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RESEARCH

Caregiving ability and perceived overload in family caregivers of patients with chronic disease

Habilidad de cuidado y sobrecarga percibida en cuidadores familiares de pacientes con enfermedad crónica

Habilidade de cuidar e sobrecarga percebida em cuidadores familiares de pacientes com doenças crônicas

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Abstract

Introduction: Family caregivers of patients with chronic illness require the development of skills that allow them to reduce the risk of overload, based on perceived nursing care in a clinical setting. **Objective:** Describe the relationship between caregiving skills and the level of overload of family caregivers of patients hospitalized in a secondary care level hospital. **Methodology:** A quantitative study with a descriptive, cross-sectional and observational approach with a sample of 107 family caregivers from a secondary hospital in Mexico City; with more than three months caring for their patient, sole caregivers and not minors. Measurements were made with the following instruments: Care Skill Inventory and Caregiver Burden Scale, with prior informed consent. Descriptive and inferential statistical analysis was performed. **Results:** 38% of family caregivers are men, 62% are married and 66% are spouses. The median age was 43 years. In caregiver skills, it was found that the knowledge and patience dimensions were low and medium in terms of value. 95.3 % had severe overload. The correlation between the dimensions of overload showed a very low correlation with occupation and education Rho= -0.60 and -0.217, p<0.05. **Conclusion:** Overload in family caregivers is a serious condition that is associated with the development of caregiving skills in patients with chronic degenerative disease.

Key words: Caregiver; Health; Illness; Fitness; Patients (DeCS).

Resumen

Introducción: El cuidador familiar de pacientes con enfermedad crónica requiere del desarrollo de habilidades que le permiten disminuir el riesgo de sobrecarga, a partir de la atención de enfermería percibida en un entorno clínico. **Objetivo:** Describir la relación entre la habilidad de cuidado y el nivel de sobrecarga de cuidadores familiares de pacientes hospitalizados con enfermedad crónica en un segundo nivel de atención. **Metodología:** Estudio con enfoque cuantitativo de corte descriptivo, transversal y observacional con muestra de 107 cuidadores familiares de un hospital de segundo nivel de la Ciudad de México; con más de tres meses cuidando a su paciente, cuidadores únicos y no menores de edad, se excluyó al cuidador familiar con paciente en áreas críticas. La medición fue con cuestionario estructurado, que contenía datos sociodemográficos, Inventario de habilidad del cuidado y Escala de sobrecarga del cuidador, previo consentimiento informado. Se realizó análisis estadístico descriptivo e inferencial. **Resultados:** El 38 % de los cuidadores familiares fueron hombres, casados 62 % y cónyuges en 66 %, con media de edad 43 años. En habilidades del cuidador se encontró que las dimensiones conocimiento y paciencia tuvieron puntuaciones bajas y la dimensión valor puntuaciones medias. Un 95.3 % tenían sobrecarga intensa. Las dimensiones de sobrecarga arrojaron correlación muy baja e inversa con ocupación y escolaridad Rho= -0.60 y -0.217, p<0.05. **Conclusiones:** La sobrecarga en cuidadores familiares es un condicionante grave que se asocia al desarrollo de las habilidades de los cuidados en los pacientes con enfermedad enfermedad no transmisible.

Palabras clave: Cuidador; Salud; Enfermedad; Aptitud; Pacientes (DeCS).

