Caregivers' Perception of Elderly Patients' Hospital Discharge and Continuity of Care at Home

Percepção de Cuidadores de Pessoas Idosas Sobre a Alta Hospitalar e a Continuidade do Cuidado no Domicílio

Percepción de los Cuidadores de Personas Mayores Sobre el Alta Hospitalaria y la Continuidad del Cuidado en el Domicilio

RESUMO

OBJETIVO: Investigar a percepção dos cuidadores de pessoas idosas sobre as orientações para a alta hospitalar, além de descrever aspectos sociodemográficos e clínicos dos cuidadores. **MÉTODO:** Estudo descritivo e qualitativo, realizado com 20 cuidadores de pessoas idosas que receberam alta hospitalar nos últimos 30 dias. A coleta ocorreu nos domicílios e na atenção primária, por meio de um questionário sociodemográfico e uma questão aberta sobre a percepção das orientações recebidas. A análise seguiu diretrizes do Discurso do Sujeito Coletivo e estatística descritiva. **RESULTADOS:** Os cuidadores eram majoritariamente mulheres (90%), casadas (50%) e tinham entre 41 e 50 anos (30%). A maioria relatou sentir-se preparada para cuidar, mas consideraram as orientações insatisfatórias. As percepções foram categorizadas em dois temas: "Percepção Positiva das Orientações" e "Percepção Negativas das Orientações". **CONCLUSÃO:** Embora se sintam preparados, a insatisfação com as orientações destaca a necessidade de estratégias mais eficazes e centradas na continuidade.

DESCRITORES: Alta do Paciente; Saúde do Idoso; Cuidadores; Continuidade da Assistência ao Paciente.

ABSTRACT

OBJECTIVE: To investigate caregivers' perception of the guidance provided for hospital discharge of elderly patients, as well as to describe caregivers' sociodemographic and clinical aspects. **METHOD:** A descriptive and qualitative study conducted with 20 caregivers of elderly patients discharged in the last 30 days. Data collection took place at home and in primary care through a sociodemographic questionnaire and an open-ended question about their perception of the received guidance. The analysis followed the guidelines of the Collective Subject Discourse and descriptive statistics. **RESULTS:** The caregivers were mostly women (90%), married (50%), and aged between 41 and 50 years (30%). Most reported feeling prepared to provide care but considered the guidance unsatisfactory. Perceptions were categorized into two themes: "Positive Perception of Guidance" and "Negative Perception of Guidance". **CONCLUSION:** Although caregivers feel prepared, dissatisfaction with the guidance highlights the need for more effective and continuity-focused strategies.

DESCRIPTORS: Patient Discharge; Health of the Elderly; Caregivers; Continuity of Patient Care.

RESUMEN

OBJETIVO: Investigar la percepción de los cuidadores de personas mayores sobre las orientaciones para el alta hospitalaria, además de describir los aspectos sociodemográficos y clínicos de los cuidadores. **MÉTODO:** Estudio descriptivo y cualitativo realizado con 20 cuidadores de personas mayores que recibieron el alta hospitalaria en los últimos 30 días. La recolección de datos se llevó a cabo en los domicilios y en la atención primaria, mediante un cuestionario sociodemográfico y una pregunta abierta sobre la percepción de las orientaciones recibidas. El análisis siguió las directrices del Discurso del Sujeto Colectivo y la estadística descriptiva. **RESULTADOS:** Los cuidadores eran en su mayoría mujeres (90%), casadas (50%) y tenían entre 41 y 50 años (30%). La mayoría informó sentirse preparada para cuidar, pero consideró las orientaciones insatisfactorias. Las percepciones se categorizaron en dos temas: "Percepción Positiva de las Orientaciones" y "Percepción Negativa de las Orientaciones". **CONCLUSIÓN:** Aunque los cuidadores se sienten preparados, la insatisfacción con las orientaciones resalta la necesidad de estrategias más efectivas y centradas en la continuidad del cuidado.

