

# Family caregivers: Competence in the care of the chronically ill

## Cuidadores familiares: Competencia en la atención de enfermos crónicos

### Cuidadores familiares: Habilidad no atendimento de doentes crónicos

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#### Abstract

**Introduction:** Because of the high demand and costs of care, chronic diseases have shown an increasing number of caregivers who develop their role without the required training and skill. **Objective:** To describe the capacity for home care of caregivers of patients with chronic illness in a service provider institution of San José de Cúcuta. **Materials and methods:** Descriptive quantitative cross-sectional study, developed in the first half of 2017. The sample was composed by 360 caregivers of patients with chronic disease. We used the instruments developed by the Chronic Patient Care Group of the Faculty of Nursing of the National University of Colombia called: GCPC-UN-C © - technical characterization chart for family caregivers of patients with chronic non-transferable disease and the instrument “Caring” - short version to measure the competence of care at home. **Results:** In the study, low and medium levels of competence of the caregivers were reported in the exercise of their role, and the categories Knowledge and Enjoyment (Welfare) were more affected. It is important to note that caregivers with a high level of competence were not reported. **Conclusion:** The results show that the need for nursing intervention in strengthening the competence of caregivers remains an important constant of professional performance.

**Keywords:** Chronic disease, chronic patient, caregiver, competencies.

#### Resumen

**Introducción:** Ante la magnitud de la demanda y costos en la atención, las enfermedades crónicas han visibilizado un creciente número de cuidadores, quienes se inician en este rol sin la capacitación y competencia requerida. **Objetivo:** Describir la competencia para el cuidado en el hogar de los cuidadores de personas con enfermedad crónica en una institución prestadora de servicio de San José de Cúcuta, Colombia. **Materiales y métodos:** Estudio cuantitativo descriptivo de corte transversal, desarrollado en el primer semestre del año 2017. La muestra estuvo conformada por 360 cuidadores de personas con enfermedad crónica. Se emplearon los instrumentos elaborados por el Grupo Cuidado de Enfermería al Paciente Crónico de la Facultad de Enfermería de la Universidad Nacional de Colombia, denominados: GCPC-UN-C©-ficha técnica de caracterización para los cuidadores familiares de personas con enfermedad crónica no transmisible y el instrumento “Cuidar” - versión corta para medir la competencia de cuidado en el hogar. **Resultados:** Se reportaron niveles bajo y medio de competencia de los cuidadores en el ejercicio de su rol, encontrándose en mayor afectación las categorías Conocimiento y Disfrutar (Bienestar). No se reportaron cuidadores con alto nivel de competencia al momento de desempeñar su rol. **Conclusión:** Los resultados muestran que la necesidad de intervención de enfermería en el fortalecimiento de la competencia de los cuidadores sigue siendo una constante importante de la actuación profesional.

**Palabras Clave:** Enfermedad crónica, paciente crónico, cuidador, competencias.

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## Resumo

**Introdução:** Dada a magnitude da demanda e custos dos cuidados, doenças crônicas têm tornado visível um número crescente de cuidadores que são novos para o papel sem o treinamento e competição necessário. Objetivo: Descreva a competência para cuidados domiciliares de cuidadores de pessoas com doença crônica em uma instituição de provedor de serviços de San José de Cúcuta. **Materiais e Métodos:** Um estudo quantitativo descritivo transversal, desenvolvido na primeira metade de 2017. A amostra consistiu de cuidadores de 360 pessoas com doença crônica. CGP-A-C © -ficha técnica de caracterização de cuidadores familiares de pessoas com doenças não transmissíveis crônicas e o instrumento: foram empregadas as ferramentas desenvolvidas pela medicina de grupo, paciente crônico da Faculdade de Enfermagem da Universidade Nacional da Colômbia chamado “cuidar” - versão curta para medir a competência de atendimento domiciliar. Resultados: Os níveis baixos e médios de competência dos cuidadores foram relatados no exercício do seu papel no cumprimento das categorias mais afetadas e Divirta Conhecimento (Bem-estar). Importante, não-cuidadores relataram um nível de competência alta na hora de desempenhar o seu papel. Conclusão: Os resultados mostram que a necessidade de intervenção de enfermagem no fortalecimento cuidadores concorrência continua a ser um importante desempenho constante.

