



LEVEL OF BURDEN ON THE CAREGIVERS OF PEOPLE WITH SEVERE DISABILITIES NIVEL DE CARGA EN LOS CUIDADORES DE PERSONAS CON DISCAPACIDAD SEVERA

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ABSTRACT:

The present study was carried out for the purpose of determining the levels of load that the carers of persons with severe disabilities have, based on a design of bibliographical or documentary study, with the participation of the population under study, comprised of thirty carers of persons with severe disabilities. For which, the Questionnaire on the burden of the Zarit caregiver was applied to them, giving as results that 60% of the total of the surveyed sample present overload, where 36.67% experience an intense overload and 23.33% a slight overload. Therefore, it was determined that the overload in the caregiver is due to many significant factors, such as not having the support of other family members in the care of the person with severe disability, difficulty in reconciling care with household tasks, family and economic problems, thoughts about the future of their family member, circumstances that over time become stressful causing alterations in the emotional well-being of the caregiver.

Keywords: Level of burden, Caregivers, Severely disabled person, Social Work.

RESUMEN:

El presente estudio se lo ejecutó con la finalidad de determinar los niveles de carga que tienen los cuidadores y cuidadoras de personas con discapacidad severa, basándose en un diseño de estudio bibliográfico o documental, contando con la participación de la población objeto de estudio conformada por treinta cuidadores y cuidadoras de personas con discapacidad severa. Para lo cual, se les aplicó el Cuestionario de carga del cuidador de Zarit, arrojando como resultados que el 60% del total de la muestra encuestada presentan sobrecarga, donde el 36,67% experimenta una sobrecarga intensa y el 23,33% sobrecarga leve. Por lo tanto, se determinó que la sobrecarga en el cuidador o cuidadora se debe a muchos factores significativos, como por ejemplo, no contar con el apoyo de otros familiares en el cuidado de la persona con discapacidad severa, dificultad al momento de compatibilizar el cuidado con las tareas del hogar, problemas familiares y económicos, pensamientos en torno al futuro de su familiar, circunstancias que con el paso del tiempo se convierten en estresores causando alteraciones en el bienestar emocional del cuidador.

Palabras Clave: Nivel de carga, Cuidadores, Persona con discapacidad severa, Trabajo Social.



1. INTRODUCTION

A study conducted by the World Health Organization and the World Bank (WHO & WB, 2011) states in the World Disability Report that more than one billion people worldwide live with some form of disability; of these, almost 200 million experience significant difficulties in functioning. In future years, disability will be an even greater concern, as its prevalence is increasing. (p. 5)

From ancient times to the present day, many studies have been conducted on the burden faced by caregivers of dependent persons, which shows that most of the time this role is assumed by women, and as a result of the various functions they perform, care causes them, health affects at the physical, emotional and social life. The term caregiver burden or overload has been used to refer to the tasks that the caregiver must face and the repercussions that this has for her. People are not prepared to care for a dependent person and must learn, and often improvise at the pace of problems that arise. (Arrieta, 2017)

In Ecuador, there are approximately 485,325 people with disabilities, noting that in the province of Loja there are 15,275 people

with disabilities, of which 3,783 are severely disabled (CONADIS, 2020). Referring to the Health Center No. 2 in the city of Loja, this has a committee that is made up of 46 informal caregivers of people with severe disabilities, where they receive training on the management and care of the dependent person, because they do not have professional training to develop the activities they perform, which causes considerable impact on the health of the caregivers.

Nowadays we live in a society that as a result of various accidents, chronic diseases, aging population or by birth, we face acquired or congenital disabilities, which means that the person with disability according to their degree of dependence, requires the care of another person. Going further in the review of literature we find that Ruiz and Nava (2012), define a caregiver as "the person who assists or cares for another person affected by any type of disability, handicap, or incapacity that hinders or prevents the normal development of his/her life activities or social relationships" (p. 2). Therefore, the caregiver, understood in terms of dependency, is "the person who facilitates



the life and complements the lack of autonomy of a dependent person, helping him or her with daily tasks such as cleaning, feeding, and moving, among others" (Ruiz & Nava, 2012, p. 163).

According to the position of several authors it was possible to determine that there are different types of caregivers, for which, emphasis is placed on the following:

Formal or professional caregiver: "is the person or persons with adequate training to care for the sick and who charge a fee for doing so" (Santamaria, 2009, p.9).