DESCRIPTORES: Alta del Paciente; Salud del Anciano; Cuidadores; Continuidad de la Atención al Paciente

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INTRODUCTION

Hospital discharge is a critical moment in care, impacting clinical outcomes, quality of care and resource utilization. When poorly planned, it can increase the risk of readmissions and complications, while a structured process improves hospital management, reducing overcrowding and optimizing care. [1] Patient recovery depends not only on the care provided during hospitalization, but also on effective planning for the post-discharge period. The transition to home care should take into account the patient's conditions and limitations, ensuring that the guidelines are understood and can be applied in practice. To this end, an interprofessional approach is essential, with clear and accessible guidelines, aiming at the safe continuity of care and the prevention of readmissions. [2-3]

Transitioning care requires more than just specific guidelines, and requires efficient coordination within the Health Care Network (HCN) and the involvement of the team, the patient, and the caregiver. Nurses play a central role, being responsible for assessing the patient, monitoring self-care, and educating the family throughout the hospitalization. Despite the challenges, such as work overload and lack of coordination between services, strategies such as standardization of guidelines, inclusion of the caregiver, and use of technologies can strengthen the process. Trained in educational actions and care planning, nurses can lead a structured discharge plan, promoting safety and continuity of care. [4]

Currently, the growth of the elderly population compared to other age groups demands public policies aimed at promoting health and preventing diseases, considering the higher prevalence of chronic conditions in this group. Population aging is a global phenomenon, with an increase in life expectancy and a projection of 2 billion elderly people by 2050. The notable growth in the number of elderly people is a consolidated reality both on a global and national scale, leading to increased demand for health resources. [5]

When hospitalized, elderly people experience significant changes in their health condition that can contribute to the loss of autonomy and independence, in addition to a reduction in their functional capacity. [6-7] This often requires the presence of a caregiver, either permanently or temporarily.

It is important to note that, in most cases, care continues beyond the hospital environment, extending to the home. Adapting the family routine and changing lifestyle habits become essential to deal with limitations and ongoing treatments. Thus, hospital discharge can generate insecurity and, without adequate guidance, increase the risk of readmissions. [8]

Even when the caregiver receives guidance and training from the interprofessional team, the complexity inherent in caring for a dependent elderly person can generate insecurity and apprehension, due to the responsibility involved. Therefore, it is crucial that, during the period of hospitalization of the elderly person, there is a plan for discharge, aiming to adapt the environment and the conditions of the caregiver, thus promoting an environment conducive to the performance of activities of daily living. [6-8]

The findings of this study reveal that nurses have little involvement in hospital discharge planning and often do not understand it as a structured process within the Nursing Care Systematization (NCS). Resolution No. 736/2024 of the Federal Nursing Council establishes that the Nursing Process (NP) must be applied deliber-

ately and systematically in all care environments, organized into five interrelated stages: assessment, diagnosis, planning, implementation, and evolution. However, its application in hospital discharge still faces challenges. [9]

Among the main obstacles to nurses' performance in this context, the following stand out: lack of teamwork, bureaucratization of care, understaffing and overload of duties. The NP, when used correctly, enables structured discharge planning, guiding care actions and assisting in the identification and management of health problems. Therefore, to ensure continuity of care and minimize risks after hospitalization, it is essential to strengthen the implementation of the NP at hospital discharge and train nurses for its effective use. [9-10]

The strategy of continuous and integrated care for the elderly person in their home after hospital discharge, together with the objective of increasing self-care capacity, strengthens adherence to planned treatment, contributes to reducing the frequency of hospitalizations and promotes closer communication between the hospital environment and the care provided to patients. Therefore, it is essential to implement strategies that improve the transition of care from the hospital to the home. [2,5,8]

The hospital discharge process is a critical and complex moment, as it involves not only the patient's transition from the hospital environment to home, but also the continuity of care outside the clinical environment. Understanding caregivers' perceptions is crucial to improving the guidance practices provided by health teams, promoting a transition that allows the maintenance of the quality of care and the recovery of the elderly person. Therefore, the objective of this research is to investigate the perception of caregivers of elderly people about the guidance for hospital discharge, in addition to describing sociodemographic and clinical aspects of caregivers.

METHOD

This is descriptive research with a qualitative approach, as it aims to identify, describe and characterize the phenomenon or fact, with the expectation of knowing a more detailed perception of subjects. For Minayo: "Qualitative research answers specific questions, focuses on a level of reality that cannot be quantified and works with a universe of multiple meanings, motives, aspirations, beliefs, values and attitudes. These methods are flexible and adaptable to the specificities of the object of study, allowing researchers to explore the experiences, perceptions and meanings attributed by participants." [11]

The study was conducted in the homes of elderly individuals and/or family members and in primary health care units in the city of Pouso Alegre, Minas Gerais. Caregivers of elderly individuals who had been discharged from hospital in the last 30 days were surveyed for this study.