**Palavras-chave:** doença crônica, pacientes crônicas, habilidades cuidador.

## Introduction

A chronic disease is the one that shows unique clinical characteristics, where the symptoms of the patient are prolonged in time, with an irreversible and progressive character, which requires continuous observation and permanent treatment during an undetermined period of years. It has an impact in all aspects of the life of the affected person, their immediate family members and the care provider, and is determined by multiple factors, such as the demographic transition (1), urbanization and globalization, being also influenced, by internal or unmodifiable factors -heritage, race, age and gender-, and external or modifiable factors related to the willingness of the person -nutrition, rest, physical activity- (2).

Globally, chronic diseases represent the principal cause of mortality. According to the World Health Organization (WHO) (3), non-communicable diseases are the cause of death of 40 million people each year, in which 17 million are people younger than 70 years, being cardiovascular diseases the main cause of these deaths.

In Colombia, non-transmissible chronic diseases are considered a national public health problem, since 71% of deaths are attributed to these conditions, being cardiovascular diseases the main cause in the epidemiological profile (4). Also, according to data from the Health Analysis Situation (ASIS) of Colombia, it was reported that circulatory system

diseases were the first cause of mortality in men and women between 2005 and 2014, being hypertensive diseases the cause of 10.47% (62,297) of deaths each year. Also, diabetes mellitus provoked 14.58% (70.309) of deaths, with rates tending to increase (5).

In the Department of Norte de Santander (Colombia), the situation is similar, registering as the highest prevalence with a considerable growth of arterial hypertension and diabetes mellitus (6).

The negative impact of these diseases when looking at the financial sustainability of the health systems is becoming more recognized. The increasing demand for care attention, the inherent costs for the specialized diagnosis, the treatment and control of the disease, have generated a higher consumption of public spending and have transferred the provision of health services from formal to informal areas, where the responsibilities of assistance are assumed by the family.

As well as chronic patients, family caregivers are an increasing population group. According to Landinez and Beltran (2016), “they are a social capital of huge importance, since their labor guarantees the rights of many people, their access to health and the daily care they need” (7). Caregivers are defined as people in charge of helping in basic and instrumental necessities of the daily life of the chronic patient for a good part of the day. In most cases, they reside in the same home as the patient, without receiving any economic benefit for their labor (8).

National and international studies have shown the sociodemographic profile of the caregivers, being evident that most of these are middle aged women, with a low education level, unemployed (9) and in a precarious economic condition (7, 8, 10). that perform as caregivers by themselves without the help of other family members; their labor is lengthy in time and results intense in demand and complex in activities, noting a high index of work overload in them (7, 10, 11).

The capacity for home care, even though is not a new concept, has been gaining strength in the last years and is considered as part of the fundamental characteristics that are required to take care of a person with a chronic disease, since it needs the capacity, ability and preparation of a person to be able to perform the care labor (12). The available literature points out the lack of capacities to solve unexpected events from the patients at home (10,13,14), since low and medium levels have been reported in the knowledge and instrumental skill to be able to do the necessities, the capacity to anticipate unexpected situations, the well-being and social relationships of the patient. (15 - 17).

In that sense, the demand for care from the patients implies, for caregivers, the combination of capacities, knowledge and attitudes that make care labor possible, basic components that define the capacity and dominance to exercise the care labor and respond in an optimal way to a specific activity (12).

This qualification, which is essential in caregivers, was created by the Nursing Care Group for the Chronic Patient from the National University of Colombia, and it was endorsed and became operational by the Latin American Network of Care for the Chronic Patient (18) under six basic categories: knowledge, uniqueness or particular conditions, enjoyment of minimal conditions for care or level of well-being, anticipation, and social relationships and interaction.

