative care and finding addresses. Even in the face of such difficulties, all those who met the eligibility criteria agreed to participate in the study, and the active search was carried out more than once in the vicinity of the address provided, which allowed to reach the proposed objectives.

Given the relevance of this study, the scarcity of studies on this topic and the limitations found in this research, new investigations are suggested, with other methodological and thematic approaches that involve the caregiver of people in palliative care. Identifying the informal caregiver profile contributes to the advancement of science and to improving the support of health professionals to caregivers. This support can broaden the knowledge of caregivers that will reflect on the quality of care for the person with cancer.

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CARACTERIZAÇÃO DOS CUIDADORES INFORMAIS DE PESSOAS EM CUIDADOS PALIATIVOS POR CÂNCER

RESUMO

Objetivo: O estudo teve por objetivo identificar a caracterização sociodemográfica, os hábitos de vida e de trabalho e atividades desenvolvidas como cuidador informal. **Método:** Estudo quantitativo, transversal e descritivo desenvolvido com 45 cuidadores informais de pessoas com câncer em estágio IV e cuidados paliativos, atendidos em Unidade de Alta Complexidade em Oncologia de Minas Gerais. Coleta de dados realizada por meio de entrevistas em visitas domiciliária com aplicação de instrumento de caracterização elaborado pelos pesquisadores. Dados apresentados em valores absolutos e estatística descritiva. **Resultados:** Verificou-se o predomínio de mulheres, filhas ou esposas, com nível de escolaridade ensino médio, com a média de idade de 50 anos, casadas ou com companheiros, referiam possuir Hipertensão Arterial, não ser fumantes nem etilistas e não praticavam atividades físicas e de lazer. Ofertavam cuidados há mais de um ano, e a maioria não exercia atividade trabalhista, corresidiam com a pessoa sob o seu cuidado e realizavam os cuidados diários entre cinco a dez horas, sem receber ajuda para os cuidados, além de não possuírem cursos de cuidador. **Conclusão:** Identificar o perfil do cuidador informal contribui para o avanço da ciência e para a melhoria do suporte dos profissionais de saúde aos cuidadores.

Palavras-chave: Câncer. Cuidados Paliativos. Cuidadores Familiares. Enfermagem.

CARACTERIZACIÓN DE LOS CUIDADORES INFORMALES DE PERSONAS EN CUIDADOS PALIATIVOS POR CÁNCER

RESUMEN

Objetivo: el estudio tuvo por objetivo identificar la caracterización socio-demográfica, los hábitos de vida y de trabajo y actividades desarrolladas como cuidador informal. **Método**: estudio cuantitativo, transversal y descriptivo desarrollado con 45 cuidadores informales de personas con cáncer grado IV y cuidados paliativos, atendidos en Unidad de Alta Complejidad en Oncología de Minas Gerais. Recolección de datos realizada por medio de entrevistas en visitas domiciliarias con aplicación de instrumento de caracterización elaborado por los investigadores. Datos presentados en valores absolutos y estadística descriptiva. **Resultados**: se verificó el predominio de mujeres, hijas o esposas, con nivel enseñanza secundaria, con promedio de edad de 50 años, casadas o con compañeros, relataron tener Hipertensión Arterial, no ser fumadores ni alcohólicos y no practicaban actividades físicas y de ocio. Ofrecían cuidados a más de un año, y la mayoría no ejercía actividad laboral, cohabitaban con la persona bajo su cuidado y realizaban los cuidados diarios entre cinco a diez horas, sin recibir ayuda para los cuidados, además de no poseer cursos de cuidador. **Conclusión**: identificar el perfil del cuidador informal contribuye para el avance de la ciencia y para la mejoría del apoyo de los profesionales de salud a los cuidadores.

Palabras clave: Cáncer. Cuidados Paliativos. Cuidadores Familiares. Enfermería.

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