Informal or family caregiver: "A person who provides care to a relative, friend or neighbor in need of long-term care on a regular basis, not through a professional or voluntary organization" (Lopez, Wens, Verhoeven & Remmen, 2012, p. 2).

From the typology of informal or family caregiver, two subcategories of equal importance can be determined, they are:

Primary caretakers: "the person in charge of most of the care of the sick person. He or she usually lives in the same home as the patient, or very close to it, and usually has a very close family relationship" (Santamaria, 2009, p.9).

Secondary caregivers: "people who collaborate with the primary caregiver in the care of the dependent person" (Álvarez & Morales, 2007, p. 23)

Significant research has been carried out that has made it possible to delimit the role of the caregiver in relation to the dependent person, such is the case of a study carried out in Colombia, in the city of Bogotá, in the year 2016, by Ana M. Gómez, Olga L. Peñas and Eliana I. Parra, who mentioned that the functions of the caregiver of people with severe disabilities are directed to assist the basic daily activities, including preparation and consumption of food, major and minor hygiene, clothing, changing body position, support movements inside and outside the home, Collaboration in basic health care tasks, carrying out domestic activities, helping in the administration of medicines, money and goods, managing access and consultation of health services, solving crisis situations (emergencies or accidents), arranging and handling medical equipment (wheelchairs, oxygen, orthopedic aids, etc.)), to mediate in the communication with third parties and in the integration of the family with the cared person (to motivate visits, economic support and



accompaniment), to attend the visits and to accompany the leisure activities of the cared person, as well as to do "small tasks", like reaching or withdrawing some element that the person with severe disability requires. (p. 373)

The execution of diverse activities of the home combined with the care of a person with severe disability causes in the caregiver an emotional wear that is considered as load or overload, being this a pathology that leads to a state of anxiety and depression, causing physical and emotional exhaustion, appearing symptoms that indicate the presence of the caregiver's syndrome. In Rueda's words, (2017), the overload can affect the physical and psychological health of the caregiver, causing symptoms of exhaustion, anxiety or depression, which put at risk the ability to continue providing care to the dependent person. Highlighting as primary factors in the emergence of overload, scarce economic resources, high costs of medications required by the caregiver, changes in multiple spheres of the caregiver's life, such as in the work, social, family situation and the lack of support from other family members in the care of the severely disabled person. Likewise,

Gutiérrez, Martínez and Rodríguez, (2013), define the "caregiver's burden" as "the psychological (mainly emotional and stress), physical, social and economic consequences that are generated in a family member or friend who is dedicated to the attention and care of another person".

Therefore, it is necessary to frame the concept of a person with a disability, according to the Organic Law on Disabilities (2012), in its article 6 it states that a person with a disability is:

All those who, as a consequence of one or more physical, mental, intellectual or sensory deficiencies, regardless of the cause that may have originated them, see their biological, psychological and associative capacity permanently restricted to exercise one or more essential activities of daily life. (p. 8)

In Ecuador, according to the Ministry of Public Health in the Regulations for the Qualification, Re-qualification and Accreditation of Persons with Disabilities or with an Impaired or Disabling Condition (2018), there are seven types of disabilities: physical, intellectual, hearing, language, visual, psychosocial and multiple disabilities.



A very serious or severe disability is considered to be one that "includes severe permanent impairments that, meeting the objective parameters specified in each device or system, result in a very serious disability" (pp. 25-26). In accordance with what is established in these Regulations, to be considered as a severe disability, a percentage of 75 % or more is required.

Since Ituarte's position (1992), Social Work in the area of Health is considered as:

The professional practice that aims to investigate the psychosocial factors that influence the health-disease process, to know the reality of each patient, in order to study and identify the networks of relationships (family, institution, situation of marginalization or exclusion). (Rodríguez, Loo & Anchundia, 2017, p. 5)

The social work professional intervenes in the social dimensions that establish the living conditions of the person with a disability, with the aim of eradicating or mitigating the social barriers that arise. He or she accompanies the person with a disability and his or her family throughout the process, deploying a range of strategies that allow them to resolve the social tension that

revolves around the person with a disability, motivating them to assume a positive attitude in the face of the different challenges that the disability brings with it, achieving autonomy and social inclusion for the person with a disability. Mobilizing the families of people with disabilities and empowering them to become aware, in order to seek alternative solutions to the complex situations that society imposes on them, and that in turn affect, prevent or delay the "process of Rehabilitation and Habilitation of the Person" (Lorna, 2014)

In addition, it has a moral obligation to help people with disabilities and their families, providing educational spaces that allow for the elimination or minimization of the barriers that disability brings with it, respecting "autonomy and self-determination" (Silva, 2015). For this reason, it is necessary to design and direct intervention strategies where Social Workers and the interdisciplinary teamwork in parallel on the "personal and environmental conditions" that involve the person with a disability and his or her family.