Since most people that have a chronic disease do not have the capacity to take care of themselves, the help of an external person is required -this person is known as caregiver-, which performs this role almost always without education or knowledge, having minimal abilities and capacities for the optimal performance

of their job, assuming it in an empirical manner and with very low quality.

The study had as its purpose to describe the capacities of the informal caregivers of people with a non-transmissible chronic disease, in a city that has high levels of unemployment and an economy with considerably limited resources (19), which does not allow the caregivers to have enough of the necessary resources to properly care for the patient, and not having the formal education, necessary to develop their role as caregivers.

The research project had as support the review and consultation of specialized literature of the topic, investigating in referred previous studies of nursing journals of high impact in the last six years, research that allowed us to have updated and reliable information for the construction of the reference framework and for the analysis of the results.

In a disciplinary level, the study is inscribed in one of the topics of research projects established by the Latin American Network for Care of a Chronic Patient and Family of the Nursing Faculty of the National University of Colombia. Its identification allows nurses to design intervention strategies that generate the qualification of caregivers in the care attention of the patient from which they are responsible, and understanding the experience and the capacities of the caregiver.

## Objectives

### General Objective

Describe the home care capacities of the caregivers of people with a chronic disease in a health service institution in San Jose de Cucuta.

### Specific Objectives

- Characterize the relationship Family caregiver-patient with a chronic disease.
- Identify the capacity that the caregiver has by the time it must perform its role with the patient.
- Determine the personal conditions of the caregiver when performing its role.
- Evaluate the instrumental and procedure capacities of the caregivers when performing their activities.

- Determine the well-being of the caregiver when performing its role.
- Identifying the predictive or anticipation abilities the caregivers have by the time they must perform their job.
- Analyze the interaction and social relationship the caregivers have with the patient and their family group.

## Materials and Methods

A quantitative and descriptive cross-sectional study was realized in San Jose de Cucuta (Colombia). The population consisted of caregivers of patients belonging to the program “Chronic Adult” of an ambulatory Health Services Institution (20) and the sample was of 360 caregivers, selected through an aleatory, stratified, and systematic sampling. To calculate the sample a probability with 0.5 success rate was used, with an error rate of 0.05 and with a trust coefficient of 95%. Caregivers of age, without cognitive impairment and voluntary consent of participation during the first semester of 2017 were included.

The data was collected in April and May, using instruments from the Group of Care for the Chronic Patient of the National University of Colombia. The characterization survey about the care of the relationship family caregiver- patient with a chronic disease allows the measurement, in the chronic patient and their caregiver, of the conditions and sociodemographic profile, the work load and support perception, and the appropriation of information and communications technologies (ICT) (10); their trust and validity as an instrument was demonstrated in the Latin American context (18). For the measurement of capacity for home care, an abbreviated version of the GCP-UN-CPC instrument was used, which is composed of 20 items with a scale of response from 1 to 4 using a Likert-type scale, where 4 describes the maximum value and 1 the minimum. These items are collected in six categories that are represented under the Spanish acronym CUIDAR (KUIEAR in English): Knowledge (3 items), Uniqueness or particular conditions (4 items), Instrumental procedure (3 items), Enjoyment of minimal conditions for care or level of well-being (4 items), Anticipation (2 items), and Social relationships and interaction (4 items), with reliable psychometric tests for national use.

In the global evaluation of capacities, the minimum possible score was 0 (zero) and the maximum score was 60 (sixty). By categories, the score interval was: Knowledge, minimum 0 (zero) and maximum 9 (nine); Uniqueness, minimum 0 (zero) and maximum 12 (twelve); Instrumental procedure, minimum 0 (zero) and maximum 9 (nine); Enjoyment, minimum 0 (zero) and maximum (12); Anticipation, minimum 0 (zero) and maximum 6 (six) and lastly, Social Relationships, minimum 0 (zero) and maximum 12 (twelve).

The required ethical perceptions for studies with human beings were guaranteed, contained in the international (21) and national (22) regulatory framework, applying the consent informed previous to data recollection. Institutional endorsement and the paperwork of intellectual property of the instruments was provided, with the authorization by the research team for its use.