Abstrato

Introdução: O cuidador familiar de pacientes com doença crónica necessita do desenvolvimento de competências que lhe permitam reduzir o risco de sobrecarga, a partir dos cuidados de enfermagem percebidos em ambiente clínico. **Objetivo:** Descrever a relação entre a capacidade de cuidado e o nível de sobrecarga dos cuidadores familiares de pacientes hospitalizados em um segundo nível de atenção. **Metodologia**: Estudo com abordagem quantitativa descritiva, transversal e observacional com uma amostra de 107 cuidadores familiares de um hospital de segundo nível na Cidade do México; com mais de três meses cuidando de seu paciente, cuidadores únicos e não menores. As mensurações foram realizadas com os instrumentos: Inventário de Habilidades de Cuidado e Escala de Sobrecarga do Cuidador, com consentimento prévio e informado. Foi realizada análise estatística descritiva e inferencial. **Resultados:** 38% dos cuidadores familiares são homens, 62% são casados e 66% são cônjuges. A idade média foi de 43 anos. Nas competências do cuidador, constatou-se que as dimensões conhecimento e paciência foram baixas e médias em termos de valor. 95,3% apresentaram sobrecarga intensa. A correlação entre as dimensões da sobrecarga apresentou correlação muito baixa com ocupação e escolaridade Rho= -0,60 e -0,217; comportamento das variáveis inversamente. **Conclusões:** A sobrecarga em cuidadores familiares é uma condição grave que está associada ao desenvolvimento de competências de cuidado em pacientes com doença crônico-degenerativa.

Palavras-chave: Cuidador; Saúde; Doença; Preparo físico; Pacientes (DeCS).

Introduction

Non-communicable diseases (NCDs), also known as chronic diseases, are usually long-term and result from a combination of genetic, physiological, environmental and behavioral factors. These factors are characterized by being the main cause of mortality and disability in elderly people. The situation is worldwide alarming. The World Health Organization (WHO) reported that 41 million people will die in 2023, almost equivalent to 74 % of all deaths in the world (1).

In the case of Mexico, according to the National Institute of Statistics and Geography (INEGI) in 2020, the main causes of death were cardiovascular diseases (141,873 cases), diabetes mellitus II (99,733 cases) and malignant tumors (60,421 cases), also adding a considerable number of deaths due to complications caused by CoVID-19 (2). For its part, the National Health and Nutrition Survey (ENSANUT) noted an increase in the prevalence of morbidity, mainly due to hypertension (13.4 %), diabetes mellitus II (10.6 %), chronic obstructive pulmonary disease (2.1 %) and cardiovascular diseases (1.7 %) (3). Another aspect to consider is the high economic costs resulting from prolonged hospital stay, slow progression of the disease, and multiple complications, among others. The approximate expenditure of a patient with diabetes mellitus II ranges between $24,000 and $90,000 pesos per year, depending on the treatment received and the evolution of the disease (4). In 2019, the estimate and secondary costs to direct care for breast cancer, on average, was 16,500 USD, leukemia 17,900 USD, chronic kidney disease 10,100 USD (5). Certainly, high secondary care costs are a severe burden for any health system, which is why it is necessary to encourage strategies that help manage them. In this regard, there is an increasing need to encourage the presence of family caregivers in hospital settings, so that they participate in the care-care-me process and strengthen the nurse-patient relationship.

Commonly, the person who takes care of the person with some illness continues to be a direct family member, who is assigned or takes the role of family caregiver (FC) and, in some cases, the role is assumed by a non-blood relative but who has a relationship of trust and commitment with the patient (6); therefore, it is important for nursing personnel to identify and evaluate the care skills for the knowledge, value and patience that caregivers possess based on the quality and safety with which they perform their work, indicators that allow generating programs aimed at improving the care they provide and influence the correct management of barriers that hinder care, reducing the stress and overload experienced by the caregiver; consequently, knowing the relationship between the care skill and the level of overload of family caregivers is of utmost importance for the health care system (7).

Caring for a chronically ill person inside or outside an institution is not an easy task; it requires the development of skills in order to prevent responsibilities beyond what is reasonable. To the extent that the skills for caring and their vulnerable points are known, it is understood why a caregiver goes through a state of exhaustion that complicates their well-being. Unfortunately, the time spent measured in hours, days or weeks is overwhelming, the demand for care is so high that work activity, family life are lost and even moments of leisure are forgotten; situations that lead directly to an inevitable and short-term overload (8).

