

Palliative care in home care: Patient safety in use of medicines

RESUMO | Objetivo: Investigar os fatores associados à segurança dos pacientes em cuidados paliativos domiciliares quanto ao uso medicamentos. Método: Trata-se de um estudo exploratório, descritivo, com abordagem quantitativa, realizado com cuidadores familiares de indivíduos com doenças crônicas acompanhados na Unidade de Cuidados Paliativos e Tratamento da dor, em um hospital de referência em Recife - PE. A coleta de dados ocorreu por meio de entrevista, utilizando um roteiro semiestruturado. Os dados foram organizados em planilha construída no programa Microsoft Excel e analisados por meio de estatística descritiva. Resultados: Verificou-se que a maioria dos cuidadores mantém o armazenamento dos medicamentos longe do calor e da incidência do sol, além da verificação rotineira da validade antes da administração. Entretanto, 43,75% dos cuidadores não possuem o hábito de ler a bula e 50% referem, em algum momento, já ter trocado a medicação e/ou horário do remédio do paciente. Conclusões: Foi evidenciado a atenção no armazenamento dos medicamentos, porém há necessidade da implementação de estratégias para garantir a segurança na administração dos medicamentos no domicílio.

Descritores: Segurança do paciente; Cuidados paliativos; Assistência domiciliar; Conduta do tratamento medicamentoso; Cuidadores

ABSTRACT | Objective: To investigate the factors associated with patient safety in home palliative care regarding medication use. Method: This is an exploratory, descriptive study with a quantitative approach, carried out with family caregivers of individuals with chronic diseases followed up at the Palliative Care and Pain Treatment Unit (UCPD), in a referral hospital in Recife - PE. Data collection took place through interviews, using a semi-structured script. Data were organized in a spreadsheet built in Microsoft Excel and analyzed using descriptive statistics. Results: It was found that most caregivers keep medication storage away from heat and sunlight, in addition to routinely checking the validity before administration. However, 43.75% of caregivers do not have the habit of reading the leaflet and 50% report, at some point, having already changed the patient's medication and/or medication schedule. Conclusions: Attention to the storage of medicines was evidenced, but there is a need to implement strategies to ensure safety in the administration of medicines at home.

Keywords: Patient safety; Palliative care; Home care; Conduct of Drug Treatment; Caregivers.

RESUMEN | Objetivo: Investigar los factores asociados a la seguridad del paciente en cuidados paliativos domiciliarios en cuanto al uso de medicamentos. Método: Se trata de un estudio exploratorio, descriptivo, con abordaje cuantitativo, realizado con cuidadores familiares de personas con enfermedades crónicas acompañadas en la Unidad de Cuidados Paliativos y Tratamiento del Dolor (UCPD), en un hospital de referencia de Recife - PE. La recolección de datos ocurrió a través de entrevistas, utilizando un guión semiestructurado. Los datos se organizaron en una hoja de cálculo construida en Microsoft Excel y se analizaron mediante estadística descriptiva. Resultados: Se constató que la mayoría de los cuidadores mantienen el almacenamiento de medicamentos alejado del calor y la luz solar, además de verificar rutinariamente la validez antes de la administración. Sin embargo, el 43,75% de los cuidadores no tiene el hábito de leer el prospecto y el 50% refiere, en algún momento, haber cambiado ya la medicación y/o el horario de medicación del paciente. Conclusiones: Se evidenció atención al almacenamiento de medicamentos, pero existe la necesidad de implementar estrategias para garantizar la seguridad en la administración de medicamentos en el domicilio.

Palabras claves: Seguridad del paciente; Cuidados paliativos; Cuidados en el hogar; Conducta de Tratamiento de Drogas; Cuidadores.

