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ORIGINAL ARTICLE

PHYSICAL AND PSYCHOLOGICAL BURDEN OF CAREGIVERS OF PATIENTS INTERNED IN DOMICILE

SOBRECARGA FÍSICA E PSICOLÓGICA DOS CUIDADORES DE PACIENTES INTERNADOS EM DOMICÍLIO

LA SOBRECARGA FÍSICA Y PSICOLÓGICA DE LOS CUIDADORES DE LOS PACIENTES INTERNADOS EN DOMICILIO

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ABSTRACT

Objective: identifying the physical and the psychological fitness and the perception of burden of caregivers of patients linked to a public program of home care. ***Method:*** a qualitative, observational and cross-sectional study with caregivers of home inpatients. The research project was approved by the Committee of Ethics in Research, CAAE: 08237612.7.0000.5553. ***Results:*** there were interviewed 33 caregivers, mostly women, daughters or wives of patients with an average age of 46 years old, and with low education level. Regarding morbidities, the highlights were hypertension, diabetes mellitus and autoimmune diseases. Most reported continuous use of anxiolytics, antidepressants and painkillers. Of the participants, 31% had slight and 41% severe burden. ***Conclusion:*** the caregiver's functions are exhausting physically and psychologically and the health team has an important role in psychological support, promoting actions aimed at the reduction of stress and improving quality of life. ***Descriptors:*** Home Care; Caregivers; Palliative Care.

RESUMO

Objetivo: identificar o preparo físico e psicológico e a percepção da sobrecarga de cuidadores de pacientes vinculados a um programa público de atenção domiciliar. ***Método***: estudo qualitativo, observacional e transversal com cuidadores de pacientes internados em domicílio. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, CAAE: 08237612.7.0000.5553. ***Resultados***: entrevistados 33 cuidadores, a maioria mulheres, filhas ou esposas dos pacientes, com idade média de 46 anos e de escolaridade baixa. Como morbidades, destacaram-se a hipertensão arterial, o diabetes mellitus e as doenças autoimunes. A maioria relatou o uso contínuo de medicamentos ansiolíticos, antidepressivos e analgésicos. Dos participantes, 31% apresentaram sobrecarga ligeira e 41% sobrecarga intensa. ***Conclusão***: a função do cuidador é desgastante, física e psicologicamente, e a equipe de saúde tem um papel importante no apoio psicológico, promovendo ações direcionadas à diminuição do estresse e em prol da qualidade de vida. ***Descritores***: Assistência Domiciliar; Cuidadores; Cuidados Paliativos.

RESUMEN

Objetivo: identificar el estado físico y psicológico y la percepción de la sobrecarga de los cuidadores de pacientes vinculados a un programa público de atención en el hogar. ***Método:*** es un estudio cualitativo, observacional y transversal hecho con los cuidadores de los pacientes internos en el hogar. El proyecto de investigación fue aprobado por el Comité de Ética en la Investigación, CAAE: 08237612.7.0000.5553. ***Resultados:*** fueron entrevistados 33 cuidadores, la mayoría mujeres, hijas o esposas de los pacientes con una edad media de 46 años, y con bajo nivel de educación. Cómo morbilidades, los aspectos más destacados fueron la hipertensión, la diabetes mellitus y las enfermedades autoinmunes. La mayoría informó el uso continuo de ansiolíticos, antidepresivos y analgésicos. De los participantes, 31% tenían una ligera sobrecarga y el 41% sobrecarga severa. ***Conclusión:*** el papel del cuidador es agotador física y psicológicamente y el equipo de salud tiene un papel importante en el apoyo psicológico, en la promoción de acciones dirigidas a la reducción del estrés y en la mejora de la calidad de vida. ***Descriptores:*** Cuidado del Hogar; Cuidadores; Cuidados Paliativos.

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INTRODUCTION

Population aging is an undeniable reality. In Brazil, 2010 demographic census data show that, in 50 years, the Brazilian population has nearly tripled from 70 million in 1960 to 190.7 million in 2010. The number of elderly grew even more; and, in 1960, they represented 4,7%, and in 2010 reached a level of 10,8%. The Brazilian Institute of Geography and Statistics - IBGE has as estimated for the year 2050 that the elderly will account for 25% of the Brazilian total population.[1]

For aging be considered active it is crucial to have quality of life and health considered as the main factors to be met for this requirement. Studies report that the prevalence of chronic diseases increases with age.[2] Chronic degenerative diseases and their consequences may compromise the independence of older people, and thus require permanent care by health professionals and family.

