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Evaluation of workload burden and the level of knowledge of caregivers regarding the transfer of neurological patients

Avaliação da sobrecarga de trabalho e grau de conhecimento dos cuidadores acerca da transferência de pacientes neurológicos

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ABSTRACT | INTRODUCTION: To identify the level of knowledge of informal caregivers regarding the transfer of neurological patients attending the physical therapy teaching clinic of the Universidade Estadual do Norte do Paraná — UENP (State University of Northern Paraná) and to assess their workload burden. **METHODS:** This is a descriptive, cross-sectional study conducted between December 2022 and November 2023, using questionnaires that assessed caregivers' sociodemographic characteristics and their knowledge of patient transfers, addressing both theoretical and practical aspects. To evaluate caregiver burden, the QASCI questionnaire was applied. **RESULTS:** It was observed that most caregivers did not know what patient transfers were, had not received any training or guidance, and had never taken any caregiving course, showing a low level of knowledge about transfers — both regarding their definition, purpose, and correct execution. Caregiver age was correlated with higher workload burden. **FINAL CONSIDERATIONS:** The study identified that caregivers have a low level of knowledge about patient transfers. These findings highlight the need for implementing health education initiatives focusing on patient handling, caregiving techniques, and caregiver self-care during transfer activities.

KEYWORDS: Caregivers. Patient Transfer. Nervous System Diseases.

RESUMO | INTRODUÇÃO: Identificar o grau de conhecimento dos cuidadores informais acerca de transferências de pacientes neurológicos que frequentam a clínica escola de fisioterapia da Universidade Estadual do Norte do Paraná (UENP) e avaliar a sobrecarga de trabalho. **MÉTODOS:** Trata-se de um estudo descritivo, de corte transversal, que foi desenvolvido no período de dezembro de 2022 a novembro de 2023, realizando aplicações de questionários sobre a caracterização sociodemográfica do cuidador, e sobre o conhecimento acerca de transferência abordando seus aspectos teóricos e práticos. Para avaliar a sobrecarga, utilizou-se o questionário QASCI. **RESULTADOS:** foi observado que a maior parte dos cuidadores não sabia o que eram transferências, não havia recebido orientações e nem realizado nenhum tipo de curso, possuindo um baixo nível de conhecimento acerca de transferências, tanto de sua definição quanto da maneira correta de realização e do motivo para ser realizado. A idade de correlacionou com maior sobrecarga de trabalho. **CONSIDERAÇÕES FINAIS:** foi possível identificar que os cuidadores possuem um baixo nível de conhecimento acerca de transferências. No presente estudo destacou-se a necessidade da realização de ações de educação em saúde, no que se refere ao manejo, cuidado com o paciente e com o cuidador na realização das transferências.

PALAVRAS-CHAVE: Cuidadores. Transferência de Paciente. Doenças Neurológicas.

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1. Introduction

A neurological patient is an individual who is either born with or develops a neurological disorder during their lifetime. These patients may present cognitive changes, functional dependency, memory deficits, among other impairments. For this reason, they require continuous and complex care, which demands knowledge, effort, and dedication from those involved in the caregiving process[1].

Caregivers play an essential role in the treatment and care of neurological patients. They may be family members or community-based service providers responsible for accompanying, assisting, and supporting the patient in tasks they are unable to perform independently[2,3]. Caregivers can be divided into two categories: formal and informal. Formal caregivers consist of healthcare professionals, whereas informal caregivers are mostly family members who take on this role due to physical and emotional proximity, often without proper training for such responsibilities[1,4].

The transport and transfer of patients are considered among the most hazardous and challenging tasks for healthcare workers and caregivers. To perform a proper transfer, it must be taught and should also include an assessment of the environment, alternatives to make the procedure less harmful and difficult for both parties, careful planning before beginning the transfer, and the use of appropriate equipment in the case of bedridden patients[5].

