


Care competence and its impact on the quality of life of caregivers

Competência do cuidar e seu impacto na qualidade de vida de cuidadores

Competencias del cuidar y su impacto en la calidad de vida de cuidadores

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Abstract

Objective: To describe the relationship between the quality of life of caregivers and their competence of caring for a person hospitalized with a chronic condition.

Methods: Quantitative, descriptive, correlation and cross-sectional study, with a convenience sample. Participants of this study were 102 caregivers of people hospitalized in a health institution, located in Neiva, Huila, Colombia. Three instruments were used for data collection: Caregiver-patient characterization survey, Caregiver's quality of life, and Homecare competency.

Results: Caregivers were mainly women (74.5%), with a negative perception of social and spiritual well-being, and a positive perception of psychological and physical well-being. A correlation was found between psychological and spiritual well-being. The dimensions of the Homecare competency instrument were related to the psychological, social, and spiritual well-being of quality of life, but they were not related to physical well-being.

Conclusion: This study shows that the feminization of caregivers persists, along with the dedication for long periods of time to the care of the sick person, thus affecting the social and spiritual well-being of quality of life. In face of this scenario, it is important to keep high scores in the different dimensions of the Homecare competency instrument to improve the quality of life of caregivers and prevent overload.

Resumo

Objetivo: Descrever a relação entre a competência do cuidar e a qualidade de vida do cuidador familiar da pessoa hospitalizada com doença crônica.

Métodos: Estudo quantitativo, descritivo, de correlação e corte transversal. Foi utilizada uma amostragem por conveniência. Participaram 102 cuidadores de pessoas hospitalizadas em uma instituição de saúde. Para a coleta de dados, foram utilizados três instrumentos: ficha de caracterização do par cuidador-pessoa com doença crônica, qualidade de vida do cuidador informal e competência para o cuidado no lar.

Resultados: Houve predomínio de cuidadores do sexo feminino (74,5%), percepção negativa do bem-estar social e espiritual e percepção positiva do bem-estar psicológico e físico. Foi encontrada uma correlação entre o bem-estar psicológico e o espiritual. As dimensões do instrumento competência para o cuidado no lar se correlacionaram com o bem-estar psicológico, social e espiritual da qualidade de vida, mas não se correlacionaram com o bem-estar físico.

Conclusão: Este estudo mostra que a feminização dos cuidadores persiste, assim como a dedicação por longos períodos de tempo ao cuidado da pessoa enferma, afetando o bem-estar social e espiritual da qualidade de vida. Nesse cenário, é importante manter altos escores nas diferentes dimensões do instrumento competência para o cuidado no lar para melhorar a qualidade de vida dos cuidadores e prevenir a sobrecarga.

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Conflicts of interest: none to declare.

Resumen

Objetivo: Describir la relación entre las competencias del cuidar y la calidad de vida del cuidador familiar de la persona hospitalizada con enfermedad crónica.

Métodos: Estudio cuantitativo, descriptivo, de correlación y corte transversal. Se utilizó un muestreo por conveniencia. Participaron 102 cuidadores de personas hospitalizadas en una institución de salud. Para la recopilación de datos se utilizaron tres instrumentos: ficha de caracterización del par cuidador y persona con enfermedad crónica, calidad de vida del cuidador informal y competencias para el cuidado en el hogar.

Resultados: Hubo predominio de cuidadores de sexo femenino (74,5 %), percepción negativa del bienestar social y espiritual y percepción positiva del bienestar psicológico y físico. Se observó una correlación entre el bienestar psicológico y espiritual. Las dimensiones del instrumento de competencias para el cuidado en el hogar se correlacionaron con el bienestar psicológico, social y espiritual de la calidad de vida, pero no se correlacionaron con el bienestar físico.

Conclusión: Este estudio muestra que la feminización de los cuidadores persiste, así como la dedicación al cuidado de la persona enferma por períodos prolongados de tiempo, lo que afecta el bienestar social y espiritual de la calidad de vida. Ante este contexto, es importante mantener una puntuación alta en las diferentes dimensiones del instrumento de competencias para el cuidado en el hogar para mejorar la calidad de vida de los cuidadores y prevenir la sobrecarga.