The inclusion criteria were: having played the role of caregiver for the elderly individual during the hospitalization period; being over 18 years old. The exclusion criteria were: not wishing to participate in the study; not having accompanied the elderly individual during the hospitalization process; not having preserved cognitive capacity.

The sample consisted of 20 caregivers of elderly individuals and the sampling was intentional, where the researcher collected the names of the elderly individuals who had been discharged from hospital and scheduled an in-person home visit.

In this study, two instruments were used: a sociodemographic and clinical questionnaire, which addressed aspects such as gender, age, education, marital status, current employment status, presence of comorbidities, use of medications and quantity of medications used. In addition, specific data related to the household and care were collected, including the number of people living in the same environment, existence of support in care, previous experience in caring for the elderly, receipt of guidance from the health team, opportunity to clarify doubts and self-perception of being prepared to provide care. In addition to the guiding question related to the theme: "What is your perception regarding the guidance of the health team regarding care for the elderly person for hospital discharge?".

The interviews were conducted at a previously established time and place and the answers were recorded manually and through recordings. The data were analyzed through descriptive narrative and according to the guidelines of the Discourse of the Collective Subject (DSC). The DSC allows the visualization of collective perception as it allows the capture of the discourse that reveals the way in which real and concrete individuals think and act. [12]

The results were presented using descriptive statistics and the following methodological figures were used to analyze the discourses: Central Idea (CI), Key Expressions (KE) and Collective Subject Discourse (CSD). The CI represents the name or linguistic expression that reveals and describes the meaning of each of the discourses analyzed and of each homogeneous set of KE. The KE are made up of literal transcriptions of parts of the discourses, which allow the recovery of the essence of the discursive content of the segments into which the testimony is divided. The CSD is a summary discourse written in the first person singular and composed of the KEs that have the same CI, as if there were only one subject speaking, as the bearer of a summary discourse of the components of the collective subject. [12]

The research began after the project was evaluated and approved by the Research Ethics Committee of the

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University of Vale do Sapucaí, in Pouso Alegre, Minas Gerais. The approval is registered by opinion no. 6,881,862 and CAEE 79525424.0.0000.5102.

RESULTS

During the research, 20 caregivers of elderly people who had been discharged from hospital in Pouso Alegre, Minas Gerais, were interviewed. The majority of participants were female (90%) and married (50%). Regarding age range, 30% were between 41 and 50 years old, while 55% were over 50 years old. Regarding education, 60% had completed high school, and the majority had formal employment (60%).

Most caregivers (75%) have comorbidities, and 45% use multiple medications. Among the most prevalent comorbidities are: hypertension and depression. The use of antidepressants (35%) suggests an emotional impact of care, while 20% use antihypertensives. In addition, 30% use three or more medications, and 25% do not use any medication. These findings highlight the need for medical and psychological support to ensure the health of caregivers and the continuity of care for elderly people.

Table 1 - Sociodemographic and clinical profile of caregivers of elderly people who were hospitalized in the hospital service of the municipality of Pouso Alegre between June and July 2024 (N=20). Pouso Alegre, MG, Brazil.

Variables	n	%
Gender		
Male	2	10
Female	18	90
Age group		
23 - 30 y/o	2	10
31 - 40 y/o	1	5
41 - 50 y/o	6	30
51 - 60 y/o or older	11	55
Education		
Complete Elementary School	1	5
Incomplete Elementary School	4	20
Complete High School or Incomplete Higher education	12	60
Complete Higher education	3	15
Marital Status		
Married	10	50
Single	8	40
Divorced	1	5
Others	1	5
Current employment situation		
Employed	12	60
Self-employed	1	5
Unemployed	4	20
Retired	3	15
Any comorbidities?		
Yes	15	75
No	5	25
Medications in use		
Antidepressant	7	35
Antihypertensives	4	20
Others	9	45

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Number of medications in use		
1 - 2 medications	9	45
3 medications	2	10
4 medications or more	4	20
None	5	25

Source: Prepared by the authors (2024)

Most caregivers (85%) live with other people and 90% have support in providing care, which can reduce the burden. In addition, 60% reported feeling prepared to care for the elderly person. However, 40% had no previous experience in providing care, and 55% did not receive guidance from the health team, compromising the continuity of care. In addition, 60% did not have the opportunity to clarify doubts, highlighting communication failures and the need for strategies to ensure safer and more effective home care.