Thus, the interdisciplinary team that deals with people with disabilities and their families, must have clear knowledge in the



field of disabilities and their problems, as well as the associative world, in the dynamics and characteristics of families, mastery of techniques and resources for working with families, updated knowledge of community resources (networking), skills and abilities with regard to the management and conduct of groups. (De Lorenzo, 2014, p. 387)

For the same reason, the Social Worker must possess attitudes and skills such as empathy, listening, receptivity, discretion, collaboration and open-mindedness without prejudice, motivation and initiative, provide emotional support, observation skills, control of oral and gestural language, flexibility to adapt to different situations, promote change in the face of negative situations, raise self-esteem and show attitudes of sensitivity, acceptance and respect towards people with disabilities and their families. (De Lorenzo, 2014, p. 387)

Based on the above, this scientific article focused on determining the levels of burden faced by the caregivers of people with severe disabilities of the "Faith and Hope" Committee, through the theoretical and methodological foundation of the categories of analysis and the identification of the levels

of burden faced by the caregivers of people with severe disabilities from the perspective of Social Work.

2. METHODOLOGY

A qualitative and quantitative study was carried out, leading to the search for information relevant to the problem under study, in different scientific databases. The population was conformed by 46 informal caregivers; and the intentional non-probabilistic sample constituted by 30 caregivers that integrate the Committee.

The scientific method was used, which allowed the search and collection of relevant information to the study variables, facilitating the construction of the research background; the inductive-deductive method, allowing to delimit and pose the problem of interest and obtain a general knowledge of the problem; the analytical-synthetic method, allowing to analyze and systematize the information obtained through the graphic representation and the interpretative analysis of the results from the questionnaire of the Zarit's caregiver.

Likewise, the "Zarit caregiver load questionnaire" was applied, which aims to

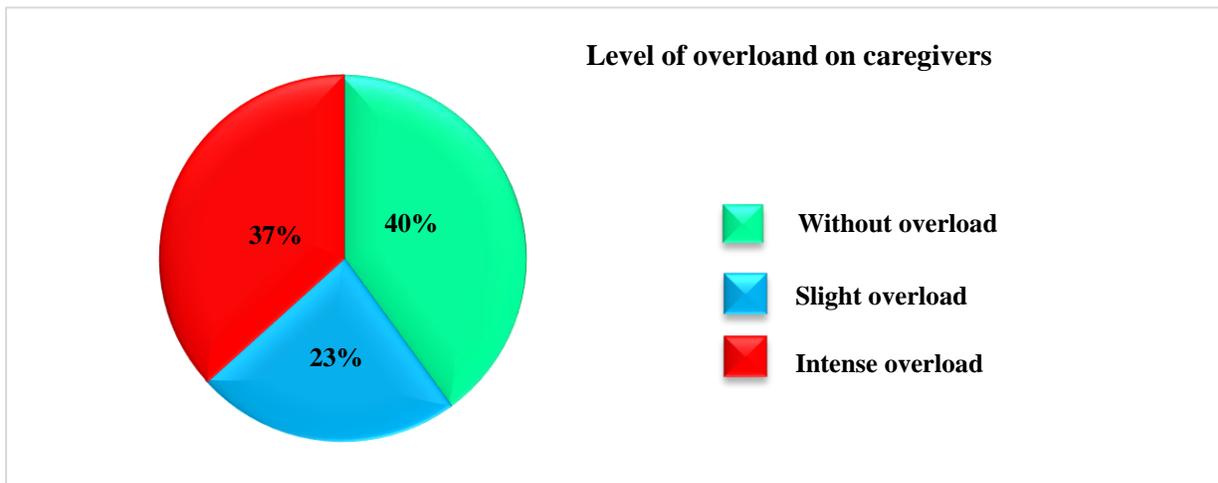


determine the levels of load felt by the caregiver, which is made up of 22 questions, the score of each question ranges from 1 to 5 points, adding up to a total score of 110, in an estimated frequency: 1 Never, 2 Rarely, 3 Sometimes, 4 Quite often and 5 Almost always. If the caregiver obtains a score lower than 46, he or she does not present symptoms of overload, if he or she has 47 to 55 it indicates slight overload and if it is higher than 55 to 110 it shows intense overload.

