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Making Visible The Role Of The Informal Caregiver "A human gaze sensitized to exhaustion"

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Abstract

The article analyzes the role of the informal caregiver, understood as the person who provides unpaid support to individuals with disabilities, dependency or chronic diseases. It is stated that this work, carried out by millions of people in the world – mainly women – involves a high physical, emotional, social and economic burden that affects multiple dimensions of the caregiver's life.

The text addresses the commitments and meanings of care, showing that the caregiver faces difficulties such as lack of institutional support, lack of training, feelings of guilt, frustration and helplessness, especially when the patient's dependence is severe. Likewise, the four phases that the caregiver goes through when assuming the role are described: denial, search for information, restructuring and conclusion, highlighting the importance of the adaptation process.

The essay also delves into the holistic effects of care on caregiver health, pointing out negative physical (chronic pain, sleep disorders, hypertension), emotional (stress, depression, exhaustion) and social (isolation, changes in leisure activities, family overload) impacts. Caregiver Syndrome, described as a response to chronic stress, is addressed and the factors that influence "caregiver role fatigue" are mentioned, according to the NANDA taxonomy.

Finally, the article highlights the urgent need to recognize the informal caregiver as a subject of care within public policies and health systems, emphasizing the role of nursing in accompaniment, burnout prevention, emotional support, and strengthening caregiver self-care.

Keyboards: Informal caregiver; Caregiver overload; Caregiver syndrome; Role fatigue; Dependence.

Introduction

A caregiver is an individual who provides assistance or care to another person who is affected by some form of disability, handicap or incapacity that hinders or prevents his or her normal performance in vital activities or social relationships (1)(2).

The term "caregiver" refers to the person responsible for providing care, two categories can be distinguished: primary and secondary.

Primary caregivers are those who have a direct relationship with the patient or patient, such as spouse, children, siblings, or parents. On the other hand, secondary caregivers do not have a direct relationship or a close bond with the patient; They can be nurses, aides, social workers, distant family members, or anyone who works in a health care institution (3).

The informal-primary caregiver is the individual responsible for assisting in the basic activities of the elderly person's daily living for most of the day, without receiving financial compensation for their services. Their work helps the dependent person to remain in their social environment (4)(5).

Around 6.5 million people globally exercise this role, and every day, another 6000 people take on a care responsibility, which equates to more than 2 million people each year. 58% of caregivers are women and 42% are men. 1.4 million people provide more than 50 hours of care per week. As of 2020, it was estimated that there are around 13.6 million people who assumed the role of caregiver during the pandemic (6).

The caregiver takes on the important responsibility of showing solidarity with the one who is suffering and is the first to understand that they cannot remain inactive in the face of the difficult situation faced by their family member or friend. Their work acquires significant importance for the group that surrounds the patient as the disease progresses, not only because they provide direct care to the patient, but also because of their role in the reorganization, maintenance, and union of the family (7,8).

This essay proposes a theoretical framework documented in the understanding of the concept and the dynamics in which the practice of informal care emerges, the phases that the caregiver experiences once they assume the role and the effects it generates in each of the dimensions that integrate the human being.

Meanings and commitments acquired in the practice of informal care

The act of caring for a family member affects the health of the caregiver because of the physical and emotional burden it carries. This can translate into physical problems such as chronic pain, impaired health perception, and depression, as well as fatigue, cardiovascular problems, and sleep disorders. In addition, caregivers often face difficulties in their family, social, and work relationships, which often leads to social isolation (9).

A proposed guide for caregivers of dependent people (10) presents a theoretical breadth related to their challenges, roles and foundation of the role of caregiving, among the main contributions it is worth highlighting that; Caregivers also face challenges such as a lack of help, both institutional and personal, to take on care, as well as a lack of adequate training, which can lead to decreased self-esteem and feelings of guilt.

In situations of physical dependence, such as paraplegia or hemiplegia, feelings of helplessness arise when faced with the circumstances that led your loved one to that condition. The duration and nature of the illness also significantly affect the care and emotions involved.

In the context of dependency, the caregiver is the individual who improves the quality of life and makes up for the lack of autonomy of a dependent person, providing help in their daily activities such as cleaning, feeding and mobility, among others. Caregiver syndrome refers to the physical and emotional exhaustion experienced by those who are completely dedicated to the care of a dependent person (11).

The informal caregiver is the individual responsible for assisting in the basic activities of the elderly person's daily living for most of the day, without receiving financial compensation for their services. Their work helps the dependent person to remain in their social environment (12).

Once caregivers assume the role of informal caregivers, they are involved in a series of activities related to the care of the dependent person. These activities include promoting personal hygiene, supervising the taking of medications, making changes of position to prevent pressure ulcers, providing assistance with feeding, among other tasks that are included within instrumental activities and daily living (13).