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INTRODUCTION

In recent decades, factors associated with patient safety have become the focus of several discussions in the health area. In this context, there is an increase in risks and the occurrence of adverse events that cause damage or even death to patients. Therefore, it is essential to broaden the discussions on this topic, considering the improvement of the quality of health care in the home environment.^{1,2}

In home care, palliative care is a challenging scenario, since it imposes the need for multidisciplinary care to patients facing life-threatening diseases, and it is essential to guarantee comprehensive care and the continuity of the care process for these patients.⁴

On the other hand, health professionals face difficulties in the face of the growing demand for care of terminally ill patients, emphasizing the need to train the multidisciplinary team, especially the nursing team, recognizing the importance of differentiated, humanized care, supporting the individual and the family throughout the disease process.⁴

In this scenario, palliative care favors a new look at the care of these patients and, in addition to promoting the necessary assistance to the sick person, professionals should direct their efforts to family members and/or related people, offering support and guidance, with the aim of promoting continuity of care, ensuring a reduction in the incidence of risks and complications.⁵

Therefore, family caregivers play an essential role in maintaining the lives of individuals who need palliative care, however they have little training or preparation for caring. In addition to physical care, caregivers are also involved in various activities aimed at the well-being and safety of the patient, such as feeding, handling and administering medications, transport

and handling household activities.⁵

From this perspective, the desire to carry out this research came from the following guiding question: What are the actions taken at home by caregivers to ensure safety in medication

on medicines.

In view of the above, this study aims to: Investigate factors associated with patient safety in home palliative care regarding medication use.

METHOD

This is an exploratory, descriptive study with a quantitative approach, carried out with family caregivers of individuals with chronic diseases followed up at the Palliative Care and Pain Treatment Unit (UCPD - Unidade de Cuidados Paliativos e Tratamento da Dor), in a referral hospital in Recife - PE. The UCPD is formed by a multidisciplinary team composed of palliative physicians, an acupuncturist, nurses, nursing technicians, social workers, nutritionists, physiotherapists, psychologists, speech therapists, who care for patients discharged from internment at the service or those referred from other specialized services, as long as they live in their area of coverage, with a diagnosis of terminality in oncology, infectology, neurology and geriatrics.

Participants were selected by sampling, and the following inclusion criteria were listed: family caregivers of both sexes, over 18 years of age and who were at home at the time of the home visit. Patients who did not depend on the caregiver to perform activities of daily living, non-family caregivers and those with incomplete addresses in the records were excluded. Therefore, 16 family caregivers participated in this study.

Data collection was carried out from December/2014 to April/2015, at the patients' homes, previously scheduled according to the service's home visits. Data collection took place through interviews, using a semi-structured script, containing questions about the sociodemographic characteristics of family caregivers, medical diagnoses of patients, as well as as-



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processes? Thus, this theme is of paramount importance, as it seeks to deepen the discussions about palliative care in the context of home care, as well as to enable a reflection on the care developed by family caregivers,

pects related to patient safety at home, such as packaging, handling and administration of medications.

Data were organized in a spreadsheet built in Microsoft Excel and analyzed using descriptive statistics. The study complied with the ethical precepts of Resolution 466/12 of the National Health Council, under Opinion Number: 986,416.

RESULTS

Regarding the caregivers' socioeconomic and demographic data, they are represented in table 1 below:

The most frequent age group was from 51 to 60 years old, which corresponds to 43.75% of the sample, with an average age of 53.12 years. As for occupation, 43.75% were housewives, followed by 18.75% being teachers. Most family caregivers (31.25%) had incomplete elementary education. Most of the interviewees were married or in a stable relationship (62.5%). (Table 1).

The degree of kinship, which establishes the bond between family caregivers and their patients, showed that children are prevalent in this type of care (65.25%), followed by spouses (18.75%), nephews (12.5%) and other family members (12.5%).

To better understand the clinical profile of patients in palliative care, the following table was prepared (Table 2):

Among the research findings, the clinical diagnoses of patients in palliative care at home were: geriatric, oncological, neurological and infectology patients, geriatric pathologies being prevalent (43.75%), having advanced severe dementia as the most frequent disease (25%), followed by oncological pathologies (37.5%) which, among them, was notorious for the supremacy of prostate cancer (Table 2).

Table 3 contains the statements

Table 1 – Socioeconomic and demographic characterization of family caregivers. Recife, PE, Brazil, 2015.

