



The relationship between overload and caregiving competencies in informal caregivers of people with chronic diseases

Relación entre sobrecarga y competencias del cuidar en cuidadores informales de personas con enfermedades crónicas

Relação entre sobrecarga e competências do cuidar em cuidadores informais de pessoas com doenças crônicas

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ABSTRACT

Introducción. When people develop chronic diseases and their possible complications, it leads to the need to receive care from someone in social or family contexts. This person becomes an informal caregiver. By playing this role, this person can experience situations or characteristics inherent to caregivers, which

impact caregiving competencies and overload. These aspects could affect the caregiver-care receiver dyad. **Objective.** To identify the relationship between caregiving competencies and overload in informal caregivers of people with chronic diseases. **Methodology.** A transversal, correlational study, n= 259, on informal caregivers of people with chronic diseases, users of two general hospitals in Tamaulipas, selected through intentional non-probability sampling. A sociodemographic data form and the Zarit and CUIDAR instruments were used. Descriptive and inferential statistics were applied for the analysis. **Results.** Caregivers were mostly women, with kinship as daughters or wives. A negative, statistically significant correlation was detected ($r_s = -.160$, $p = 0.01$) between overload and caregiving competencies. **Discussion.** Caregivers' profiles in this study concur with international literature. The correlation between research variables has been documented in very few studies, reason why it represents progress in knowledge in the field of caregiving. **Conclusion.** A correlation that can be interpreted as follows was observed: "more overload implies less caregiving competencies." This finding demonstrates the need for knowledge and skills to optimally provide care and, therefore, have the capacity to face overload situations

Keywords:

Caregivers; Chronic Diseases; Patients; Adults; Diabetes Mellitus; Hypertension.

RESUMEN

Introducción. El desarrollo de enfermedades crónicas y sus posibles complicaciones conllevan la necesidad de recibir cuidados de alguna persona del entorno social o familiar, quien se convierte en cuidador informal. Al desempeñar su rol, esta persona puede experimentar situaciones o características propias del cuidador que repercuten en las competencias del cuidar y sobrecarga, aspectos que podrían afectar la díada cuidador-cuidado. **Objetivo.** Identificar la relación entre competencias del cuidar y sobrecarga en cuidadores informales de personas con enfermedades crónicas. **Metodología.** Estudio transversal-correlacional, n= 259 cuidadores informales de personas con enfermedades crónicas, usuarios de dos hospitales generales de Tamaulipas, seleccionados por muestreo no probabilístico, intencional. Se aplicó una cédula de datos sociodemográficos, instrumento Zarit y CUIDAR. Para el análisis, se aplicó estadística descriptiva e inferencial. **Resultados.** Los cuidadores fueron mayormente mujeres, con parentesco de hija y esposa. Se detectó una correlación negativa y estadísticamente significativa ($r_s = -.160$, $p = 0.01$) entre la sobrecarga y competencias del cuidar. **Discusión.** El perfil de los cuidadores de este estudio concuerda con la literatura internacional. La correlación entre las variables de investigación se ha documentado en escasos estudios, por lo que representa un avance de conocimiento en el ámbito de los cuidadores. **Conclusión.** Se evidenció una correlación que se puede interpretar de la siguiente manera: "a mayor sobrecarga, menor competencias del cuidar". Hallazgo que evidencia necesidades en conocimientos y habilidades para ejercer de forma óptima el rol de cuidador y por ende, tener la capacidad de afrontar situaciones de sobrecarga.

Palabras clave:

Cuidadores; Enfermedades Crónicas; Pacientes; Adulto; Diabetes Mellitus; Hipertensión.

RESUMO

Introdução. O desenvolvimento de doenças crônicas e suas possíveis complicações acarretam a necessidade de receber cuidados de alguém no ambiente social ou familiar, que se torna cuidador informal. Ao desempenhar seu papel, essa pessoa pode experimentar situações ou características próprias dos cuidadores que tange às competências para cuidar e sobrecarga, aspectos que podem afetar a díada cuidador-cuidado. **Objetivo.** Identificar a relação entre as competências do cuidar e a sobrecarga em cuidadores informais de pessoas com doenças crônicas. **Métodos.** Estudo transversal correlacional, n= 259 cuidadores informais de pessoas com doenças crônicas, usuários de dois hospitais gerais de Tamaulipas, selecionados por amostragem intencional não probabilística. Foram aplicadas informações sociodemográficas, escala Zarit e CUIDAR. Para a análise, aplicou-se estatística descritiva e inferencial. **Resultados.** Os cuidadores eram em sua maioria mulheres, com o relacionamento de filha e esposa. Foi detectada correlação negativa e estatisticamente