Introduction

Chronic noncommunicable diseases (CNCDs) are not infectious and not transmissible from one person to another.⁽¹⁾ They are long-lasting and develop slowly. They are considered the main cause of morbidity and mortality in the world. The four main CNCDs are: cardiovascular diseases, cancer, respiratory diseases and diabetes.⁽¹⁾ In 2016, they led to the death of 41 million people, which represents 71% of total deaths on a global scale,⁽¹⁾ therefore becoming a major concern for developed and developing countries.

Aging, greater life expectancy and CNCDs are increasing people's dependency and need for support in their daily lives,⁽²⁾ thus requiring the assistance of informal caregivers, defined as a member of the family or a friend, paid or not, in charge of providing support in the performance of daily tasks of people with changes in their physical and/or mental health.⁽³⁾

It is acknowledged that care of people with CNCD is taken on by a caregiver and the family, and these interactions may result in stress, due to the health conditions and the behavior of the ill person.⁽⁴⁾ Also, tasks such as practical and emotional assistance, decision-making and health services paperwork are assigned to caregivers,⁽⁵⁾ and this results in an overload and a consequent impact on them and the patient's family, since the family dynamics are changed as well as their quality of life with regard to social, personal, and economic aspects, mainly.⁽⁶⁾

Similarly, in the care of chronic patients, caregivers experience different forms of interaction,⁽⁷⁾ due to the challenges they are faced with: admin-

istration of medicines, physical care routine, special nutrition when required, responding to health issues they may have,⁽⁸⁾ support in daily routine, going shopping, making medical appointments, speaking to doctors and ordering drugs.⁽⁷⁾ These factors may lead to an overburden⁽⁹⁻¹¹⁾ and affect their quality of life,⁽¹²⁾ in addition to the different tasks and roles they have to take on.

Given this background, it is important to assess home care skills, which allows health professionals to support family caregivers in meeting the demand.⁽¹³⁾ Skills for home care are defined as the ability, capacity and readiness of the chronic patient and/or the family caregiver to perform home care.⁽¹³⁾ It is considered an essential aspect, which must be strengthened by health professionals within institutions. Their assessment and diagnosis are indispensable to people with chronic diseases, due to the numerous recommendations and the complexity of treatment.⁽¹³⁾ Appropriate care skills will result in positive effects on the quality of life of caregivers and patients with CNCD.

The literature review resulted in studies that addressed the quality of life and overload of caregivers,^(3,9-11,14) as well as the competence of providing care at home.⁽¹⁵⁻¹⁷⁾ However, there is a lack of research on the impacts of the competence of providing care on the quality of life of caregivers, which is considered a relevant aspect to designing strategies to contribute to improve the safety of people with CNCD at home. For the aforementioned reasons, the objective of this study was to describe the relationship between the quality of life of caregivers and their competence of caring for a person hospitalized with CNCD.

Methods

Quantitative, descriptive, correlation and cross-sectional study. A convenience sample was used, which was composed of 102 caregivers of patients with CNCD in hospital services, located in Neiva, Huila, Colombia. Inclusion criteria for participants were: being aged over 18, to have been the main caregiver for more than three months, and provided care for more than three hours a day.^(5,9,10,12) Participants were informed of the objectives and procedures to be carried out before signing an informed and consent form. Data were collected in 2019 by the researchers and research assistants trained for the application of the instruments.

The study was approved by the Research Ethics Committee of Hospital Hernando Moncaleano Perdomo, minutes number 001-003 of 2019, considering the following bioethical principles: respect of human dignity, privacy, freedom of speech and feelings, confidentiality and reciprocity.

Data were organized and entered into a Microsoft Excel® 2019 spreadsheet and processed in SPSS® statistics software version 23. A univariate descriptive analysis was carried out by means of the aforementioned instruments. Qualitative variables were described using frequency tables and quantitative variables were described by central tendency measures (mean, median), dispersion measures (standard deviation) and position measures (minimum, maximum, range). A bivariate analysis was performed using the Kruskal Wallis test and a correlation analysis with the Spearman's method. We considered differences as statistically significant when $p < 0.05$.

Three instruments were used with the authorization of the Research Group on the Care of Chronic Patients (GCPC), at the Nursing School of Universidad Nacional de Colombia:

- GCPC-UN Caregiver-patient characterization survey:⁽¹²⁾ with 42 items that survey the pair in three categories: overall conditions and socio-demographic profile, burden and perception of support, and available means of information and communication.
- Family caregiver's quality of life, version 02-2013-GCPC-UNC:⁽¹⁸⁾ by Dr. Ferrell, va-

lidated to assess caregivers of people with CNCD, with 35 Likert items and Cronbach's alpha of 0.866. The score for each well-being dimension ranged as follows: physical 5-20; psychological 16-64; social 9-36; spiritual 7-28. A positive perception was identified for scores <12.5 , <22.5 and <17.5 in the physical, social and spiritual dimensions, respectively. A score <40 in the psychological dimension was equivalent to a negative perception.