Socioeconomic and Demographic Variables	Frequency	Percentage
Caregiver's gender		
Female	14	87,5
Male	02	12,5
Age group		
20-30	01	6,25
31-40	01	6,25
41-50	03	18,75
51-60	07	43,75
61-71	04	25,0
Occupation		
Housewife	07	43,75
Professor	03	18,75
Housekeeper	02	12,5
Retired	01	6,25
Administrative Assistant	01	6,25
Sales manager	01	6,25
Student	01	6,25
Education		
Illiterate	01	46,25
Incomplete Elementary School	05	31,25
Complete Elementary School	03	18,75
Complete High School	04	25,0
Complete Higher Education	02	12,5
Post-graduation	01	6,25
Marital Status		
Married	10	62,5
Single	05	31,25
Widow(er)	01	6,25

Source: survey data, 2015.

that family caregivers reported regarding the packaging, handling and administration of medications performed by them at home.

It appears that the vast majority report storing medicines away from heat and sunlight, followed by the predominance of the number of caregivers who check the validity of medications

before administering them, however, a significant number are not used to reading the package insert of the medications used by their patients.

When asked about the distribution of medication, 81.25% of caregivers reported following medical guidelines regarding the time of medication administration. However, 50% of

respondents reported, at some point, having already changed the patient's medication and/or medication schedule.

DISCUSSION

The findings of this research corroborate with other studies 6,7, in which the prevalence of the female gender in caring is dominant, despite the increasing participation of men in recent times. Historically, the woman assumes centrality as a representative of care, whether with the house or with the family. In relation to men, they usually participate in the care in a secondary way, through financial help or external activities.⁷

Considering the data collection time of this research, it is noteworthy that the profile of caregivers is similar to that of other recent studies^{8,9,10,11}, highlighting that such caregivers are more prone to the negative impact of care because the greater wear and tear and overload¹², it can make it difficult to provide care, especially if patients are dependent, reflecting on patient safety.¹³ On the other hand, some authors claim that younger caregivers are more vulnerable to having a greater impact on caregiving actions, as their professional and social life is often affected by such activity.¹¹

When the caregiver performs other activities, in addition to the care provided to the patient, these can bring him/her benefits, as the possibility of alternating activities usually provides an opportunity to rest from direct tasks with the patient, in addition to favoring social interaction, minimizing problems such as isolation, anguish or depression.¹⁴ These findings are not found in the current research, since most caregivers are housewives, having no other occupation. This fact can contribute to the financial difficulty of these caregivers, reducing family income, which is often insufficient to

Table 2 - Clinical Diagnosis of patients in palliative care assisted by the UCPD. Recife – PE, 2015.

Diagnosics	Frequency	Percentage
Geriatrics		
Advanced severe dementia	04	25,0
Parkinson's disease	02	12,5
Alzheimer	01	6,25
Oncology		
Prostate cancer	02	12,5
Breast cancer	01	6,25
Kidney cancer	01	6,25
Ovary cancer	01	6,25
Stomach cancer	01	6,25
Neurological		
Severe Stroke Sequelae	01	6,25
Severe Stroke Sequelae	01	6,25
Infectious diseases		
Advanced Chagas Disease	01	6,25
TOTAL	16	100%
Fonte: dados da pesquisa, 2015.		

meet the basic needs of the patient, let alone the members of a multi-generational family.

Regarding education, caregivers had incomplete elementary school education. Regarding the low level of education, this factor may present itself as a barrier during the performance of care, as many activities performed by caregivers require not only techniques and manual skills, but also specific knowledge. Therefore, it is essential to implement and develop educational practices, both at the hospital and home levels, aimed at these caregivers.¹⁵

It was found in studies that adult children assume the role and responsibility of being the caregivers of their family members, when they are single, widowed or when their spouse cannot play this role, for needing care, which can generate the feeling of moral obligation, making it necessary to make a

greater effort on both sides to re-signify relationships and develop strategies to alleviate the possible psychological suffering that this function will provide.⁶

In this study, all patients who were married had their female spouse as caregiver, which corroborates the findings of other studies, in which the fact of being a spouse often allows for greater support and emotional strengthening, giving new meaning to care.¹⁶