The guide for caregivers of people with disabilities, proposed by the Andalusian Association of Community Nursing, details the rights and responsibilities of people in charge of informal care (10) see table 1

Table 1 Rights and duties of caregivers (10)

Rights	Homework

The right to dedicate time and perform activities for ourselves without guilt.	The duty to safeguard the dignity of the person you care for.
The right to experience negative emotions when caring for the sick or losing loved ones.	The duty to provide the person who cares for such essential items as housing, food, water, clothing and health care.
The right to solve what we can on our own and to ask for help when necessary.	The duty to provide security and comfort, promoting the autonomy of the person they care for, until the last moment.
The right to seek solutions that meet our needs and those of our loved ones.	The duty to collaborate in complying with the rules and instructions established in the Health Centre or Hospital in which they are located.
The right to be respected when seeking advice and assistance.	The duty to treat the staff of the Health Centres with the utmost respect.
The right to make mistakes and be forgiven.	The duty to request information on the rules of operation of the Health Centres and the communication channels (complaints, suggestions, claims and questions).
The right to be recognized as valued members of the family, even if we differ in opinions.	The duty to take care of the facilities and help in the maintenance of the habitability of the Health Centres.
The right to love ourselves and accept our efforts.	The obligation to make appropriate use of the services offered by the health system, mainly with regard to the use of pharmaceutical and social benefits.
The right to learn and take the time necessary to do so.	The duty to demand that their rights be fulfilled.
The right to express emotions, both positive and negative.	
The right to refuse excessive, inappropriate, or unrealistic demands.	
The right to continue with our own lives.	

Therefore, it is worth recognizing that the role of the caregiver is not only focused on the rights that they must acquire in their process, but also on the commitment and social responsibility aimed at ethical, dignified and compassionate treatment of the person cared for.

Phases before adopting the informal caregiver role

The literature reports four phases that the caregiver goes through once they assume the role: phase one is denial or lack of awareness of the problem**,** in the initial stages of facing the chronic illness of a loved one, it is common to resort to denial as a way to deal with fears and anxiety. Therefore, it is common to observe that the person refuses to accept evidence that his or her family member is sick (or sick) and requires the help of others to adapt. This period is usually transitory. As time progresses and the difficulties of the sick person in maintaining their functional independence become more noticeable, it becomes increasingly difficult to maintain the belief that it is a "temporary disease" (15).

The second phase is the search for information, which is characterized by the caregiver beginning to seek information about their loved one's disease, its consequences, possible sequelae, resources for help, second opinions and alternative medicine options. All this is done in the hope that your family member can recover their previous state. During this period, it is common for caregivers to experience feelings of discomfort due to the feeling of injustice of being in that situation. Anger, and even anger or guilt in its most intense form, are normal human reactions to the loss of control over one's life and circumstances. There are negative circumstances in life that are inevitable and cannot be changed, and it is precisely these types of situations that caregivers of dependent people often face (16).

The third phase is restructuring, in which feelings of anger and frustration may persist. Life often loses its usual meaning, and new responsibilities can be overwhelming for the caregiver. However, in this phase, a certain degree of control begins to be regained. Thanks to the external information and resources available, as well as the family's support in sharing responsibilities and a clearer understanding of the challenges they face, the caregiver will be better equipped to deal with the caregiving situation appropriately. This period of reorganization will lead to the adoption of a more familiar lifestyle. Over time, the caregiver will feel more able to control the situation and will be more accepting of changes in their life (16).

Finally, the fourth phase is presented, called conclusion. During this stage, people learn to take better care of themselves; they are more open to seeking help from others who have gone through similar experiences; they generally become more independent, spending more time on recreational and social activities, and may seek out and find other sources of emotional support, such as strengthening existing friendships or building new relationships (16).

However, the conditions of care provided predict the degree of affectation in all dimensions that integrate the human being, therefore, it is essential to examine, with an interdisciplinary approach that includes the participation of nursing (15).

Holistic effects on caregivers

Informal care offers a comprehensive overview of all studies seeking to determine the causal effect of informal care. The findings indicate that there is evidence to suggest an adverse impact on both the physical and mental health of the caregiver. The magnitude and nature of these effects vary considerably by caregiver group. In particular, it is observed that women, married caregivers, and those who provide intensive care tend to experience negative consequences for their health as a result of caregiving (17).

Caregivers often experience a wide range of emotions, which can be diverse and contradictory depending on the situation and who they are directed at, such as, "This can't be happening" or "I'm sure the medical tests are wrong." How do I tell this to my partner?" or "Oh my God, what can I do to help?" Why is this happening to me?" I feel like my life doesn't have meaning anymore." "I can't do anything to make this better" or "I feel like I'm losing control over my life."

Likewise, towards the social and health system and society in general, it generates a feeling of loneliness and social isolation in the caregiver due to the growing dependence of the person cared for on their support network, which can generate a feeling of helplessness if expectations are not met. A lack of expression of negative feelings can have negative consequences for the well-being of both the caregiver and the person being cared for.