- Home care skills - caregiver, short version:⁽¹³⁾ with 20 Likert items, and answer options: almost never or never, a few times, frequently, almost always or always, in a scale ranging from 0 to 3, respectively; and Cronbach's alpha of 0.928. It is composed of six categories: *Knowledge*, related to the conceptions about the disease, its treatment and daily care; *Uniqueness*, the personal conditions to face and overcome issues and challenges; *Instrumental and procedural*, the skills and abilities to carry out care tasks and meet basic needs; *Enjoyment*, the extent of well-being and personal satisfaction related to the perceived quality of life; *Anticipation*, to foresee the needs of caregivers and to identify risks; and *Relationship and social interaction*, social relationships and support networks that improve the task of providing care.⁽¹³⁾

Results

One hundred and two pairs of individuals participated in the study. Caregivers were mainly women (74.5%), aged between 36 and 59 years and average of 48.2 years ($SD \pm 14.9$), with primary school completed (43.1%), working in the household (53.9%), low economic status (90.2%), with a partner (73.5%), and their relationship with the patient with CNCD was parent-child or spouse (38.2% and 37.3%, respectively). Being committed to care since the diagnosis (87%), as the sole caregiver (66.7%), for more than 37 months (49%) and more than 20 hours a day (60.8%). There was a high rate of patients with high levels of dependency (52.9%), with no intellectual alterations (61.8%)

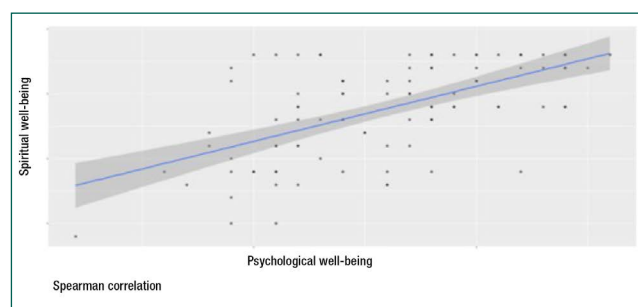
and who saw themselves as a moderate or light burden (36.2% and 43.1%, respectively).

In the general assessment of the aspects of quality of life, the data reported on physical well-being indicate an average of 11.8, which is in line with a positive perception of their health conditions when taking on the role of caregiver. Likewise, a score of 46 was found in psychological well-being, which indicates a low impact and a positive perception. Social well-being obtained a score of 22.8, with a negative perception of their social relationships, which negatively impacts their quality of life when they take on the role of caregivers. Finally, the spiritual aspect, with an average score of 23.9, indicating a negative perception of spirituality (Table 1).

Table 1. Assessment of caregivers' quality of life (n=102)

Quality of life	Mean	Median	SD	Minimum	Maximum	Range
Physical well-being	11.8	12	2.7	5	17	12
Psychological well-being	46.0	46	5.1	32	56	24
Social well-being	22.8	23	4.0	14	33	19
Spiritual well-being	23.9	24	3.7	14	28	14

After an analysis of the correlation between aspects of quality of life, a significant correlation was found between psychological well-being and spiritual well-being ($p < 0,05$), where caregivers with high scores in psychological well-being also had high scores in spiritual well-being, whereas caregivers with low scores in psychological well-being had also low scores in spiritual well-being (Figure 1).



Spearman correlation

Figure 1. Correlation between psychological and spiritual aspects of quality of life

The overall assessment of the CUIDAR instrument shows a correlation with psychological well-being ($p=0.000 < 0.05$), social well-being ($p=0.005 < 0.05$) and spiritual well-being

($p=0.005 < 0.02$) of quality of life. The dimensions Knowledge, Uniqueness, Instrumental and procedural, Anticipation and Relationship and social interaction had a correlation with psychological and spiritual well-being ($p=0.000 < 0.05$). On the other hand, the Enjoyment dimension was correlated to psychological well-being ($p=0.000 < 0.05$), social well-being ($p=0.005 < 0.05$) and spiritual well-being ($p=0.005 < 0.05$). However, the different dimensions and the overall assessment of the CUIDAR instrument did not show any correlation with physical well-being (Table 2).