This acceleration in the demographic transition associated with increased chronic degenerative diseases imply growth in costs of health services due to the need to incorporate costly technologies without necessarily getting in assistance the expected actual results.[3]

In general, chronic degenerative diseases generate the need for hospitalization for initial treatment. After stabilization of the pathological picture, they may be continuously treated with special care provided in the home environment. This type of admission brings the advantage of reconciliation of health care needed and the family and friends life in a healthy and safe environment.

Home care (AD) can reduce the hospital stay, agility in the hospital discharge process and the humanization of care. In this type of care, health services are offered to the patient together with his family, made in house resulting in greater interaction between the health service user and the professionals who serve him.[4]

Since the creation of Household Medical Assistance Services and Emergency - SAMDU by the Ministry of Labor in 1949, Brazil has been improving this type of care and discussing who would take the patient's caregiver role.[4]

One of the axes of AD, the deinstitutionalization of patients, provides personalized service, link with health professionals through comprehensive and humanized care, preservation of autonomy, greater participation of the family in treatment due to the reintegration in the family environment, and possible increase quality of life.[5]

For this inpatient care be done in patient's home it is important to have the figure of the caregiver. The Ministry of Health determined that the caregiver can be a community person who has acquired experience, taking care of sick people and made this an informal care profession or a family member who is willing to stay more time in patient care.[4]

In April 2002, there was sanctioned by the President to Law n. 10.424 which sets forth the conditions for the promotion, protection and recovery of health, the organization and the functioning of corresponding services and other provisions regulating the home care in the Unified Health System (SUS).[6]

To continue the establishment of this health care in Brazil, the National Health Surveillance Agency (ANVISA) published the Collegiate Board Resolution - RDC n. 11/2006 establishing the operational requirements for Care Services Public and Private Household in the whole country. The modalities are provided for assistance and admission, and are intended for patients with impossibility of movement and who requires less complex admission procedures and can be dispensed at home.[7]

The State Health Secretary of the Federal District created in its organogram Home Care Management, which is linked to Primary Care Board on Health Care Health Secretariat, and serving ten (10) Regional Centers for Home Care (NRAD). To these nuclei is responsible patient care in various forms of attention at home and guidance to caregivers about providing care to the patient and to maintain their own health.

By necessity, often, caregivers' of home inpatients are closed people, such as family, which, in consequence of their lack of preparation, have difficulties in exercising this function that takes time, dedication and knowledge.

On the basis of the above, it becomes evident the need of physical and mental fitness of carers who provide assistance indefinitely, developing this daily and constant activity in home health care. This study aims to:

- Identifying physical and psychological fitness and the perception of burden of caregivers of patients linked to a public program of home care.

METHOD

Qualitative, observational and cross-sectional study with caregivers of patients in

the home, of both sexes and of legal age, linked to a Regional Center for Home Care in a locality of the Federal District.

There was used the sample saturation criterion and performed data collection until the collected information began to repeat. Saturation is achieved when the new information in the analysis of the products no longer produce changes in the results previously achieved.[8]

Household interviews were carried out using two search tools. First, we used a specific instrument to meet the demographic and clinical aspects of caregivers and inpatients.

Then we used the Caregiver Overload Scale (ESC) summarized[9] to assess the burden on caregivers of patients. This scale, in the short version, consists of 22 questions, including aspects related to the physical and psychological health, work, economic resources, social relationships and the relationship with the patient. It aims to assess the objective and subjective caregiver burden including information on health, social life, personal life, financial situation, emotional situation and type of relationship.

For data analysis, each item of Caregiver Overload Scale was scored qualitatively and quantitatively as follows: never (1); rarely (2); sometimes (3); often (4) and almost always (5).With the application range is obtained a total score ranging from 22 to 110, where a higher score represents a higher perception of overcharging according to the following cut points: less than 46 - not overload; between 46-56 - mild overload and over 56 - intense overload. The collection and data analysis occurred concomitantly.

Pursuant to Resolution No. 196/96 of the Ministry of Health, which deals with Research Involving Human Subjects, this project was submitted to the Research Ethics Committee of the State Health Department of the Federal District by CAAE n. 08237612.7.0000.5553 and approved under number 187 211. [10]

To participate in the study all subjects were informed about the objectives, rationale, methodology adopted and the certainty as to the confidentiality, reliability, protecting your image and stigmatize, and free and targeted manner opted to participate by signing the Instrument of Consent.