Taking care of oneself would therefore be the first commitment for all those who care for others; reflecting on the importance of the role as a shared responsibility, due to the imminent risk of developing an illness and/or injury during the course of constant support, as long as a series of personal activities that benefit physical and emotional health are considered. It is suggested that people exchange caregiving experiences among themselves and/or seek professional counseling from health and educational institutions as required, for formal training and development of skills that allow better adaptation to the caregiver role (9).

Consequently, generating programs or strategies that help caregivers to carry out self-care has benefits for developing adequate ease and skill in performing care tasks. In addition, the patient gains strength to face the different difficulties that the disease process entails with the best tools, through the physical and emotional efforts required by the different tasks. Therefore, it has to be maintained a posture of integrity and peace at all times, regardless of the circumstances that may arise. Considering regard to the above, the purpose of the research was to describe the relationship between caregiving skills and the level of overload of family caregivers of patients hospitalized in a secondary level of care.

Methodology

Quantitative, descriptive, cross-sectional and observational study carried out in a second-level hospital in Mexico City, in the period from August 1, 2020 to August 1, 2021, in which 107 CFs from the internal medicine, outpatient and emergency services participated. The sampling was non-probabilistic and convenience (10). The population of interest was CF of both sexes, over 18 years of age, with more than three months of patient care and who were sole caregivers. Exclusion criteria were considered to be CFs who had their patients in critical areas and all those who did not wish to participate in the study. One elimination criterion was not answering the questionnaire completely. The information was collected in the outpatient waiting room, before being called for consultation. First, they were invited to participate by explaining the scope and benefits of the research. Later, they were asked to sign the informed consent once doubts and concerns were clarified. A structured questionnaire was completed containing sociodemographic data (age, sex, education, marital status, occupation, kinship, and time of care). The Zarit Caregiver Burden Scale (11) was used, widely used worldwide, and has several validations for Latin American countries, including Mexico (12-14). It consists of 22 Likert-type items and three subscales that measure the impact of care (13 items), interpersonal relationship (06 items) and expectations for self-efficacy (03 items), obtaining for this study a Cronbach's Alpha reliability coefficient of 0.88, with an overall internal consistency of 0.89 (16).

The Care Ability Inventory (CAI) instrument by Ngozi O. Nkongho (15) was provided for completion. It consists of 37 items with a Likert-type scale, and is organized into 3 subscales: a) Knowledge (14 items), b) Patience (10 items), and c) Value (13 items) (16). The instrument has a reliability of 0.84 and a validity of 0.80 (17). The internal validity analysis showed an Alpha of 0.89 and by categories knowledge 0.82, value 0.86 and patience 0.91.

The research was carried out within the framework of the National Program of Social Service in Health Research according to letter DGCES-DEF-3-2021. (Call 2020-2021). The study observed the requirements stipulated in the Regulations of the General Health Law on research, with prior informed consent of the participants (18). Furthermore, the Statistical Package for Social Sciences (SPSS) Version 22 was used; in general, descriptive statistics were used to describe the sociodemographic variables and the characteristics of the CF through frequencies and percentages.

In the exploratory analysis, variables with a distribution other than normal were identified using the Kolmogorov-Smirnoff test; the data were presented with medians and percentiles. Comparisons were made between sociodemographic variables considering the cut-off points established in the scales of both questionnaires. Comparisons between continuous variables were carried out using Spearman's correlation. A result was considered statistically significant when the probability value was lower than 0.05.

Results

Participants were 61.7 % women and 38.3 % men. The average age was 43 years ± 8.3 years. According to age groups, 42.1 % were young adults between 36 and 44 years old and 35.5 % were between 45 and 53 years old. Regarding the occupation of the respondents, the predominant activities were home (48.6 %) or employed (46.7 %). As for schooling, higher secondary education predominated with 38.3 %. In the rest of the baseline characteristics, the marital status of the CF was recorded, with married patients predominating with 61.7%, free union 29 % and single 9.3 %. In terms of kinship, 65.5 % of the cases were the spouse, 25.2 % siblings and 9.3 % were children. Regarding the time they had dedicated to caring for the patient, 60.8% had been with the CF for more than 7 years, followed by 29.9 % for 4 to 6 years and 9.3 % for 1 to 3 years, with an interquartile range of 2 to 3 years, (Table 1).