Regarding the profile of patients in palliative care, regarding the clinical diagnosis, the presence of chronic diseases is highlighted. Home care as an alternative for the chronic patient, especially in a terminal state, allows the optimization of hospital beds, benefiting other patients who need hospital care, with real possibilities of cure.³

The findings of this study contradict a research carried out in a home care service in southern Brazil, in which

ch the most prevalent diseases were advanced severe dementia, on the other hand, neoplasms in both studies were equally prevalent, occupying the second place of home hospitalizations. Home care appears to improve the care of this profile of patients who often end up saturating services that have the curative philosophy as a guide.¹⁷

Among the various activities performed by caregivers, there is medication administration, care related to handling, proper packaging and storage, seeking clarification on pharmacotherapy, among others.¹⁸

Considering medication administration as a practice of essential importance for patient safety, this activity requires attention from the caregiver, who needs to follow medical prescriptions, which often involve complex medication regimens, in addition to analyzing the need to administer medications. Such factors can compromise patient safety regarding the proposed treatment and influence the incorrect use of the medication, favoring adverse events.¹⁹

A problem constantly observed is the inadequate storage of medicines, associated with mixing with familiar medicines and the presence of an expired expiration date.²⁰ Results from another study²¹ contradict those of this research regarding the inadequate storage of medicines, which may be within reach of children or in places that predispose the drug to degradation, being exposed to humidity and high temperatures.

The existence of expired medications is common along with other medications that are being used by the patient at home, in addition to the lack of the family caregivers' habit of reading the medication package insert before offering them to patients. This fact opposes the research findings, which in both cases more than half of the interviewees check the vanity date

Table 3 - Packaging, handling and administration of medications performed by family caregivers. Recife, PE, Brazil, 2015.

Variables	Frequency	Percentage
Are Medications protected from heat and sunlight?		
Yes	15	93,75
No	01	6,25
Do you usually check the expiry date of medicines before offering them?		
Yes	14	87,5
No	02	12,5
Do you usually read the patient's medication leaflet?		
Yes	09	56,25
No	07	43,75
Is the patient offered any medication that is not prescribed?		
Yes	06	37,5
No	10	62,5
Is the medication schedule distributed according to medical advice?		
Yes	13	81,25
No	03	18,75
After the administration of any medication, did the patient present any complaints?		
Yes	05	31,25
No	11	68,75
Has the patient's medication and/or medication schedule been changed?		
Yes	08	50,0
No	08	50,0

Source: survey data, 2015.

and read the package insert of the drugs prescribed to patients, before they are administered.¹⁸

Given the above, family caregivers play a central role in the safe use of medications. Involvement and active participation in care implies the clarification of their doubts and concerns, as well as knowledge of the medicines they use and why, always highlighting the importance of not administering any medication to the patient that is not prescribed and correctly following the distribution of medication schedules followed by doctors, they should also always be aware of the possible side effects of medications, passing on any complaints after the use of any

medication to the health team.^{18,20}

All participants in this research had in common the use of some type of medication at home. It is evident that this is a very relevant variable, as the use of drugs alone or in combination and their side effects are factors that favor the risk of falls, which can also occur due to inappropriate dosages, adverse effects and drug interactions. Thus, it is important that the professional, when guiding the use of drugs, prepare an individualized care plan establishing a careful assessment of the relationship between drugs and the patient's health situation: encompassing from what they understand about medications and covering clinical

cal and nutritional status.²²

CONCLUSION

The characterization of caregivers and patients facilitates the understanding of the context of the care process at home and helps to identify some needs and weaknesses to which nur-

ses can direct their attention, choosing priorities in their work. As for the factors that predispose to patient safety at home, attention to the storage of medicines was evidenced, but this research identified the need to implement strategies to ensure safety in the administration of medicines at home. The limitations of the study are related

to the number of participants interviewed, as well as the conduction of the research in a single health institution. This research contributes to the discussion of new scientific productions about patient safety in palliative home care and the implementation of actions with a positive impact on home care. 🐦

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