RESULTS

The study gathered 33 caregivers of patients admitted at home, linked to the Health Regional NRAD. As for the sociodemographic characteristics, the sample was composed of people with an average age of 46 years old, and 30% were more than 60, and having the youngest of the caregivers, 20 years old and the oldest, 73 years old. Females predominated, with 87,6% of the participants, and poor education level and 61% had between 3 and 5 years of formal study.

Regarding religion, there was a predominance of the Catholics, and practitioners of evangelical religions of different fronts and orders. The degree of kinship, the sample of caregivers was made up of children, wives, patients and caregivers had no direct relationship with the patient. Only two caregivers, representing 6%, do not reside in the same household with the patient (Table 1).

Table 1. Sociodemographic characteristics of caregivers interviewed. Brasilia, DF, 2013.

Variable	n	%
Age (years)		
20 - 29	06	18
30 - 39	03	09
40 - 49	02	06
50 - 59	05	15
60 or older	10	30
Education level (in years)		
1 - 2	02	06
3 - 4	05	15
4 - 5	12	36
6 - 7	03	06
8 - 9	03	06
10 or more	01	03
Religion		
Catholic	18	55
Evangelic	15	45
Relationship		
Son/Daughter	12	36
Wife	07	21
Other	08	24
No relationship	06	19

With regard to their own health, pain in the spine or back was the most recurring complaint. Other complaints that appeared frequently associated were the pains in limbs and joints.

Regarding morbidity there was reported the existence of diseases such as: hypertension, diabetes mellitus and autoimmune diseases, such as Rheumatoid Arthritis and Osteoarthritis (Table 2).

The use of medicines to relieve pain or to induce sleep, according to the interviewees themselves, is constant, and anxiolytics, antidepressants and analgesics were the drugs mentioned as daily and continuous use.

Sleep rated in quality and quantity had a bad result, with the majority of the participants reported having less than 6 hours of sleep (Table 2).

Table 2. Clinical characteristics of caregivers interviewed. Brasilia, DF, 2013.

Variable	n	%
Reports of presence of pain		
Pain in spine/back	15	45
Limbs and joints	13	39
Other types of pain	04	12
Did not report	01	03
Pathologies		
Systemic Hypertension	10	30
Diabetes Mellitus	05	15
Arthritis, osteoarthritis and other autoimmune diseases	06	18
Other diseases	06	18
No disease reports	14	42
Continuous use of medicines		
Antidepressants	06	18
Anxiolytics	08	24
Painkillers	10	30
Hours of sleep		
Up to 6 hours/day	20	60
Between 6 and 8 hours/day	10	30
More than 8 hours/day	04	12
Quality sleep		
Good	07	21
Bad	26	78

The pursuit of the caregiver function of time, the average was 10 years, and which exercised for less time, was only for 3 months on the job and he held longer, by his own account, was for 40 years (Table 3).

Of caregivers, 9% exercised the caregiver role in most of life, whether of children or the

elderly. A caregiver had previous occupation as a housewife. The others had various roles in the commercial and autonomous and had to leave to devote to take care exclusively of hospital at home family. None of the respondents have specific training caregivers and all exert the function with the support of NRAD, offering specific guidance related to the difficulties presented individually and in groups (Table 3).

With the application of the scale for assessing caregiver burden, the results showed that 28% of respondents did not have significant overhead, 31% had slight overhead and 41% showed significant results that represent intense burden (Table 3).

Table 3. Exercise time caregiver role, previously exercised function and the result of applying the Caregiver Overload Scale - ESC. Brasilia, DF, 2013.

Caregiver	Exercise time of caregiver function of this patient (in years)	Previously exercised function	Result of Caregiver Overload Scale
C1	2	Caregiver of a child	SI
C2	4	Commerce-sales	SI
C3	13	Housewife	SI
C4	6	Receptionist	SS
C5	3	Technician in accounting	SS
C6	15	Bus ticket	SI
C7	6	Seller	SI
C8	3 months	Receptionist	SI
C9	2	Seller	SS
C10	2,5	Commercial representative	SS
C11	11	Bus ticket	SL
C12	1,5	Administrative Assistant	SL
C13	8	Housewife	SL
C14	5	Seamstress	SS
C15	5	Seller	SI
C16	10	Seller	SI
C17	5	Accounts And Finance	SS
C18	3	Receptionist	SI
C19	3	Office clerk	SL
C20	40	Merchant	SS
C21	3	General Services	SL
C22	3	Administrative Assistant	SL
C23	8	Office clerk	SI
C24	4	Bus ticket	SS
C25	9	Mechanical workshop	SI
C26	11 months	Farm/farmer	SL
C27	10	Marketer	SL
C28	4	Traffic school instructor	SL
C29	10	Caregiver of a child	SI
C30	16	General Services	SS
C31	10	Seller	SI
C32	8	Seller	SL
C33	9	Self-employed	SI