significante ($r_s = -.160$, $p = 0.01$) entre a sobrecarga e as competências do cuidar. **Discussão.** O perfil dos cuidadores deste estudo concorda com a literatura internacional. A correlação entre as variáveis de pesquisa foi documentada em poucos estudos e, portanto, representa um avanço no conhecimento na área de cuidadores. **Conclusão.** Evidenciou-se uma correlação que pode ser interpretada da seguinte forma: “quanto maior a sobrecarga, menor a competência do cuidar”. Achado que evidencia a necessidade de conhecimentos e habilidades para exercer de maneira ideal o papel de cuidador e, por tanto, ter a capacidade de enfrentar situações de sobrecarga.

Palavras-chave:

Cuidador; Doenças crônicas; Pacientes; Adulto; Diabetes Mellitus; Hipertensão.

Introduction

Desdemerit changes in the population pyramid and, in turn, the development of chronic diseases, which cause 40 million deaths worldwide (1). In Mexico, 8.6 million people have diabetes, 15.2 million have high blood pressure and approximately 18 million people have some kind of cancer. The State of Tamaulipas is specifically one of the five states with the highest percentage of people medically diagnosed with diabetes (2,3).

Developing these diseases, in addition to directly affecting those who have them, also impacts their families, since a chronic disease’s evolution and its complications involve an increase in the need for caregiving provided by someone in the family, who becomes the Informal Caregiver (IC). This person is in charge of facilitating the patient’s basic instrumental daily needs most of the day without payment or formal training to perform the task (4, 5).

Various studies state that most IC’s are women between the age of 40 and 73, have primary/secondary education (high school), and are the patients’ wives/husbands or daughters/sons. They are caregivers for between 6.5 and 8 years and 43.5% receive no support for caregiving (6-13). It is worth highlighting that an IC’s role implies facing critical situations related to stress, exhaustion and a decrease in opportunities, motivation and social relationships, as well as the possibility of experiencing symptoms of depression and anxiety, health issues and deterioration of quality of life. This can impact the healthiness of the caregiver-care receiver dyad (10,14,15).

Studies performed on informal caregivers of people with chronic diseases and dependency have shown different overload levels, in which intense overload percentages have stood out from 33 to 85.6% in the first study, 62% in the second and 33% in the third (12,16,17). Furthermore, they documented how less functional dependency from the care receiver implied

less subjective overload (12). On the other hand, another study performed on caregivers of people with chronic diseases at a high complexity hospital reported that 70.7% did not experience overload, 13.4% experienced mild overload and 15.7% experienced intense overload (18).

Along with the above, various studies have demonstrated that there are factors related to the roles of informal caregivers that directly impact overload development, such as gender, age, level of education, work activity, support from other informal caregivers, having a disease, their time as caregivers, relationship to the sick person, the complexity of the sick person’s needs and the chronic disease’s time of evolution (8,18-21). One study performed on caregivers of people with chronic diseases identified a negative and statistically significant correlation between the time a person has had a disease and overload (21).

One aspect to be highlighted is that an IC’s role implies responsibility, commitment and morality, reason why it has been demonstrated that it requires caregiving competencies. These are defined as the capacities, skills and preparation to provide care at home (22). These competencies can differ according to the type of chronic disease, time and dedication to the care receiver, since they can be related to caregiving experience and skill development and the relationship to the sick person (23). Caregivers of people with chronic diseases demonstrated moderate (40.7%) and high (40.5%) caregiving competencies in some documentation (24). However, a similar study identified that 89.3% of caregivers had high levels of caregiving competencies on a global scale, not by dimensions. Nevertheless, dimensions such as knowledge, uniqueness and instrumentality recorded moderate levels, which represent areas with significant opportunities (25). Moreover, caregivers of people with more demanding diseases, such as cancer and heart failure, mostly reported a moderate level of caregiving competencies (37% to 79.7%) (13,23,26).

A significant correlation between the dimension of caregiving competencies and caregiver overload was observed in a study performed on IC's of children with cancer (13). Considering how an IC's role has various consequences on physical, mental and emotional health, and that it is important to understand the interactions of variables associated with this role and their consequences, this study's objective is to identify the relationship between caregiving competencies and overload in informal caregivers of people with chronic diseases.