3. RESULTS

The load levels in the caregiver of severely disabled people according to the application of the Zarit load questionnaire are represented in the following way (see graph 1): 40.00% of the population surveyed does not present overload, while 36.67% has intense overload and only 23.33% slight overload, giving a load level of the total sample 60% with a range between 47-86 points.

Graphic 1. Levels of overload in caregivers



Elaborated by: Research Team

The following is a general presentation of the percentages broken down by items in Table 1, taking as a reference the questions of the Zarit Caregiver Load Questionnaire:



Table 1. Zarit Caregiver Loading Questionnaire

| | | Never | Rarely | Sometimes | Quite often | Almost always |
|----|--|-------------|-------------|-------------|-------------|---------------|
| 1 | Do you think your family member is asking for more help than he or she really needs? | 9 (30,00%) | 8 (26,67%) | 5 (16,67%) | 6 (20,00%) | 2 (6,67%) |
| 2 | Do you think that because of the time you spend with your family member you don't have enough time for yourself? | 7 (23,33%) | 7 (23,33%) | 9 (30,00%) | 4 (13,33%) | 3 (10,00%) |
| 3 | Do you feel burdened by trying to balance care with other responsibilities? | 5 (16,67%) | 9 (30,00%) | 12 (40,00%) | 3 (10,00%) | 1 (3,33%) |
| 4 | Are you embarrassed by your family member's behavior? | 28 (93,33%) | 2 (6,67%) | 0 (0%) | 0 (0%) | 0 (0%) |
| 5 | Do you feel angry when you are around your family member? | 25 (83,33%) | 4 (13,33%) | 1 (3,33%) | 0 (0%) | 0 (0%) |
| 6 | Do you think that caring for a family member negatively affects other family members? | 25 (83,33%) | 2 (6,67%) | 2 (6,67%) | 1 (3,33%) | 0 (0%) |
| 7 | Are you afraid for your family member's future? | 0 (0%) | 2 (6,67%) | 9 (30,00%) | 8 (26,67%) | 11 (36,67%) |
| 8 | Do you think your family member is dependent on you? | 0 (0%) | 0 (0%) | 3 (10,00%) | 8 (26,67%) | 19 (63,33%) |
| 9 | Do you feel tense around your family member? | 19 (63,33%) | 9 (30,00%) | 2 (6,67%) | 0 (0%) | 0 (0%) |
| 10 | Do you think your health has worsened because you have to take care of your family member? | 13 (43,33%) | 7 (23,33%) | 6 (20,00%) | 4 (13,33%) | 0 (0%) |
| 11 | Do you think you are not as intimate as you would like to be because of caregiving? | 15 (50,00%) | 12 (40,00%) | 2 (6,67%) | 1 (3,33%) | 0 (0%) |
| 12 | Do you think your social life has been negatively affected by caregiving? | 18 (60,00%) | 11 (36,67%) | 1 (3,33%) | 0 (0%) | 0 (0%) |
| 13 | Do you feel uncomfortable distancing yourself from your friends because you have to take care of them? | 22 (73,33%) | 4 (13,33%) | 4 (13,33%) | 0 (0%) | 0 (0%) |
| 14 | Do you think your family member considers you the only caregiver? | 3 (10,00%) | 3 (10,00%) | 3 (10,00%) | 7 (23,33%) | 14 (46,67%) |
| 15 | Do you think you don't have a lot of income for care and your own expenses? | 1 (3,33%) | 4 (13,33%) | 9 (30,00%) | 8 (26,67%) | 8 (26,67%) |
| 16 | Do you think you will not be able to care for your family member for much longer? | 15 (50,00%) | 10 (33,33%) | 3 (10,00%) | 0 (0%) | 2 (6,67%) |
| 17 | Do you feel that you have lost control of your life since the family member's illness began? | 21 (70,00%) | 5 (16,67%) | 2 (6,67%) | 2 (6,67%) | 0 (0%) |
| 18 | Do you wish you could leave your family member's care to someone else? | 24 (80,00%) | 5 (16,67%) | 1 (3,33%) | 0 (0%) | 0 (0%) |
| 19 | Are you undecided about what to do with your family member? | 24 (80,00%) | 5 (16,67%) | 1 (3,33%) | 0 (0%) | 0 (0%) |
| 20 | Do you think you should do more for your family member? | 6 (20,00%) | 6 (20,00%) | 8 (26,67%) | 6 (20,00%) | 4 (13,33%) |