A database was created, in which the information was processed in the SPSS program version 24.0. In the analysis of the data, statistical tests were applied to obtain the primary statistic descriptive calculations of the information, such as mean, median and mode, variance and standard deviation of the quantitative variables of the used instruments, followed by an analysis of the qualitative variables. After, an analysis for each of the components of the instrument was done.

## Results

The results are presented according to the established objectives of the study.

### **Sociodemographic characteristics:**

It was found, by gender distribution, that 79% of the participants were female and 21% were male. Most caregivers were around the age of 40 and 49 years (48%), the highest percentages regarding the status of the participants corresponded to single and married with 41% and 28% respectively. Referring to their role as caregivers, it was found that 81% performed their labor without any help from other family members and their experience as caregivers exceeded three years (50%). Regarding the time variable for daily care it was found that the time

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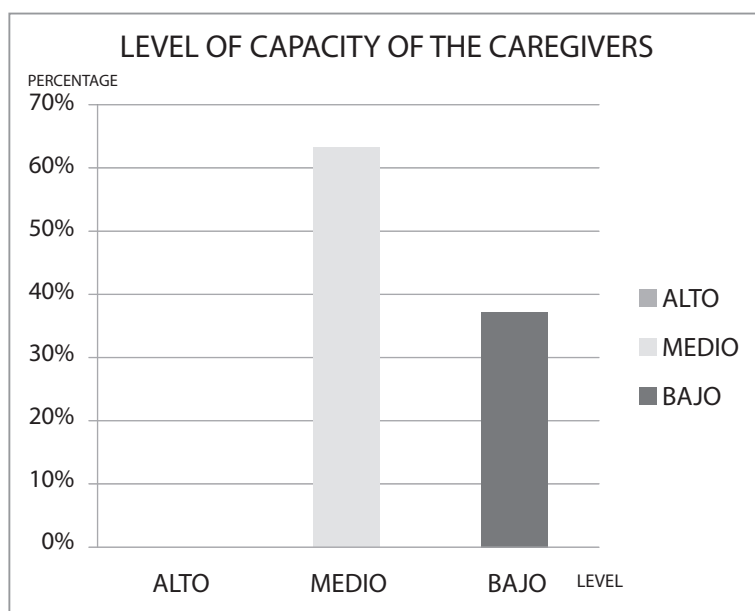
dedicated to this labor had a range between 5 to 12 hours (45%), followed by a significant time that exceeded twelve hours (35%).

Concerning the use of Information and Communications Technology (ICT), it was found that 73% of the participants used them as a help source for the care of the patient, while 23% did not use ICT. The most used ICT was internet, referenced in 41%, followed by the use of cellphones with 21%. In relation to the medical diagnosis given to the patient, Arterial Hypertension was reflected in 64%, Diabetes Mellitus 9% and both pathologies 27%. It was also evidenced that 13% of caregivers had a high perception of work overload, 34% a medium level perception, and 53% a low-level perception.

### Level of Capacity of the caregivers

According to the global capacities for care, a non-optimal level was reported in the caregivers, considering the totality of percentage obtained, caregivers were positioned in medium and low levels respectively (63% and 37%) and data of high qualification was not obtained in the role performance (Figure 1).

The classification was made according to the established evaluation in the instrument, which mentioned that the caregivers that got a score between 0 and 35 were in a low level of capacity, between 36 and 48 had a medium level, and a score higher than 48 was considered a high level.



**Figure 1:** Level of capacities of the caregivers

**Source:** Research data.

### Components of the capacities of the caregivers

An analysis of global results and a specific one were made, to better visualize the components of the instrument, in the interest of obtaining the reached capacity for the care of the participants, referring to the categories of Knowledge, Uniqueness (especial conditions), Instrumental and Procedure, Enjoyment (well-being), Anticipation (predictive), and Social

relationship and interaction, according to the measurement method established in the instrument created by the National University of Colombia. (High, Medium, Low).

From this, the components with the greatest weaknesses were knowledge and enjoyment, while the component with the greatest positive aspect was uniqueness (Figure 2).