Recent evidence highlights that caregiver education and training programs are critical for ensuring safety during patient transfers and for promoting functional rehabilitation[1-4]. For instance, Bosch et al.[9] observed that caregiver availability and training are associated with higher rates of functional discharge in post-stroke patients. Similarly, Hong et al.[1] found that educational interventions directed at caregivers significantly contributed to the functional recovery of patients with neurological sequelae.

Furthermore, international guidelines emphasize the importance of safe manual patient handling protocols, particularly in home and palliative care settings, as an essential strategy to prevent physical overload, fatigue, and injuries[2,3]. Recent studies reinforce that training conducted by physical therapists is fundamental to reducing movement errors, improving patient positioning, and optimizing safety during transfers.

Caregiver burden is regarded as a stressor resulting from managing the physical dependency and mental incapacity of the person requiring care. It impacts daily activities, social relationships, and emotional balance, and may contribute to the onset of physical and mental illnesses[6,7]. Functional dependency is defined as the inability to maintain the physical and mental abilities necessary for independent living[8,9].

Therefore, therapeutic and social support provided by institutions and professionals is extremely important to help families and informal caregivers face challenges more calmly. It contributes to better understanding of the illness and provides knowledge on how to care for, treat, and handle these situations on a daily basis[6]. It is crucial that therapists focus on both rehabilitating patients and guiding caregivers, aiming to prevent musculoskeletal injuries and caregiver overload caused by performing tasks incorrectly. However, there is a lack of materials focused on proper patient positioning, making education and knowledge sharing difficult for caregivers[7,9].

The objective of this study was to identify the level of knowledge of informal caregivers regarding the transfer of neurological patients who attend the physical therapy clinic at the Universidade Estadual do Norte do Paraná - UENP (State University of Northern Paraná). In addition, the study aimed to identify the association between caregiver workload burden and both age and duration of caregiving.

2. Method

This is a descriptive, cross-sectional study conducted between December 2022 and November 2023, following approval by the Research Ethics Committee – CAAE: 68522523400008123. All participants who agreed to take part in the study signed the Informed Consent Form (ICF).

Inclusion criteria were: being an informal caregiver, providing care to only one person, being over 18 years of age, and caring for a neurological patient undergoing physical therapy at the Clínica Escola de Fisioterapia Alfredo Franco Ayub (Alfredo Franco Ayub Physical Therapy Clinic) of the State University of Northern Paraná (UENP). Exclusion criteria included having formal training as a caregiver or receiving payment for caregiving services.

Data collection was carried out through interviews conducted by the study's researchers, using two questionnaires. One was a sociodemographic questionnaire addressing variables such as sex, age, education, relationship to the patient, place of origin, other occupations, and whether the caregiver assumed the role out of necessity. The second questionnaire, entitled "Caregiver Knowledge on Patient Transfers Questionnaire", was specifically developed for this study and has not undergone formal validation. Following a thorough literature review, the most relevant aspects were selected to assess caregivers' knowledge regarding the transfer of patients with functional dependence, including information derived from the Guide for Positioning Caregivers of Individuals with Stroke[9,10], Positioning and Transfer Techniques, and Internal Hospital Patient Transfer[8]. The instrument consists of 20 questions — 19 closed-ended ("yes" or "no") and one with three response options. Some "yes" responses allow for descriptive information. Scoring was organized so that "yes" responses correspond to 1 point and "no" to 2 points, with higher scores indicating lower caregiver knowledge on the topic.

Although the knowledge questionnaire has not undergone formal validation or pilot testing, its development based on specialized literature enables an exploratory assessment of caregivers' knowledge levels. It is recommended that future studies consider validating the instrument or using standardized questionnaires to enhance comparability of results.

The third questionnaire applied was the Informal Caregiver Burden Assessment Questionnaire (QASCI). This instrument consists of 32 items assessing the following domains: personal life implications (eleven items); satisfaction with the caregiving role and with the family member (five items); reactions to demands (five items); emotional burden (four items); family support (two items); financial burden (two items); and perception of efficacy and control mechanisms (three items). Each item is rated on an ordinal scale ranging from 1 to 5 points according to the following responses: "No/Never" (1 point), "Rarely" (2 points), "Sometimes" (3 points), "Almost always" (4 points), and "Always" (5 points). The final score results from the total sum of the responses to the 32 items (possible range: 32 to 160) corresponding to each domain, where higher values indicate situations of greater weight or higher burden in this population.