Methods

This is a transversal, correlational study with intentional non-probability sampling. The sample included 259 informal caregivers of people with chronic diseases who were users of two General Hospitals in Tampico-Tamaulipas. The inclusion criteria were: being the primary caregiver of the person with a chronic disease, having been a caregiver for at least three months, receiving no financial compensation, having no education or training related to health, providing authorization and granting informed consent. The exclusion criteria were being only an attendant or paid caregiver of the person with a chronic disease and having no reading or writing skills, since this interfered with the measurement instrument's application. Caregivers with visual, hearing or cognitive disabilities were also excluded. It is important to indicate that this investigation is derived from the "Chronic Disease Self-management Network" Project.

The sociodemographic data was obtained from a sociodemographic data form made up of two sections. The first section included items on the person with the chronic disease, such as gender, age, marital status, level of education, occupation, first chronic disease diagnosis and the time since the diagnosis. The second section included items related to the IC, such as age, gender, occupation, current employment situation, time dedicated to the care receiver in months, relationship to the care receiver and, in addition, support received from others while caregiving and the IC's perception of their health.

The CUIDAR instrument was used with a Cronbach's alpha of 0.92 in order to evaluate caregiving competencies. The instrument consists of 20 items grouped by dimensions: Knowledge, Uniqueness, Instrumentality, Enjoyment, Anticipation and Social Relationships. Each item has four Likert response options from 0 to 3, which are 0 (never or almost never), 1 (sometimes), 2 (many times) and 3

(almost always or always). The instrument is evaluated by cut-off points, which reflect caregiving competency levels. Zero to 36 are low, 37 to 48 are moderate and 49 to 60 are high caregiving competencies, and the instrument has reported a Cronbach's alpha reliability of 0.92 (22).

Zarit Burden Interviews (ZBI), validated in Mexico in 2008 with a Cronbach's alpha of 0.90, were used to evaluate overload. The instrument has 22 items and a Likert response scale from 0 to 4 points. It is interpreted following these categories: 0 to 47 is no overload, 48 to 55 is mild overload and 56 to 88 is intense overload (27).

The data collection procedure always followed the Mexican General Health Law in terms of health care research. Both health care institutions' authorizations were obtained and the hospitals were subsequently visited, where team members invited family caregivers to participate in the research voluntarily. Measurement instruments were applied once consent was provided by signing. The obtained data was processed and analyzed by means of descriptive and inferential statistics with Statistical Package the Social Sciences (SPSS), version 22 for Windows.

Results

With respect to the sociodemographic data of people with chronic diseases, it was observed that the majority were women (58.3%), and users' ages were between 18 and 96 years (\bar{X} =67 years SD =15.1). When it comes to marital status, 48.6% were married and 31.3% were homemakers, while 14.7% were retired or pensioned. The average level of education was 8.2 years (high school). The first disease most diagnosed in users was diabetes, with 40.5% of cases. Twenty-seven point four percent had high blood pressure, 10.8% kidney failure, 6.2% cancer and 15.1% were grouped in a category that included various neurological, respiratory and mental illnesses. These diseases were diagnosed between 1 and 60 years earlier (\bar{X} = 14.64 years, SD = 12.1).

In terms of the informal caregivers' sociodemographic data, it was observed that most were women (82.6%). Age was between 18 and 87 years (\bar{X} = 49 years, SD = 12.5), of which 77.7% were adults and 22.3% were seniors. Moreover, 69.1% of users were married, 44.8% were homemakers, 21.2% were employed and the average level of education was 11.3 years (high school) (Table 1). Furthermore, the average time dedicated to caring for their family members was 80.6 months, which is approximately 6.7 years. Caregivers' relationship to

the sick person was mostly wife (21.2%) and daughter (37.8%). Forty-eight point six percent of caregivers are currently employed and 49% are unemployed. In the same way, 8.1% reported having completely left their jobs and 25.1% partially left them. Fifty-five point six percent indicated someone supported them to take care of their family member. These people were usually also

family members. With respect to perceptions on their health, 3.9% of informal caregivers reported health issues (bad health), 38.4% reported normal health, 35.7% good health, 13.6% very good health and 8.4% excellent health.

Table 1. Sociodemographic characteristics of informal caregivers of people with chronic diseases.