Table 1**.** Sociodemographic characteristics of family caregivers of patients with non-communicable diseases, 2021 (n=107)

Characteristics		f	%
Age groups	n ± DE (43 ± 8.32)		
	18-26 years	1	0.9
	27-35 years	12	11.2
	36-44 years	45	42.1
	45-53 years	38	35.5
	More than 54 years	11	10.3
Sex	Female	66	61.7
	Male	41	38.3
Marital status	Married	66	61.7
	Common-law marriage	31	29
	Single	10	9.3
Occupation	Housewife	52	48.6
	Employee	50	46.7
	Unemployed	3	2.8
	Student	2	1.9
Schooling	Elementary	29	27.1
	Secondary	36	33.7
	High School	41	38.3
	University	1	0.9
Kinship	Son/Daughter	10	9.3
	Brother//Sister	27	25.2
	Spouse	70	65.5
Time for care	01 to 03 years	10	9.3
	04 to 06 years	32	29.9
	More than 07 years	65	60.8

Source: Own-development

Once the CAI instrument was applied to quantify the caregiver's skills, it was found that the general or global median score was 181, with an interquartile range (IQR 25-75) of 173-188. In the analysis of the instrument, the knowledge subscale had a median of 71 points with a RIC of 67-75, the patience subscale had a median of 51 with a RIC of 47-53 and finally the value subscale had a median of 60 with a RIC of 55-64 points. Stratifying the different categories of the instrument in the knowledge subscale, 52.3 % was low, followed by medium at 43 %. Regarding the patience subscale, it was found that the highest level was the low level with 46.7 %, and the medium level with 39.3 %. Finally, in the value subscale, a distribution was found where the medium level was the most frequent with 59.8 %, and the low level with 38.3 %, (Table 2).

Table 2. Description of the general and subscale skills of family caregivers of patients with non-communicable diseases, 2021 (n=107)

Sub-scale	Median (Interquartile range)	Category	n
Knowledge	71(67-75)	Low	56 (52.3 %)
		Medium	46 (43 %)
		High	5 (4.7 %)
Value	60(55-64)	Low	41 (38.3 %)
		Medium	64 (59.8 %)
		High	2 (1.9 %)
Patience	51(47-53)	Low	50 (46.7 %)
		Medium	42 (39.3 %)
		High	15 (14 %)
General	181(173-188)		107

Source: Own-development

Regarding the caregiver overload scale, a median of 67 was found with IQR 64-71, 95.3% had intense overload, 2.8% mild overload, and 1.9% had no care overload, (Table 3).

Table 3. Description of the level of overload of family caregivers of patients with non-communicable diseases 2021 (n=107)

Category	Median (Interquartile range)	n
Severe overload	67(64-71)	102 (95.3 %)
Mild overload		3 (2.8 %)
No overload		2 (1.9 %)

Source: Own-development

In the comparison between the dimensions of overload, a very low correlation was found with schooling and kinship (Rho= -0.217 and 0.271) with the variables behaving inversely, (Table 4).

Table 4. Correlations between the dimensions of overload and demographic characteristics

Characteristics	Value of Rho	p
Groups of age	0.156	0.109
Sex	0.098	0.316
Marital status	0.135	0.164
Schooling	- 0.217	0.024*
Kinship	0.271	0.005*
Occupation	- 0.60	0.539

Source: Own-development

* The correlation is significant with $p<0.05$

Discussion

In accordance with the objective of describing the relationship between caregiving skills and the level of FC burden in patients hospitalized with chronic disease at a second level of care, it was found that the majority were women, with an average age of 43 years, were dedicated to the home, had studied up to high school, were married, and the caregiver was the spouse with more than 7 years providing care to the person. With respect to gender, women continue to be the main caregivers, an activity that is culturally relegated; however, the presence of men in the care of patients with NCDs is increasing (19). In this regard, it should be noted that the care of a sick person is delegated mainly to the female member of the family due to the prevalence of stereotypes in terms of behavior, although it is not ruled out that in the near future this activity will be shared equally with men. Likewise, it also highlights the peace of mind experienced by patients, regardless of sex, when they are cared for by a family member or female personnel (20).