Discussion

The limitations of this study are related to the convenience sampling technique used, which prevents generalization of its results. This study contributes to the practice emphasizing the importance of addressing the caregivers of people with CNCD, as a mechanism to improve the competence of providing care at home, thus improving indicators of quality of life of both caregivers and patients. In addition, it contributes to the development on knowledge in nursing, oriented to a comprehensive approach of caregivers, early detection of the competence of looking after caregivers works to generate intervention protocols directed to improve the caregiver skills before the medical discharge of a person with CNCD and diminish the risk of complications in these population.

Most caregivers, mainly women above 45 years, with low education level, had a partner. These findings are in line with the sociodemographic characteristics of caregivers of other studies.^(10,14) In addition, they were housewives and provided care to CNCD patients for over 37 months and more than 20 hours days. Consequently, caregivers who have such workload have to make adjustments to their labor obligations⁽¹⁹⁾ when needed. The aspects mentioned are predictors of well-being and quality of life.⁽²⁰⁾

In the assessment of quality of life, it was found that social and spiritual well-being were affected, with minor changes in psychological well-being.

Table 2. Correlations between quality of life and CUIDAR instrument dimensions (n=102)

CUIDAR dimension	Quality of life (well-being)								
	Psychological			Social			Spiritual		
	Mean	Median	p-value	Mean	Median	p-value	Mean	Median	p-value
Knowledge									
Low	45.9	47.0	0.000				23.5	24.5	0.000
Average	42.3	42.0					22.0	22.5	
High	48.5	48.5					25.2	26.0	
Uniqueness									
Low	39.6	40.0	0.000				20.0	20.0	0.000
Average	42.9	42.0					22.4	22.5	
High	48.8	49.0					25.3	26.0	
Instrumental and procedural									
Low	42.3	41.0	0.000				22.0	21.0	0.001
Average	43.1	43.0					22.3	23.0	
High	48.3	48.0					25.1	26.0	
Enjoyment									
Low	40.7	41.0	0.000	24.4	25.0	0.026	20.1	21.0	0.000
Average	43.4	43.0		23.7	25.0		22.7	23.0	
High	48.7	48.5		21.9	21.5		25.4	26.0	
Anticipation									
Low			0.000						0.000
Average	42.8	42.0					21.8	21.0	
High	48.2	48.0					25.1	26.0	
Relationship and social interaction									
Low	41.8	41.5	0.000				20.6	19.0	0.000
Average	44.1	42.5					23.3	23.5	
High	48.4	48.0					25.2	25.5	
Overall appreciation									
Low	41.6	42.0	0.000	23.0	23.0	0.005	23.0	24.0	0.002
Average	41.7	42.0		24.7	25.0		21.6	21.0	
High	47.9	48.0		22.0	22.0		24.8	26.0	

Kruskal-Wallis Test

However, physical well-being was not affected. Several studies report that caregivers' physical, mental and psychological health is affected, as well as social support and spirituality.^(14,20,21) With regard to physical health, caregivers experience exhaustion due to the different roles they take on and time they dedicate to care.⁽²¹⁾ Effects on mental health are associated with low education level, the presence of comorbidities, female gender, unemployment and depressive symptoms.^(20,22) Similarly, anxiety and functional impairment have a significant impact on patients with CNCN.⁽¹⁴⁾ Social well-being is affected by confinement, lack of freedom and social isolation⁽²³⁾ in association with severity of symptoms and dependence. On the other hand, the spiritual aspect is mainly related to the belief in God and it is based on values and hope of finding life after death.⁽²⁴⁾ In that sense, caregivers suffer less and feel better when they use strategies that help them deal with the patient's disease and find meaning to life, which is a positive adaptation to the role of caregiver.⁽²⁵⁾

Also, in the assessment of quality of life in its different aspects, a correlation was found between psychological and spiritual well-being. No correlation was found between social and physical well-being. Spirituality is associated with better results in mental health and quality of life of caregivers, where the greater the spirituality, the better their quality of life.⁽²⁶⁾ It was observed that caregivers with high scores in the spiritual aspect experience some psychological effects but to a lesser extent, despite being exposed to high levels of stress. This confirms the hypothesis that spirituality mitigates the stress, anxiety and anguish⁽²⁷⁾ experienced by caregivers.

