BURDEN OF INFORMAL CAREGIVER OF FUNCTIONALLY DEPENDENT PATIENTS TREATED AT THE PHYSIOTHERAPY CLINIC OF THE STATE UNIVERSITY OF NORTHERN PARANÁ

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ABSTRACT

Introduction: Addiction occurs when a person needs help from another or equipment to perform daily activities, due to illnesses, accidents, or disabilities. This condition affects not only the dependent, but also the family and the caregiver, usually informal and without training or remuneration. With the aging of the population and the increase in chronic diseases, the demand for family caregivers has grown, making it relevant to study the burden they face. **Objective:** The objective of this study was to analyze the level of emotional, social and physical burden of caregivers of functional dependent patients treated at the Physical Therapy Clinic of UENP. **Method:** A cross-sectional study was conducted between November 2023 and July 2024, with 37 caregivers of functional dependent patients undergoing physical therapy treatment at UENP. Participants completed a sociodemographic questionnaire and the Informal Caregiver Burden Assessment Questionnaire (QASCI), which assesses seven domains of burden. Data analysis was performed based on means, percentages, and standard deviation. **Results:** About 72.96% of the caregivers had severe or extremely severe burden, while 27.07% had moderate burden. The highest levels of burden were in the "reaction to demands" (11.70 ± 5.66) and "emotional burden" (9.24 ± 5.01) domains, while other domains, such as "family support" (2.51 ± 1.46), had lower levels. **Conclusion:** The data show that the dependence and role of informal caregivers have a great impact on both caregivers and their families, with most facing a severe and extremely severe burden. The main factors of overload are linked to the perception of defense mechanisms, emotional overload and reactions to demands.

Keywords: Informal Caregivers; Functional Dependence; Caregiver Burden.

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INTRODUCTION

A dependent person is one who for a more or less prolonged period of time, needs the help of another person or equipment to carry out some activities (Santos et al., 2022). Therefore, any disease is always a crisis situation, a stressful event, which produces effects on the patient, the family and the caregiver. With this scenario, dependence arises, which can be found in the aging process, but is also associated with many other factors of origin, such as congenital or acquired disabilities, oncological diseases, degenerative diseases, work accidents, or even sequelae of road accidents (Corral et al., 2023; Mendes et al., 2019). In this way, the number of individuals, regardless of their age group, who require daily and regular care by third parties has increasingly increased (Alves et al., 2019).

Despite the changes in family functions and structures recorded in recent decades, it is still in most cases female family members who mostly support these patients, thus playing the role of informal caregivers (IC) (Corral et al., 2023). The IC is any person, family member or not, who is responsible for assisting the dependent person in their day-to-day life, in promoting their quality of life, ensuring that their daily needs are met. These are people who perform this function on an informal basis, without prior professional training or any contractual relationship and without any type of remuneration (Moura et al., 2019) and the overload of the IC comes as a consequence of this close contact between the caregiver and the patient or dependent elderly (Garcia, et al., 2020).

Experts estimate that by 2030 the number of caregivers will reach 21.5 million and that caregivers will care for patients or provide care for at least 20 hours a week (National Alliance for Caregiving & AARP, 2015).

In view of the above, the study aimed to analyze the level of emotional, social and physical overload of caregivers of functional dependent patients treated at the Physical Therapy Clinic of the State University of Northern Paraná (UENP).

METHODOLOGY

This is a cross-sectional study, which was carried out from November 2023 to July 2024, approved by the Ethics Committee under opinion: 6,027,475. All participants who agreed to participate in the research signed the Informed Commitment Agreement (ICF).

Among the inclusion criteria were to be an informal caregiver, provide care to only one person, be over 18 years of age, and be a caregiver of a functionally dependent patient, classified through the Functional Independence Measure (MIF) scale, who performs physical therapy treatment at the Alfredo Franco Ayub Physical Therapy Clinic of the State

University of Northern Paraná - UENP. The exclusion criteria were to have training as a caregiver and to care for patients under 3 years of age.

Data collection took place through interviews with the respective caregivers of each patient and a sociodemographic questionnaire adapted by the researchers was applied, addressing variables such as gender, age, education, kinship, place of birth, other occupations and whether the caregiver assumed this function out of necessity.

The questionnaire for the assessment of informal caregiver burden (QASCI) was also applied, consisting of 32 items covering seven domains (emotional burden; implications for personal life; financial burden; reactions to demands; perception of efficacy and control mechanisms; family support and satisfaction with the role and with the family member), whose answers are obtained in values ranging from one to five (1 = never; 2 = rarely; 3 = sometimes; 4 = almost always; and 5 = always), having a total score ranging from 32 to 160 points (the higher the value, the greater the overload). To verify the overload, the following normative analysis of the QASCI was used: 0 points = Absence of Overload; 1 to 25 points = Light Overload; 26 to 50 points = Moderate Overload; 51 to 75 points = Severe Overload and > 75 points = Extremely Severe Overload. (CANDIDO et.al, 2020)

Through a descriptive analysis of the data using tables, a spreadsheet in Microsoft Office Excel 2010 was used, through percentage, mean and standard deviation to obtain the distribution of the total score of informal caregivers and to analyze the QASCI domains.