For data analysis, the R Core Team (2023) software was used. The results of the sociodemographic and transfer knowledge assessment questionnaires were presented in tables using descriptive statistics. As a secondary outcome, a multiple linear regression analysis was performed to examine the influence of age and duration of caregiving on workload burden.

3. Results

Initially, 18 caregivers were identified. Of these, one was a formal caregiver and three declined to participate in the study. Fourteen caregivers were interviewed, of whom twelve were female (85.71%). The majority of the sample was between 31 and 59 years of age (64.29%). Regarding place of origin, most caregivers (57.14%) were from the city of Jacarezinho, while the remaining six were from nearby towns. In terms of education level, 8 caregivers had completed high school (57.14%). All participants were related in some way to the person they cared for. When asked about other occupations in addition to caregiving, 7 caregivers (50%) reported having other jobs. Regarding the necessity of becoming a caregiver due to the lack of someone else to assume the role, 13 caregivers (92.86%) responded affirmatively, indicating they became caregivers out of necessity (Table 1).

Table 1. Sociodemographic characteristics of the caregivers

Variable	*N*	%
Gender		
Female	12	85.7%
Male	2	14.2%
Age		
18–30 years	3	21.4%
31–59 years	9	64.2%
60 and above	2	14.2%
Place of Origin		
Jacarezinho	8	57.1%
Santo Antônio da Platina	1	7.1%
Ribeirão Claro	1	7.1%
Wenceslau Brás	1	7.1%
São Paulo	1	7.1%
Itaquaquecetuba	1	7.1%
Ibaiti	1	7.1%
Education Level		
Elementary School	5	35.7%
High School	8	57.1%
Higher Education	1	7.1%
Family Relationship		
Yes	14	100%
No	0	0%
Other Occupations		
Yes	7	50%
No	7	50%
Caregiver by Necessity		
Yes	13	92.8%
No	1	7.1%

Source: the authors (2025).

As for the caregivers' knowledge about transfers (Table 2), twelve (85.68%) had experience in the role and had been providing care for more than five years. Thirteen (92.85%) reported never having taken any caregiving course, and nine (64.26%) had not received any guidance on how to perform transfers. Seven caregivers (50%) did not know what pressure injuries were. Regarding their understanding of transfers, ten caregivers (71.4%) did not know what transfers were, and nine (64.26%) did not know the purpose of performing a transfer or repositioning the person they cared for. Twelve caregivers (85.68%) were unfamiliar with transfer levers and did not know of any tools that could assist in patient handling. Regarding diagnosis, ten caregivers (71.4%) knew the diagnosis of the person under their care, and thirteen (92.85%) understood the limitations caused by the disease.

Table 2. Caregivers' knowledge regarding transfers (to be continued)

Question	*N*	%
Do you have experience as a caregiver?		
Yes	2	14.2%
No	12	85.6%
Do you know what transfers are?		
Yes	4	28.5%
No	10	71.4%
Do you know the reason for performing transfers?		
Yes	5	35.7%
No	9	64.2%
Have you been a caregiver for more than 5 years?		
Yes	12	85.6%
No	2	14.2%
Do you know what transfer levers are?		
Yes	2	14.6%
No	12	85.6%
Do you know the diagnosis of the person you care for?		
Yes	10	71.4%
No	4	28.5%
Do you understand the illness and its limitations?		
Yes	13	92.80%
No	1	7.0%
Have you received guidance on how to perform transfers?		
Yes	5	35.7%
No	9	64.2%
Have you taken any caregiver or transfer technique course?		
Yes	1	7.1%
No	13	92.8%
Which transfers do you perform most often?		
Chair to sofa, bed, or shower chair	4	28.5%
Bed to chair, car, floor	1	7.0%
None of the above	9	64.2%

Table 2. Caregivers' knowledge regarding transfers (conclusion)