Caregiver Syndrome is a condition that arises as a result of the prolonged period spent caring for a loved one, which carries a considerable physical and emotional burden. Expressions such as "I can't take it anymore", "I don't care about everything anymore" are signs of this syndrome, characterized by an inadequate response to chronic emotional stress, manifesting itself in physical and/or psychological exhaustion.

Several stages in its development can be identified:

- Work Stress Phase: It involves an excess of physical work without sufficient help, with little or no free time, focused exclusively on the care of the dependent person.

- Affective Stress Phase: A feeling of lack of affection and understanding from those close to them is experienced, with the perception of a lack of emotional support.
- Personal Inadequacy Phase: The physical and psychological consequences of care overload begin to manifest themselves without adequate support.
- Personal Emptiness Phase: It occurs after the death of the person cared for, accompanied by feelings of guilt and emotional emptiness (18)

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From the discipline of nursing, Nanda presents through the taxonomy a diagnosis entitled fatigue of the caregiver role (19), associated with the burden and difficulty that must be carried to fulfill the role of "care", which is influenced by a variety of interrelated factors that affect both the caregiver and the recipient of care.

The health status of the care recipient is crucial, as the severity and chronicity of the disease, coupled with increasing care needs and uncertainty about the course of the disease, add additional pressure on the caregiver. In addition, problematic behaviors, psychological or cognitive problems, and the presence of addictions or codependency can further complicate the situation, increasing the emotional exhaustion of the caregiver (19).

The caregiver's activities also play an important role in their daily wear and tear. The number and complexity of tasks, the continuous 24-hour accountability, and the constant change of activities can be overwhelming. Providing care for long periods of time, coupled with uncertainty about the care situation, can further affect the caregiver's emotional health, leading to stress and burnout (19).

The health status of the caregiver himself is another determining factor, since physical, psychological or cognitive problems, as well as addictions or codependency, can affect his ability to perform his role effectively. In addition, unrealistic expectations about oneself or the inability to meet one's own or others' expectations can generate additional stress and decrease the caregiver's self-esteem (19,20).

Socioeconomic aspects also contribute to the caregiver's burden. Social isolation, playing competing roles, and alienation from the support network can increase feelings of burden and lead to feelings of loneliness. Lack of recreational activities and insufficient financial resources can also lead to additional concerns and increase pressure on the caregiver (19).

Relationships between caregiver and caregiver can also be complicated, especially if there is a history of bad relationships, abuse, or violence. The recipient's unrealistic expectations of the caregiver and the receiver's mental state, which can inhibit communication, can further hinder interaction and caregiving, generating tension in family dynamics (19).

Family processes and available resources also play an important role in the caregiver's burden. Dysfunctional family dynamics or marginal coping history can increase the caregiver's emotional burden. In addition, a lack of adequate resources, such as an inadequate physical environment for providing care or lack of access to community resources, can make the situation even more difficult and increase feelings of overload.

Together, these factors create a significant burden for the family caregiver. It is essential to address these challenges and provide the necessary support to ensure the well-being of both the caregiver and the recipient of care.

The defining characteristics of caregiver burnout and caregiver health encompass a wide range of physical, emotional, and socioeconomic aspects. From difficulty completing tasks to worries about the future to dysfunctional changes in caregiver activities, these factors can have a significant impact on the caregiver's quality of life (19).

In terms of physical health, gastrointestinal disorders, changes in body weight, rashes, hypertension, and other medical conditions can contribute to caregiver burnout and fatigue. On an emotional level, feelings of depression, stress, impatience, and lack of time for one's own personal needs can affect the caregiver's mental health, generating a vicious circle of worry and tension (21).

In addition, socioeconomic aspects, such as lack of participation in social life, changes in leisure activities, and low work productivity, can exacerbate caregiver stress, affecting their overall well-being.

Relationships between caregiver and recipient of care, as well as family processes, also play a crucial role. Grief and uncertainty about the change in relationships with the care recipient, as well as concern for other family members, can add an additional burden to the caregiver (19,22).

FINAL AWARDS

The act of caring implies not only an affective and moral responsibility but a practice that requires social recognition. It is established that the role of the informal caregiver is based on acts based on values such as solidarity, commitment and responsibility but also with high demands of emotional, physical, family and social overload. Hence the importance of considering this phenomenon as a priority, seen as subjects of attention that need to be addressed from their own needs and not in a generalized way.

Likewise, it is essential that public policies and community programs incorporate the figure of the caregiver as a subject of care and not only as an agent of care. In the first instance, recognizing and addressing the needs of the caregiver is essential to ensure a better quality of life.

Therefore, although policies and standards are exposed to offer support to sick people and people with disabilities, there is a lack of greater holistic protection for caregivers. In effect, it has been an invisible population in regulatory frameworks, recognized as a care-providing agent and not a subject that deserves attention.

Hence, the importance of the nursing professional as a manager of health promotion and direct assistance to identify risks and control the symptoms that arise from the process. The premise is that from its humanistic approach it contributes through the care process to promote community support actions and empowerment of their own self-care. It is important to focus on support strategies and psychosocial support programs aimed at this population.

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