Table 2 - Support, experience and guidance received by caregivers of elderly people (N=20). Pouso Alegre, MG, Brazil.

Variables	n	%
Do more people live in the residence?		
Yes	17	85
No	3	15
Do they have support for care?		
Yes	18	90
No	2	10
Do they have experience in caring for elderly people?		
Yes	12	60
No	8	40
Do they receive guidance from the health team for home care?		
Yes	09	45
No	11	55
Do they have opportunities to pay off debts?		
Yes	8	40
No	12	60
Do they feel prepared for care?		
Yes	12	60
No	8	40

Source: Prepared by the authors (2024)

Next, the collective CSD corresponding to each CI and KE will be presented.

Negative perception of guidelines

I felt that the guidance was poor, very vague and left many questions unanswered. I think they should have given more explanations and that the hospital discharge should have been more elaborate. I had the impression that the team talked to each other, but they didn't give me clear information, they just said that the patient would leave with the tube. I missed the team's attitude and the assistance directed at me as a caregiver. The guidance was terrible, it seemed that each professional followed it on their own, without any guidance. There was no team, they didn't explain anything to me. They simply informed me that the patient had been discharged and that she should return after six months, without any other explanation about the necessary care [CSD].

Positive perception of the guidelines

I received very good guidance, everything was explained clearly and in detail. I had no doubts, as the information was conveyed accurately and reinforced whenever necessary. They explained everything at all times, ensuring that I understood every aspect of the care. The instructions regarding the medications were very clear, and the doctor who performed the surgery not only explained

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but also provided all the instructions in writing, which was essential for my safety and for the continuity of home care. This support gave me the confidence to take care of myself correctly, knowing exactly what needed to be done.

The CSD reflect opposing perceptions about the guidelines for hospital discharge. While some caregivers reported clear and satisfactory information, others described the guidelines as vague, insufficient or non-existent, generating insecurity in home care. The lack of communication and team fragmentation were highlighted as challenges, highlighting the need to standardize guidelines, strengthen interdisciplinary communication and ensure the active involvement of nursing for safer and more effective home care.

DISCUSSION

When analyzing the results of this study based on the sociodemographic and clinical profile of caregivers of elderly people who were discharged from hospital in the last 30 days, a predominance of females was observed, reinforcing the social role culturally attributed to women of taking care of the home and looking after the health of their family members. [13]

The responsibility for care falls on individuals in the productive and reproductive phase of life. However, the significant presence of caregivers in older age groups highlights a scenario in which elderly people care for other elderly people. As age advances, it is natural for physical, social and psychological changes to occur, making these caregivers also vulnerable and often in need of support. This finding reinforces the importance of strategies aimed at caring for the caregiver, especially when they themselves are already at a stage of life that may require assistance. [13-14]

The analysis of the participants' level of education revealed that the majority had completed secondary education or had not completed higher education, indicating a relatively high level of education among caregivers. This finding does not corroborate other studies, which often indicate low levels of education among caregivers, which may impact the understanding and implementation of health guidelines. [13-14]

Despite this higher educational profile, a significant number of caregivers reported not having received adequate instruction on home care. This finding is concerning, since adequate guidance is essential to promote the recovery of the elderly person's functionality and prevent new hospitalizations. The fact that a potentially more educated group of caregivers still reported difficulties shows that the gap in communication between health professionals and caregivers goes beyond educational level, reinforcing the need for more effective strategies for transmitting information and supporting home care.