Question	*N*	%
Do you feel tired or in pain after performing a transfer alone?		
Yes	0	0%
No	14	100%
Do you have difficulty performing a transfer?		
Yes	3	21.4%
No	11	78.5%
Does the person you care for need help from more than one person to transfer?		
Yes	3	21.4%
No	11	78.5%
Do you know how to perform a transfer with more than one person?		
Yes	0	0%
No	14	100%
Do you know what pressure injuries are?		
Yes	7	50%
No	7	50%
Do you know how to use your body weight correctly?		
Yes	5	35.8%
No	9	64.0%
Do you know the appropriate footwear for transfers?		
Yes	4	28.5%
No	10	71.4%
Do you plan the movement before performing it?		
Yes	4	28.5%
No	10	71.4%
Do you explain to the person what you are about to do?		
Yes	6	42.8%
No	8	57.0%
Do you know any tools that can assist with transfers?		
Yes	2	14.0%
No	12	85.6%

Source: the authors (2025).

Most caregivers reported not performing any type of transfer (64.26%), while four (28.56%) stated they transferred the person from the wheelchair to a sofa/bed/shower chair, and one (7.14%) commonly transferred the person from bed to the floor, chair or car.

All participants reported not knowing how to perform a transfer with the help of others. Eight (57.12%) did not know how to explain the transfer process to the patient. Ten (71.4%) were unaware of the appropriate footwear for such activity, nine (64.26%) did not know how to use their body weight to their advantage, and all caregivers who performed transfers (35.7%) stated they did not feel tired after performing a transfer alone.

The multiple linear regression analysis indicated that the model presented a coefficient of determination $R^2 = 0.42$ (adjusted $R^2 = 0.34$), explaining a significant proportion of the variability in caregiver burden. After adjusting for the independent variables, age remained directly associated with the total QASCI score (β = 0.93, 95% CI [;], *p* = 0.005), indicating that the higher the age, the greater the perceived burden. No association was found with caregiver duration (*p* > 0.05).

4. Discussion

The results of this study indicated that only the caregiver's age showed a significant association with the perceived burden, as measured by the QASCI, suggesting that older caregivers tend to experience higher levels of burden. This finding may be related to the greater physical and emotional demands imposed by continuous caregiving, combined with potential functional and health limitations inherent to aging. Previous studies support this relationship, highlighting that older caregivers often report greater exhaustion, lower coping capacity, and poorer quality of life indicators[10-12].

According to the results obtained, it was found that most caregivers were under 60 years of age, female, and all had some family relationship with the person they cared for. This supports findings from other studies reporting that family members often take on the role of caregiver, even without formal training or guidance, with women being the most common caregivers. They usually take on this responsibility in addition to continuing to carry out all household activities, without sharing caregiving duties with others[10,13-16].

Regarding education, only one caregiver in the sample had a university degree, consistent with Ballarin et al.'s[14] study in which only 3.3% of caregivers had completed higher education, and Crescente et al's[17] study, where 40.7% had not completed elementary school. Moreover, caregivers often become such out of necessity, as also seen in this research. This may be explained by low education levels limiting access to the job market, making it economically more viable for a family member to assume the caregiving role. Gratão et al.'s[12] also found that limited access to education negatively affects caregiver independence and influences the functional status and cognitive disability risk of the person being cared for.

When analysing caregiver experience, other occupations, and understanding of the illness and its limitations, the findings in this study reinforce the insights of Ballarin et al.[14] and Siqueira et al.[18], indicating that most caregivers have been in the role for over 5 years, which predisposes them to develop caregiving skills and better understand the patient's limitations. Additionally, caregivers tend to prioritize caregiving and household duties over leisure and self-care.

Regarding pain and fatigue, the results of this study differ from those in the literature[11,16], which report caregiver burden and pain present in 55% of caregivers. In Ballarin et al.'s study[14], 46.6% of caregivers had moderate burden and 43.4% had moderate to severe burden. In contrast, none of the caregivers in this study reported feeling tired or in pain, likely because only 35% performed any type of transfer, meaning fewer caregivers were exposed to physical strain.