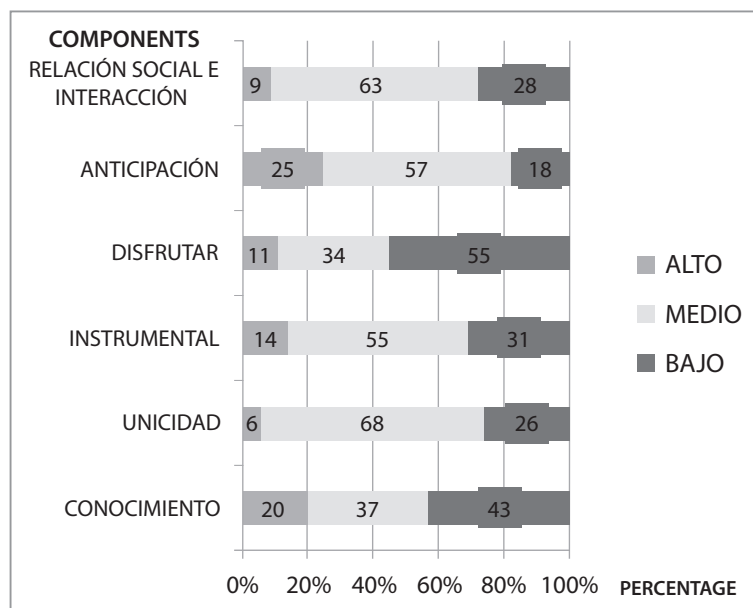


Figure 2: Components of the capacities of the caregivers.

Source: Research data.

### “Knowledge” Component

Regarding this component, it was reported in the studied population that 43% had a low level of capacity, 37% a medium level, and 20% a high level. In a specific analysis for this dimension it was found that 42% of the participants declared having some knowledge on how to make the follow up procedures to the health conditions for the person they oversee, 44% expressed having little to none, and only 14% expressed knowing it. Furthermore, 67% do not know the signs of alarm of the disease suffered by its family member (rarely or never), 22% expressed on knowing the signs with frequency, and only 11% affirmed on always knowing them. Concerning the procedures required for the patient, 56% of surveyed people do not know how to proceed (rarely or never), 23% considers they can roughly handle them, and 11% assume they can always do the procedure.

### “Uniqueness” Component

Regarding this component, it was evidenced a low level in 26%, medium in 68%, and high in 26% of the participants. The confidence reported by the caregivers to assume the home care was reflected in 82% of the participants (frequently or almost always), the capacity to simplify care tasks in 66% (frequently and/or almost always) and the capacity to easily overcome guilt or

anger emotions was 68% (frequently or almost always). However, it is significant that 63% affirmed that few times the caregivers can establish their own lifestyle.

### “Instrumental” Component

Regarding the instrumental dimension, a low level was reported on 31% of the sample, medium level on 55%, and a high level on 14%. In the analysis of this dimension it was found that 82% of the participants act following the prescribed recommendations given to the person they take care of (with frequency and/or almost always), the capacity to organize the instrumental support available for the person they take care of was reflected in 69% (rarely and/or never) and the capacity to adequately administer formulated medication was 82% (frequently and/or always).

### “Enjoyment” Component

In this component, it was found that 55% of the studied population was in a low level, 34% in a medium level and only 11% in a high level. In the specific analysis of this dimension it was evidenced that 67% of the participants were satisfied with their lifestyle (rarely or almost never). Concerning having enough energy to respond to their care responsibilities, 76% considered that they did have it (frequently or almost always).

Regarding if they feel their care labor contributes to their life plan, 58% manifested that rarely and/or almost never; while their time availability for activities and personal stuff, 56% considered they did have the time (frequently).

### “Anticipation” Component

Referring to this component, it was found, that 63% of the participants had a medium level, 28% a low level and only 9% had a high level. In the specific analysis of this dimension, it was found that 69% of the participants organized the available resources to attend the patient efficiently (frequently or almost always). On the other hand, 69% of the caregivers predicted handling risks and the health necessities of the patient (frequently or almost always).