RESULTS and DISCUSSION

In our research, of the 37 volunteers evaluated, it was observed that 72.96% of the caregivers are severely or extremely severely overloaded, corroborating the study by Candido et al. (2020) that showed (61.1%) of the caregivers severely and extremely severely overloaded. The study by Candido et al. (2020) found that informal caregivers of elderly people with Alzheimer's have overload (100%), also in agreement with our study showing that all volunteers are overloaded either physically, socially or emotionally. Because it is not only your family member who needs care, he is also a human being who has his needs that need to be met (Table 1).

Table 1: - Distribution of the total burden score of caregivers.

OVERLOAD SCORE	N	%
Moderate Overload (from 26 to 50 points)	10	27,07%
Severe Overload (from 51 to 75 points)	18	48,64%
Extremely Severe Overload (>75 points)	9	24,32%
Total	37	100%

Source*:* Data from the survey itself

These data can be explained by the fact that these patients have a considerably high level of dependence, thus increasing the level of burden on their respective caregivers. The results of Fuhrmann et al. (2015) are in line with the findings of the present study, in which there was a prevalence of older older adults who had severe dependence, identifying a significant correlation between the functional capacity of the elderly and the burden of caregivers. The authors indicate that, as the dependence of the elderly increases, the greater the burden faced by caregivers.

The study by Silva and Delfino (2018) revealed that people who suffer from a higher level of overload and stress are those who have a "care" role and have close and direct contact with those who are cared for. This fact can generate a feeling of powerlessness, frustration or attachment. Therefore, these results may be related to the fact that, generally, the informal caregiver is a close relative, and often the responsibility for home care falls on this single individual in the family, generating the burden. Thus, it is essential that health professionals develop skills such as leadership, communication, people management, and teamwork to work effectively in the Family Health Strategies (FHS), so that there is a harmonious division of tasks and does not overload anyone (Lopes et al., 2020).

According to our studies, 3 main domains of burden in informal caregivers were identified: Implications for personal life; Reactions to demands; and Emotional overload. These results differ from those found in the study by Silva and Delfino (2018), in which the three main domains of high burden were: Satisfaction with the role and with the family member; Reactions to demands; and Perception of efficacy and control mechanisms. (Table 2).

Table 2: - Descriptive analysis of the QASCI* domains of the sample studied (n=37).

QASCI DOMAINS (number of items, possible range)	**AVERAGE**	**STANDARD DEVIATION**
Emotional Overload (4 items, 4 to 20)	9,24	± 5.01
Reactions to the requirements (5 items, 5 to 25)	11,07	± 5.69
Implications in personal life (11 items, 11 to 55)	20,09	± 8.85
Perception of efficacy and control mechanisms (3 items, 3 to 15)	7,35	± 1.77
Satisfaction with the role and with the family member (5 items, 5 to 25)	7,54	± 3.37
Family support (2 items, 2 to 10)	2,51	± 1.46
Financial burden (2 items, 2 to 10)	2,81	± 1.37

Source*:* Data from the survey itself.

In Brazil, there is a strong cultural expectation that the family is responsible for the care of its members. Thus, even if family caregivers are satisfied with this role, they face several sources of stress due to the accumulation of roles that is imposed, in addition to often not being prepared for the tasks required and consequences that care has in their daily routine. Many informal caregivers have no time for themselves or to carry out social and cultural activities, as the family member depends on assistance for most of their basic activities for much of the time (Mendes et al., 2019).

The result of high emotional overload observed in this study can be explained by the feeling of saturation of the caregiver in relation to the task of care, since, when performing activities for the physical and psychological well-being of his family member, the caregiver reduces the time dedicated to his personal life, also contributing to a greater burden in his personal life and reactions to demands (Silva; Delfino, 2018).

Another important finding of the present study was the low levels of family support and satisfaction with the role of caregiver and with the family member. Lins et al. (2018) observed that high satisfaction with the role of caregiver and with the family member is related to the support received and the division of tasks between the caregiver and the others involved, explaining this strong association between high satisfaction with family relationships and the perception that the emotional support received was adequate.

In addition, the fact that they are patients with a higher level of dependence also explains the high rates of emotional overload, implications in personal life and reactions to demands. The study by Lopes et al. (2020) found that the level of disability of the family member, the various changes in personal life, the amount of time allocated to caregiver functions and the task of caring without support, are the main factors that contribute to high values of burden.

Therefore, the high levels of burden in the domains: Implications in personal life, Reactions to demands, and Emotional overload, can be explained by the findings of Lins et al. (2018), which showed that when caregivers do not have an adequate division of tasks and do not receive sufficient emotional support, their ability to cope with stress is impaired and this can hinder the performance of their functions, in addition to reducing the time dedicated to personal life, well-being and mental health, generating a cycle of exhaustion and dissatisfaction both in the role of caregiver and in the relationship with the family member.

CONCLUSIONS or FINAL CONSIDERATIONS

It was possible to identify that most informal caregivers demonstrate a severe or extremely severe burden, presenting the need for support strategies and interventions aimed at improving the quality of life of these informal caregivers.

In relation to the domains, it was observed that the domains of greater burden are associated with the Perception of defense mechanisms, Emotional overload and Reactions to demands. These values indicate that individuals are facing high levels of emotional pressure and difficulties in coping with demands, as well as a heightened perception of challenges related to defense mechanisms. These domains reflect areas of greater vulnerability and stress in the group assessed.

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