Proper planning of hospital discharge plays a fundamental role in the patient's recovery in a more humanized way, promoting not only their rehabilitation, but also the well-being of the caregiver. [1,4-5] The lack of such planning can result in a higher risk of health complications at home and an increase in stress and burden on the caregiver. Elderly people, due to functional losses associated with aging, are more susceptible to readmission, a risk that is aggravated by hospitalization. [15] However, many of these hospitalizations and readmissions could be prevented with a better understanding of post-discharge complications and with effective strategies for guiding and supporting caregivers. [1,4-5,8]

Studies indicate that when the hospital service meets this need during hospitalization, risks at home are reduced. [1] During this period, the nurse plays an essential role in providing care to the patient together with their family members, allowing them to clarify doubts and actively participate in the care process. This involvement favors the acquisition of security and autonomy by caregivers, contributing to a more efficient and safe continuity of care after returning home. [1,4-5]

The analysis of the health conditions of caregivers revealed that the majority had comorbidities, and a significant portion used antidepressants, suggesting a direct impact on the mental and physical health of these individuals. Continuous care for a dependent elderly person, especially without adequate support, can generate overload and increase the vulnerability of the caregiver, making them more likely to develop problems such as depression, anxiety and deterioration of general health. [14,16]

Furthermore, this overload can lead to the use of substances such as hypnotics, anxiolytics and tobacco, reflecting inadequate strategies for dealing with stress. The lack of support reinforces this cycle of vulnerability, highlighting the need for policies and interventions that promote adequate assistance and support for caregivers, ensuring both their quality of life and the continuity of care for the elderly. [13-14,16]

The study revealed that most caregivers also perform other activities, which increases the risk of overload and predisposition to mental illness. The double work shift is often driven by social factors, such as the lack of financial resources to hire a caregiver, leading family members to take turns caring for the elderly. [13-14,16]

Furthermore, since caregiving is usually the responsibility of women, many face a triple shift, balancing formal work, childcare and caring for dependent elderly people. This accumulation of responsibilities increases physical and emotional exhaustion, making it essential for the healthcare team to be attentive to the well-be-

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ing of caregivers, especially those who perform multiple functions, ensuring support and strategies to minimize the impacts of this overload. [13-14,16]

The statements highlighted communication failures, with reports of caregivers receiving little or no explanation about appropriate practices, especially when handling specific procedures, such as catheters. These gaps in guidance can compromise the quality of home care, making it difficult for caregivers to adapt to the patient's needs and increasing the risk of preventable complications. In view of this, it is essential to improve communication and ensure that information about care is transmitted in a clear and accessible manner, ensuring a safer transition from hospital to home. [8,17]

It is essential to recognize that most caregivers do not have technical training and are far removed from the routine and practices of health services, which can generate insecurity when taking on home care. Therefore, hospital discharge planning must go beyond the simple transfer of responsibility, and must be structured with an educational approach that includes clear explanations, practical training and support materials to ensure the assimilation of information. [17] In addition, the health team must consider the individual difficulties of caregivers, such as health literacy, emotional overload and physical limitations, promoting an accessible and humanized guidance process. [8]

The caregivers' statements reveal discrepancies in their perception of the explanations and guidance received. Although some reported adequate information, this was not enough to ensure the continuity of home care in a safe and effective manner. This reinforces the need for a structured hospital discharge plan that includes strategies to promote patient self-care and caregiver training, reducing insecurity and preventing readmissions.

When developing a care plan, it is essential to recognize the importance of the nursing professional, who remains by the patient's side 24 hours a day during hospitalization and plays a central role in transmitting information about the necessary care.

> “Hospital discharge should be accompanied by clear and detailed instructions, ensuring that the caregiver is aware of the essential procedures for home care. [1,4-5] ”

This study has limitations such as the small sample size (N=20) and the fact that the research was conducted in a single municipality, which may limit the generalization of the results to other populations and regions of the country. However, the findings highlight critical points about the need to strengthen communication at hospital discharge and ensure effective support for caregivers.

CONCLUSION

The findings of this research highlight the need for a structured program to plan the hospital discharge of elderly individuals, considering the increase in longevity and the growing demand for care for elderly individuals with a higher degree of dependency. Hospitalization often results in loss of functionality, insecurity and family burden, making coordination between hospital services and the health care network essential.

Primary Health Care plays a central role in this process, being the point of reference for the continuity of care at home. The hospital team must work in an integrated manner with Primary and Secondary Care services, ensuring that the demands of the elderly are directed correctly, minimizing the risk of complications and readmissions.

In addition, the preparation of the caregiver, whether family or professional, is essential for the safety and quality of home care. Understanding caregivers' perceptions about home care contributes to the creation of effective care protocols, especially for the nursing team.

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