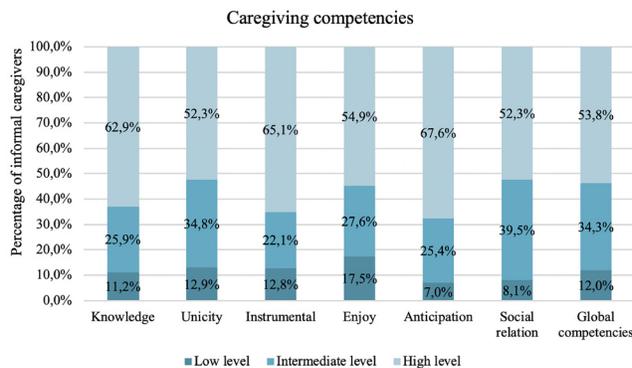
Variable	f	%	Variable	f	%
Gender			Relationship to the sick person		
Female	214	82.6	Wife/partner	55	21.2
Male	45	17.4	Husband/partner	16	6.2
Marital Status			Mother	16	6.2
Married	179	69.1	Daughter	98	37.8
Single	18	6.9	Son	23	8.9
Divorced	51	19.7	Sister	14	5.4
Widow	11	4.2	Brother	3	1.2
Occupation			Daughter-in-law	12	4.6
Home	114	44.8	Son-in-law	5	1.9
Retiree/Pensioner	22	8.5	Female Neighbor	2	0.8
Employee	55	21.2	Female Friend	2	0.8
Business person	15	5.8	Other	12	4.6
Unemployed	2	0.8			
Professional	33	12.7			
Construction worker	6	2.3			

n=259

Source: Sociodemographic data form

Figure 1 presents the global results and results by dimensions of the caregiving competencies variable. In terms of global competencies, it was reported that 53.8% of IC's had a high level, 34.3% a moderate level and 12% a low level of competencies. Regarding the dimensions, all of them presented a high level of caregiving competencies of above 50% of the sample. However, what stood out was that the uniqueness, instrumentality and enjoyment dimensions have the highest percentage of low competency levels.

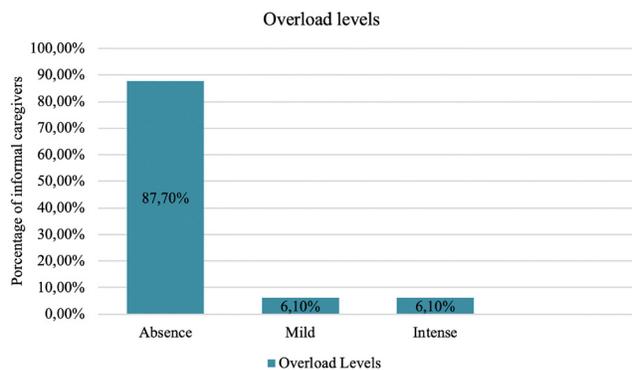
Figure 1. Total caregiving competency levels and the dimensions of informal caregivers of people with chronic diseases



Source: CUIDAR Instrument

This problem was mostly absent when assessing overload. Nevertheless, 12.2% of caregivers had mild to intense overload (Figure 2).

Figure 2. Overload levels in informal caregivers of people with chronic diseases



Source: Zarit Instrum

A Spearman Rho correlation coefficient was used to identify the relationship between caregiving competencies and overload in informal caregivers of people with chronic diseases, in which a negative, statistically significant correlation ($p=0.01$) was detected. This indicates that less caregiving competencies imply a higher level of overload, and vice versa (Table 2).

Table 2. Correlation between caregiving competencies and overload in informal caregivers of people with chronic diseases.

Caregiver competency level		
Spearman	Overload	-0.160*
Sig. (bilateral) .0013		

*Correlation is significant at 0.05 (2 tails).

Discussion

The sociodemographic data demonstrated that most of the sample of informal caregivers consisted of women (83.6%). This data coincides with other previous studies, in which between 78% and 88% of IC's were women (6-11). In terms of the relationship between informal caregivers and sick people, it was identified that most were daughters or wives. This data coincides with that of various studies (6, 8, 12). Gender and relationship may be explained by what other authors suggest with respect to the sociocultural structure of families, where women become those responsible for home-based care (13)

With respect to the age of informal caregivers, the average age was 49. This figure coincides with other studies performed in Mexico, Colombia and Cuba (10-12). This data confirms that informal caregivers are adults, and one can assume that caregivers' ages can vary based on the sick person's age and the relationship between the caregiver and care receiver. Informal caregivers' level of education was an average of 11.3 years (high school), a result that is similar to those of other studies, which reported middle and high school education (7-9,11). This implies considering a functional scenario to reinforce caregiver knowledge and training, since one can infer they have learning capacities and can exercise or acquire caregiving skills and decision-making and contribute to sick people's safety and quality of life.