### “Social relationships and interaction” Component

In this section it was evidenced that 63% of the caregivers presented a medium level, followed by 28% with low levels, and only 9% had high levels. To specify this dimension, it was found that 83% of the participants strengthened the bond of affection with the patient they took care of (frequently and almost always), 87% of the caregivers communicated efficiently with the patient (frequently or almost always) and 85% maintained the emotional tranquility of the chronic patient. However, 62% of the caregivers did not count with the support of other family members (rarely or almost never).

## Discussion

According to the obtained results, the level of capacity of the caregivers of people with a chronic disease, is mostly located at a medium level, followed by a low level, findings that are similar to other studies (17, 23) were it is evidenced, in respect of care capacities, that most caregivers do not have optimal conditions to perform as caregivers in the totality of the components that this labor requires.

Regarding the caregiver, the results showed that, mostly, the caregivers were females and the age range varied between 40 and 49 years old, a situation that can be associated with what Barreto et al. (24) found, in which the majority of caregivers are females and the age range is between 36 and 58 years old. Also, Pinzon et al (23)

and Garcia (25) had determined in their study, that most of the informal caregivers of the sample were people older than 40 years. In society, the fact that women are the ones that dedicate more time to homecare, indicates it is more prone for women to also do the homecare for the patient; however, it is important to note that these practices are not only for women, but that men can also do them without any difficulty.

The predominant characteristics were an educational level of elementary school, single marital status, the occupation for most caregivers was homecare, the dominant socioeconomic stratus 2 and the dominant religion was catholic. Chaparro et al. (8) referred in their study that the main occupation was homecare, the religion beliefs was mostly catholic, and the dominant social stratus was 2. Carrillo et al. (26) also argued in his study that the educational level was uncompleted elementary school, a social stratus of 1 for the greater proportion, and the predominant marital status was single, as for religious orientation, most of the surveyed people were catholic.

This implies that the education and the socioeconomic stratus are important factors at the moment of performing care actions, since a low education level can result in a struggle to comprehend more easily the disease process the patient that needs care is going through. In the other hand, the fact of having a low socioeconomic level, limits the actions that can be done to improve the well-being of the person that is being taken care of.

In the knowledge component many weaknesses were found: very frequently it was found that caregivers do not know the health follow-up procedures, the necessary procedures and the signs that can be triggered by the disease of the patient. The studies (27, 17) demonstrate the studied population has low knowledge about the topic, which shows the necessity for caregivers to acquire knowledge and skills that allows them to comprehend the patient.

In that sense, Gonzalez (28) determined that this component, along with the value and patience, are insufficient in most caregivers. In his study, the low educational level reported by the caregivers could be established as the determinant element of what is found in this category and argument enough for the implementation of educational programs adjusted to

the educational and cultural reality, and the cognitive capacity of the caregivers. Aspects such as the care of basic needs, the skill of handling instruments and the specialized knowledge are proposed as topics to consider in the structuration of educational contents in this population.

In the uniqueness component, a great strength was found in the studied population, since caregivers have the necessary confidence to assume homecare, and their capacity to simplify and do tasks correctly when necessary is outstanding. These results are similar to the result of Vega (10), who argued that caregivers are in a superior level at the moment of evaluating this component, demonstrating better personal characteristics to face obstacles brought to them by the care of the patient. Additionally, in the study made by Chaparro et al. (29), it was concluded that the strengthening of characteristics and capacities of the caregivers, their self-recognition and their assumed role is vital, and this allows them to adequately face problems they can find at the moment of providing care.

The instrumental component showed that caregivers demonstrated weaknesses regarding the organization of instrumental support represented in, transportation, equipment, and resources. However, and in a general manner, it is noted that the studied population was positioned in a medium level, since the caregivers referred as having the necessary tools to supply the basic needs of the patients. This coincides with the discovery by Vega (10), his study demonstrated that the reduced portion of caregivers that presented a high level in the instrumental component, made necessary the reinforcement in this category to improve the care given.