On the topic of transfer levers, most caregivers in this study lacked knowledge, aligning with Lee et al.'s study[20], in which more than half of respondents reported positioning their hands under patients' armpits to lift them, increasing the risk of injury. This can also be explained by the sample's low frequency of transfers and lack of practical experience.

Regarding caregivers' overall knowledge, most were unaware of what transfers were, had not received guidance, and had never attended any training courses. This affected responses to questions about footwear, movement planning, explaining the procedure to the patient, and use of assistive devices — all of which showed low levels of knowledge. This supports findings by Lee et al.[20], where fewer than 10% of caregivers reported receiving regular information, showing that caregiver education is not systematic. Similarly, Lopes et al.[21] note that caregivers are not adequately prepared to meet the care needs of their patients. According to Almeida et al.[13], caregivers often do not recognize caregiving errors and usually receive only medication and feeding instructions. Other studies[11,14,19,20] show that caregiver knowledge of patient positioning is limited.

In contrast, Prieto et al.[19] found that most informal caregivers had regular knowledge, with only 3% scoring poorly in caring for and transferring bedridden patients. This discrepancy may be due to the fact that the patients in this study were not bedridden, unlike those in Prieto et al.'s[19] study. Patients with greater functional capacity may assist caregivers during care, which could explain the more favourable knowledge level observed here, as caregivers performed fewer activities than would be required for bedridden individuals[21-24].

These findings highlight the importance of health professionals providing guidance to caregivers on how to manage patients, offering them the necessary support to perform daily care activities, thus preventing complications, reducing accident risks, and minimizing caregiver burden[21-24].

Additionally, the results of this study have significant practical implications for health education policies and clinical protocols. The identification of knowledge gaps regarding patient transfers highlights the need for structured training programs for informal caregivers, including practical training sessions, educational materials, and regular professional supervision[3,23,24]. Such initiatives may reduce the risk of accidents, improve safety, and enhance the quality of life for both caregivers and patients. Furthermore, the findings can support the development of clinical protocols that incorporate detailed guidance on safe transfer and positioning techniques, strengthening preventive practices in home and institutional settings, and contributing to public policies aimed at caregiver training.

Finally, this study contributes to the scientific evidence by emphasizing the importance of ongoing training for informal caregivers and professional support in the rehabilitation of neurological patients. By identifying knowledge gaps and factors associated with caregiver burden, the findings underscore the need to integrate educational programs into clinical practice and health policies, promoting not only patient safety but also the physical and emotional well-being of caregivers. Thus, the results reinforce the exploratory nature of the study and its social relevance, providing a foundation for future research, the development of educational materials, and the formulation of standardized patient transfer protocols.

5. Conclusion

It was found that caregivers have a low level of knowledge regarding transfers — both in terms of definition, purpose, and correct procedures — demonstrating uncertainty about positioning, appropriate footwear, and assistive materials. However, most caregivers, despite having limited access to information, were knowledgeable about the primary illness of the person they care for, including their main difficulties, needs, and how to assist with some daily living activities.

There is a clear need for health education initiatives related to patient handling, care, and caregiver safety during transfers, in order to prevent musculoskeletal injuries for both patients and caregivers. It is also recommended to implement caregiver-focused educational strategies to reduce caregiver burden, allowing more time for other personal or professional activities. Families should be encouraged to share caregiving responsibilities and allow patients to carry out tasks they are capable of, fostering a more harmonious and satisfying home environment.

Authors' contributions

The authors declared that they have made substantial contributions to the work in terms of the conception or design of the research; the acquisition, analysis or interpretation of data for the work; and the writing or critical review for relevant intellectual content. All authors approved the final version to be published and agreed to take public responsibility for all aspects of the study.

Competing interests

No financial, legal, or political conflicts involving third parties (government, private companies, and foundations, etc.) were declared for any aspect of the submitted work (including but not limited to grants and funding, advisory board participation, study design, manuscript preparation, statistical analysis, etc.).

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