Regarding the review of caregiving time, it was noted that there was a predominance of FCs who had been performing caregiving for their family member for a long time as a constant of normality that become mechanized and routine activities to “juggle” with the commitments of their lives and cover the demands of the chronically ill (21), in addition to continuously feeling fatigue that leads to a progressive deterioration that weakens their health.

Likewise, a fact worth highlighting is the prevailing schooling of the population, since it speaks of the degree of knowledge they can have. In the study it was found that more than half of the caregivers only had basic studies, similar results have been reported by those who found that age and schooling are factors that influence the willingness to provide care, even the older the caregiver, the ability to develop care skills is different with those of young caregivers with higher education; that is, the younger the caregiver, the less experience to provide care and the less ability to appropriate the role of caregiver (22). In turn, the time of care is a conditioning factor in the development of physical and mental fatigue in older caregivers, since it was found that most of the FCs had been exercising the role of caregiver for more than 7 years (23).

Analyzing the ability to care, it is clear that most of the FCs were not in optimal conditions to perform the role of caregiver, so the burden due to the activity was sufficient, to the point of generating exhaustion and demotivation to provide care to their family member. Regarding the subscales of knowledge and patience, a deficiency was found in the quality of care (24). However, in the value subscale, it was observed that the FCS had the disposition to manage adversities through resilience to face all those complex situations that may arise during the course of caring for their loved ones.

A distribution was observed in which the middle level was the most frequent, reflecting the positive intention on the part of each caregiver to perform the role, either because of the relationship they share with their family member or because they are the main source of support for the family member (25). It is essential to strengthen knowledge and patience, so that the caregiver's feelings of fear, uncertainty and/or hopelessness can be reduced. At the institutional level, the nursing personnel plays a vital and fundamental role in the patient-caregiver dyad by training, motivating and supporting the PCs involved in caregiving, remembering that the main purpose of the profession is care (26). By putting this into practice with FCs, health improvement objectives can be achieved for the sick family member, the caregiver and the family in general, also preventing that the FC from becoming a new sick subject due to physical and mental burden.

Regarding the overload associated to the caregiver, most of the FCs were found in a state of intense overload, which correlates with the time of care (27), extra activities such as employment or work at home, lack of knowledge and willingness to seek patience to perform the care demanded by their sick family member. Another factor that influenced the burden found was that during the study, the world was experiencing the effects of the SARS-CoV-2 (COVID-19) pandemic, where people with a NCD were among the group vulnerable to the virus (28), so it was necessary to take extra and greater care of people because of the dangerous signs and symptoms of the disease as well as the consequences or implications that death would represent, conditions that generated feelings of anguish, anxiety and stress in the sick person as well as in his caregiver. On many occasions, family members evaded the responsibility of care or lose their skills due to lack of motivation, training and adequate support (29). One of the limitations to practical and constant access to the study population was that the sample was collected during the Covid-19 pandemic period.

Conclusions

With the results obtained, it was possible to identify the relationship between caregiving skills and the level of burden of FCs of hospitalized patients with non-communicable diseases. It was also seen how different factors influenced the ability of each caregiver to perform the role correctly. In addition, it was determined that the subscales of knowledge and patience when they are low have a negative impact on the development of caregiving skills, which implies that they develop situations of crisis, anxiety and uncertainty as a consequence of how the care of their loved one is performed; although the participation of FCs is active, in most cases it is due to acts of compassion, love and respect for the cared-for person. Health institutions should generate policies that modify deficient programs in terms of care, so that FCs can enhance their capabilities and skills. From this point of view, in the care of people with NCDs in health institutions, guidelines, manuals and continuous training courses for FCs should be established.

Conflict of interests

The authors state that there is no conflict of interest.

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