In regard to the Enjoyment component, the obtained results showed weaknesses, since the target population referred that their role as caregivers does not contribute to their life plans and their life quality is not the best, giving as a result a low personal satisfaction. In the studies (10, 26) is mentioned how the caregivers did not present a high appreciation of this component, since they did not feel satisfied with their lifestyle at the moment of performing their daily life role, making life quality decrease.

The anticipation category is understood as capacity, ideas and tools the caregivers have, to act in anticipation regarding unexpected events or risks

that the patients might be exposed to. Here, it was found that the caregivers counted with a favorable or positive level related to the organization of the available resources to serve the patient efficiently and predict the management of risks and health necessities.

In the study of Herrera et al. (30), it is mentioned that the caregivers were satisfied with the labor they performed, demonstrating dominance on knowing how to perform and act when facing unexpected situations, attributing to this the knowledge given by the nursing personal. Also, Vega et al. (10) reported that the caregivers almost always or always organized the available resources in an efficient manner to attend the patient.

In the study, the anticipation capacity of the caregivers, was mostly positioned in a medium level, which makes necessary the immediate nursing intervention for the strengthening of this capacity, constantly training caregivers for specific necessities of the patients, and the risk factors which the patients might be exposed to, developing in the caregivers mechanisms of facing and prevention to unexpected complications.

The dimension of relationship and interaction was composed by four items, in which high and favorable results were found, such as a strong bond of affection with the patient, effective communication and the aim for the caregiver to maintain the emotional tranquility of the patient. However, a great weakness was found in the study population regarding not being able to have the support of other family members for the care labor. These results differ from other studies about the topic (31, 32), in which caregivers demonstrated having family support to perform the care labor. On the other hand, the results obtained by Gelvez et al. (27) showed that the caregivers had low tolerance regarding the daily tasks they must perform, giving rise to behavior and attitudes such as intolerance, bad communication and a bad caregiver-patient relationship.

However, Carrillo et al. (26) and Pinzon et al. (23) found in their studies that the person in charge for the care of the patient had to do this for most of the day without any help in their labor. It is important to note that family support regarding the care of the patient is of vital importance not only for the caregiver but also for the patient, since family support makes part of the



capacities to assume and deal in a proper manner the process the patient is going through. The nursing labor is then necessary, to create a fundamental net support for the caregivers, and also develops and proposes strategies that allow the integration to the nuclear family in the care attention the patient requires, avoiding the work overload of just one caregiver and contributing to the strengthening of the care labor.

## Conclusions

- Regarding the sociodemographic data of the target population for the study, it can be concluded that the caregiver role is primarily performed by females, a matter that makes necessary an awareness campaign to the general population in order to motivate the male gender to also develop a caregiver role.
- The caregivers provide their labor in an age range between 40 to 49 years old, which is important to highlight since people of this age range have a greater experience for their role performance, making care more effective. In relation to the previous approach, it was identified that the time experience is greater than three years, making the caregiver role better assumed and performed at the time of doing the corresponding activities.
- However, it was identified that the caregivers have an emotional bond with the patient, and are also

the ones that have the home care occupation. From this, it is important to highlight that, maintaining an emotional bond and doing the homecare work, strengthens the relationship with the patient and satisfy in a better way the necessities of the patient they are in charge of.

- It was concluded also, that the caregivers, in their labor, are positioned in a medium level of capacities. It was found a higher weakness in the Knowledge and Enjoyment (well-being) components, and caregivers with a high level of capacities at the moment of performing their role were not found. For this reason, it is important to provide training for the caregivers about the necessary components to improve the care quality, and issues such as the, attention to basic, instrumental and specialized needs, are proposed as topics to consider in the structuration of the educational contents addressed to this population.
- During the research process, limiting factors were not found at the moment of performing and knowledge gaps were filled when identifying the capacities of the caregivers or patients with a chronic disease in the city of Cucuta, which did not have a wide background framework. Additionally, it is different from other research studies for considering the relationship between unemployment and economic difficulties that are presented in this city.

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