| | | | | | | |
|----|---|----------------|----------------|---------------|--------------|----------------|
| 21 | Do you think you could take better care of your family member? | 1 (3,33%) | 9 (30,00%) | 8 (26,67%) | 2 (6,67%) | 10 (33,33%) |
| 22 | In general: Do you feel very overburdened by having to take care of your family member? | 16 (53,33%) | 10 (33,33%) | 3 (10,00%) | 1 (3,33%) | 0 (0%) |

Note: Results of the application of the Zarit Caregiver Loading Questionnaire

4. DISCUSSION

The burden on the caregivers of people with severe disabilities is a problematic situation that requires prompt attention from the competent bodies in order to design strategies that help mitigate the situation. Referring to the review of literature it became evident that in many investigations the population studied has presented levels of light and intense burden, such is the case of the caregivers under study, who through the application of Zarit's caregiver burden questionnaire was found that more than half of the sample surveyed presents symptoms of light and intense overload, due to the role they play. The fact of providing help for a long time causes discomfort, fatigue and physical and emotional exhaustion in the person who provides it. The study shows that some caregivers must provide excessive care, which implies the overload of tasks, preventing or leaving little time for the caregiver to develop their personal activities, so they are forced to extend their

tasks, causing, over time, stress and the acquisition of feelings of vulnerability and guilt, symptoms that prevent the proper performance of activities regarding care.

Many of the caregivers experience fatigue, overwhelm, suffering or frustration, while performing the activities of daily living and providing care to another person who is totally or partially dependent on them. This suggests a certain degree of overload on caregivers, taking into account that the responsibility of caring falls on the main caregiver, who does not have social, emotional and in the worst case family support. When this insecurity or imbalance occurs, the caregiver is exposed to stress, which can negatively affect their life in all areas, feeling alone, frustrated and misunderstood. Similarly, some caregivers have had broken relationships with their families because they do not have their support in caring for the person with severe disability, leaving the caregiver with full responsibility.



Another factor that affects the level of acquired burden is that caregivers live with uncertainty and concern about the condition of the person with a disability, where fear takes over, generating stress, tension, worry and anguish, thinking almost all the time about the worst future for their family member. As a result of caregiving, caregivers maintain that they have experienced health problems due to the functions that this role requires them to perform for long hours, a situation that emerges as a result of the physical effort they make to mobilize the dependent person on repeated occasions, stimulating physical alterations such as back and joint pain, tiredness and headaches, in addition to experiencing few hours of sleep, a situation that prevents the correct functioning of the human being, becoming a stress and this in turn becomes an overload, considerably affecting the physical and psychosocial health of the caregiver.

The economic factor is another condition for the appearance of the burden, due to the function of caring, it is difficult to have a paid job, therefore, they must rely on the assistance provided by the Ecuadorian state through the Health Center, with the delivery of technical assistance. On the other hand,

they recognize that they are overburdened and consider the idea of sharing the functions to be beneficial since it allows them to alleviate the burden of responsibilities involved in taking care of a person for a long time.

5.CONCLUSIONS

- 60% of the committee's caregivers are overloaded, with 36.67% experiencing intense overload and 23.33% mild overload.
- Factors such as not having the support of other family members in the care of the person with severe disability, economic problems, thoughts about the future of their family member, among others, generate overload in the caregiver affecting their emotional well-being.
- The long days of care, cause affectations in the physical, psychological and social health of the caregiver, exposing them to fatigue, exhaustion and difficulties in decision making.
- The economic factor is one of the greatest concerns of the caregivers, despite being beneficiaries of the



Manuela Espejo Solidarity Mission with an economic incentive of \$240 per month, they argue that they do not fully cover their basic needs.

- In spite of the psychosocial effects that the role of caregiver brings with it, this is assumed by discarding the idea of giving care to another family member.

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