The average time dedicated to taking care of the person with a chronic disease was 6.7 years. This coincides with other studies, which reported an average time dedicated to taking care of the sick person of 6.5 to 8 years (10, 12). The similarities between the times dedicated to taking care of a family member with a chronic disease could be due to the fact that IC's have a family relationship and emotional bond with the person they are caring for, reason why taking care of a sick family member becomes a moral commitment for an indefinite period (12).

With respect to caregivers' perceived health, the category with the highest percentage (38.4%) stated their health was normal. Even though it had the highest percentage, this differs from the results reported in another similar study, in which 67% of IC's stated their health was normal (6). This result can be attributed to the fact that caregivers face critical situations derived from providing care to a person with a chronic disease. Stress, exhaustion, a lack of support from other family members, health problems and symptoms of depression or anxiety represent some of the multiple factors that can impact an IC's perception of their health (10,14,15).

Caregiving competencies were identified at a significantly high level on a global scale and by dimensions. This data coincides with that of another study performed on a similar sample (24). However, dimensions such as knowledge, uniqueness and instrumentality were identified as areas of opportunity, which could be improved through interventions or programs focused on IC's (25). Another study performed on IC's of children and adults with cancer mostly observed a moderate level of caregiving competencies (13, 23), while they reported a moderate (37%) and low (24%) level of caregiving competencies in IC's of people with heart failure. The above can be explained by the type of disease the person under the caregiver has, since the evolution and chronicity of the different chronic diseases can vary depending on the type of disease. For example, cancer and heart failure are more aggressive and complex diseases that generate dependency and a need for care. In addition, the time and dedication an IC provides could favor the development of experience and skills (23).

When it comes to overload, 87.8% of IC's were not overloaded. However, 12.2% were moderately overloaded. This information coincides with a study performed on caregivers of people with chronic diseases in a high complexity hospital (18). Notwithstanding the above, other studies mostly reported intense overload. These differences can be attributed to various

factors, such as the dependency of the person with a chronic disease, since it has been observed that less dependency implies less overload. Furthermore, time of care, perceived support and family and emotional relationship between the caregiver and care receiver are considered variables that could generate a sociocultural commitment and moral duty "burden" to take care of the sick family member, which could impact overload perception (13, 18).

The negative, statistically significant correlation allowed deducing that "more caregiving competencies imply less overload." This result was not able to be compared to those of similar populations, since few studies cover these variables' relationship. However, one study on IC's of children with cancer showed no correlation between global caregiving competencies and overload, although it did identify a significant correlation between the anticipation dimension and overload (13). The observed differences could be derived from the fact that the previously mentioned study was performed exclusively on IC's of children with cancer, for which reason the IC was usually a child's mother or father. This relationship creates an important emotional bond that could impact overload perception. Alongside the above, it is worth nothing that the chronic diseases included in this study, such as high blood pressure and diabetes, have different deterioration and evolution processes. This information confirms what various authors have previously indicated, which is that overload and caregiving competencies can be different depending on the type of disease and its deterioration process (17,23).

Finding the correlation between caregiving competencies and overload could also be explained in previous studies that state a prolonged time as caregiver can develop physical and mental deterioration, financial trouble (28), symptoms of depression and anxiety (10), which translate to caregiver overload. This issue directly impacts the capacities, skills and preparation to practice home-based caregiving.

Conclusion

The results allowed meeting the study objective and identifying a negative correlation between IC's caregiving competencies and overload, which can be interpreted as "less caregiving competencies imply more overload." These findings show how IC's have various knowledge and skill requirements to optimally perform an IC's role and, therefore, have the capacity to face overload situations. Moreover, based on the sociodemographic data, we can conclude that caregivers'

profiles are women with an average age of 49, most of whom have a high school education and are the wives or daughters of the people with a chronic disease.

Therefore, this study's results contribute the knowledge to generate educational nursing strategies to increase caregiving competencies and decrease IC overload and the risk of informal caregivers developing illnesses, as well as to prevent complications in the people under their care.

Finally, we recommend implementing studies on samples of caregivers of people with various chronic diseases in advanced stages, since the care receivers can generate more dependency and needs, and studies that analyze the relationship between overload, competencies and other variables, such as dependency. We also recommend implementing studies with probability samples to be able to make conclusions on a populational level.

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