The findings of this study show that caregivers have different needs with regard to quality of life and the dimensions of the CUIDAR instrument, many of which are correlated. The results show how psychological and spiritual well-being are correlated to the Knowledge dimension. High scores in this dimension are associated with high scores in psychological and spiritual well-being.

Caregivers who are not provided with accurate information regarding the handling of the disease are not ready to assist their families and therefore, will suffer from greater stress and workload,^(28,29) thus affecting their quality of life. The need for information has an influence on learning processes and their evolution over time.⁽³⁰⁾

Likewise, caregivers who do not know what to expect about the disease forecast or where they can have access to formal support can feel overwhelmed by the absence of information required to manage and plan the provision of care.⁽³¹⁾ In conclusion, adequate knowledge of the diagnosis, symptoms, health issues, disease management, drugs, and access to health services reduce anxiety, anguish, and depression, and they are also a positive factor for spiritual well-being.

A correlation was found between psychological and spiritual well-being in the Uniqueness dimension. Caregivers fully take on the role to assist their loved ones. When they acknowledge the patient's personal preferences in terms of culture, spirituality and religion, they manage to identify essential elements that make planning easier.⁽²²⁾ Caregivers who are committed to providing care to a family member are granted with compassion, in exchange for the care being provided. "Mutual compassion" can be a protective factor for the dyad,⁽³²⁾ resulting in better psychological and spiritual conditions for caregivers, and better perception of well-being for the patient.

Caregivers often assist patients with different daily tasks, such as eating, moving, going to the restroom, and other instrumental tasks, such as medication, food preparation, house chores, and finance.^(31,33) They require support to perform these tasks,⁽³¹⁾ and it is a positive strategy that helps to reduce overburden and to improve the quality of life of caregivers. The description above is in line with the results of this study, in which the correlation between the instrumental and procedural dimension and psychological and spiritual well-being is highlighted. Moreover, the relation between high scores in the instrumental and procedural dimension and a better perception of psychological and spiritual well-being is also evident.

The Anticipation dimension is correlated to the psychological and spiritual well-being, showing that higher scores in this field improve the perception of psychological well-being and spiritual well-being. The Anticipation dimension of home care can prove that when caregivers are ready and able to anticipate care needs or emergency assistance, they can prevent an overload⁽¹⁵⁾ and improve their quality of life.

The correlation between Relationship and social interaction and psychological and spiritual well-being shows how a positive perception of a relationship can be an important protective factor. Disease and care can often disrupt the homeostasis of family relationships and result in the deterioration of significant interactions and reciprocity.⁽³⁴⁾ Frequent participation in community activities is associated with low scores of depression. These activities provide people with the opportunity to obtain different types of support through interaction and creation of bonds with other people. As care responsibilities increase, caregivers often have less time for social activities, so they have fewer opportunities to share their experiences with others or to play other roles in their lives.⁽³⁵⁾

On the other hand, the Enjoyment dimension is correlated to the psychological, social, and spiritual well-being. In this dimension, we investigate the perceived well-being of caregivers when they actually take on the responsibility in the household regarding basic aspects of daily life and personal satisfaction related to quality of life.⁽³⁶⁾ This study found that caregivers with high scores in the Enjoyment dimension obtained higher scores in psychological, social and spiritual well-being, as opposed to average or low scores, for which the perception of quality of life is poorer.

Conclusion

There was a prevalence of women, the degree of kinship was mostly spouse or child, with low levels of education, committed to care for long periods, and with low socioeconomic status. Positive perceptions were found for physical and psychological well-being, whereas social and spiritual well-being are poor-

ly perceived with regard to quality of life, resulting in an impact on caregivers' lives and in situations that can make them feel overloaded by their roles. A correlation was found between social and spiritual well-being, an aspect that must be strengthened in order to improve care and ensure the patient's safety. As for the home care instrument skills, the dimensions Knowledge, Uniqueness, Instrumental and procedural, Anticipation, and Relationship and social interaction were correlated to psychological and spiritual well-being, whereas Enjoyment was correlated to psychological, spiritual and social well-being. Having high scores in the CUIDAR instrument dimensions must be a goal of health professionals so as to improve the quality of life of patients with CNCND before home care is provided.

Collaborations

Romero AYP contributed to the study conception and design, and data analysis and interpretation; Medina CPC contributed to the study design and approval of the final version to be published; Perdomo CAR contributed to the study design, data analysis and interpretation, writing of the article, and relevant critical review of the intellectual content.

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