SS – Without burden / SL – Mild burden / SI – Intense burden

DISCUSSION

The results of this study reinforce the point that the caregiver role is played mostly by women, and that, also like most of these women belong to the immediate family of the person receiving the care. The family caregiver role is performed by women for centuries and socially represented in the role of mother, homemaker and caregiver. This function approaches the nursing profession, exercised, mostly, even today, women and whose main aspect, the role of care.

For the most part, the family caregiver of this study failed to engage in gainful function in the labor market, especially in trade. The choice of which family will no longer work with formal employment is related to the monthly income of the same. This process can also be analyzed by the lack of choice. That is, there is no way choosing not to take care of sick family. Usually this role is played by the wives or daughters women who suffer this social pressure to assume the role of caregiver and stop exercising the profession or social function previously performed. This decision leads to psychological stress[11].

The little formal study time is considered one of the factors in favor of making a decision to leave work to care for a family. The income is smaller and does not allow the

hiring of specialized caregivers for this function.

Studies indicate that the caregiver participates actively in the disease process; it follows the patient all the time and is always looking for alternatives and more knowledge to provide care with better quality.[12-3]

The process of care to a patient in home must start date, but no expiration. The beginning is a subsequent fact to a particular situation as crash recovery or sequel of a condition, often degenerative suffered by the patient. The end, when it comes to degenerative disease sequel occurs only at the end of life. This also represents an increase in stress levels, for the life of the caregiver often changed very significantly and very quickly.

Caring for a patient with advanced disease admitted at home, is considered a heavy load and can cause significant burden to the caregiver and also the rest of the family. Several studies show that caring for someone is continuously high costs on the psychic level, physical, social and even financial. Studies have shown that there is increased risk of acute myocardial infarction and sudden death for adult caregivers and elderly.[14-5] Several points analyzed stand out as precursors to psychosocial caregiver changes, such as the social and emotional isolation, depression, decline in relationships, loss of life perspective, sleep disturbances and the constant use of psychotropics.[16]

One of the problems identified in the lives of caregivers was being deprived of his self-care, which directly affects the quality of life, even causing a psychic wear. Other studies also showed this result and suggested the implementation of public social policies aimed to caregivers.[13,17-8]

Caregivers are dedicated full time to care, and 94% of them live in the same house as the patient, and therefore do not have a predetermined time to perform the function. This reinforces the result of intense overload, as it is to provide intense and continuous care. In addition, the question of illness of a member of close family, as in the case of the son, parent or spouse caused deep changes in family dynamics, allowing the emergence of crises and psychological stress.[13]

Another important factor for analysis of caregiver's burden is his own health condition, which often is not evaluated and not perceived. In this study, a report of chronic diseases such as systemic hypertension is present in many of the caregivers. This result was expected because these chronic diseases are often present in people over 60 years of age.

Osteoarticular diseases, which were also present in the study of major proportion, represent the physical wear that is perceived by caregivers due to the necessary drive to exercise care for bedridden patients. Physical activity and muscle strengthening exercises are not practiced by caregivers regularly, what favors the appearance of lesions in joints and muscular pain effort. The pain complaints were prevalent and the most cited was back pain or back. Similar results were obtained in other studies. [19-20]

As a result, the use of medication for pain relief, most often without prescription of antidepressants and anxiolytics and prescribed by doctors drugs became common, even to induce sleep, and sleep difficulty can also be a result of pain. It impairs the reasoning and the quality of life, leading to a high level of stress, which was demonstrated in this study. Among the caregivers who reached the intense overload in the evaluation, 95% reported having less than 6 hours of sleep and sleep quality was bad.

CONCLUSION

Exercising primary caregiver role to a close relative at home is an arduous and an exhausting task, which can strongly interfere with the family's quality of life.

It is felt that it is necessary to close monitoring of the caregiver, by the health team responsible for the patient in the form of continuing education and psychological support, promoting actions aimed at the reduction of stress and improve quality of life. The health team must know the burden on caregivers to organize the actions that are deemed relevant to each case.

The support that the caregiver receives from family and health team has a positive aspect in the reduction of physical stress, as the emotional. It is also important he has an agenda with free time for self-care and the health team play an important role in this direction.

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