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Research Article

Role of caregivers: construction of clinical pathway by specialised nurses

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Abstract

Background: greater longevity raises challenges in several areas, including health and care provision. With advancing age, many morbidities and co-morbidities arise, leading to a higher rate of dependency and a greater need for formal or informal care.
Objective: to assess the perception of a group of specialist nurses about the care provider's role.
Methodology: an exploratory and descriptive qualitative study was designed. As a data collection technique, a focus group was used through an intentional sample consisting of 13 EEEMC. The data was categorized by consensus based on the content analysis technique and Bardin's assumptions.
Results: the content analysis created six categories and two subcategories. In all of them, concordant validations were obtained, revealing that nurses valued the domains above. The roles of caregiver, caregiver stress, and caregiver potential to take care of, were cited as key domains in the decision-making process. On the other hand, the domains of family process, support and continuity of care were understood as secondary but essential to ensure continuity of care.
Conclusion: the results reveal that EEEMC unanimously values care providers in the context of hospitalization.

Keywords: caregivers; nursing; medical-surgical nursing; hospitalization

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Introdution

The increase in average life expectancy has been a prevalent trend. The 2018-2020 triennium balance sheet revealed that for each decade, there was an increase of 1.77 years of life for the total population (Instituto Nacional de Estatística [INE], 2023). The increase in longevity of society is creating different challenges in various areas, including health and the provision of care. Naturally, with advancing age, many morbidities and co-morbidities arise in the human body, and consequently, there is a higher dependency rate. This is associated with a greater need for formal or informal care (Sequeira, 2018).

Background

For the Portuguese State, an informal carer is someone who looks after someone in a situation of dependency on a regular or permanent basis. It differentiates the concept of main or non-main informal carer according to the remuneration for providing care. However, there is no correlation with academic preparation for this purpose. On the other hand, the same source refers to formal carers as those who are duly qualified and trained to provide professional care (República Portuguesa, 2021).

The role of the caregiver is of such importance that in 2019, the Portuguese State approved the Informal Carer Statute (Lei n.º 100/2019). This establishes the duties and rights of both carers and dependent family members. It should be noted that the rights of carers include strategies aimed at maximizing the carer's literacy as well as their physical and mental well-being. Identifying a carer is not always straightforward, as it is a dynamic process, depending on social, professional, emotional, and economic factors (Guimarães et al., 2020). Carers are essential sources of support for the dependent person, taking responsibility for most of the care (Aman et al., 2020). They are also considered to be the backbone of health and social care services worldwide (Zarzycki et al., 2023). Given the importance of the carer's role, it is important to define the concept. The European Association Working for Carers (2023) uses the definition of an individual who provides care without financial compensation to a person with a chronic illness, disability, or permanent care outside of their professional context (European Association Working for Carers, 2023). The International Council of Nurses (ICN), in 2019, defines a carer, as an individual who assists in the identification, prevention, or treatment of illness or disability, or who attends to the needs of a dependent person (ICN, 2019). Throughout this work, the term caregiver will be used in favor of the terms family carer and/or carer, as it is intended to include all those who, in addition to the consanguineous bond, can take on the role of caring for a dependent person. Caring for a person with dependency requires the carer to fulfill a role for which they do not always have the resources or skills to guarantee effective care. (Observatório Nacional de Luta Contra a Pobreza, 2020). Performing the role of carer has implications for health, work, and social activities that impact their well-being (Kong et al., 2021; Santos et al., 2023). Most carers consider that they do it out of obligation and not out of a sense of family responsibility (Nightingale, 2011).

The experience of caring can put the carer in an uncomfortable position. Not only because of the abandonment of their life project but also because of the low levels of literacy that prevent them from providing safe and informed care. There are few studies investigating the literacy of carers, but Li et al. (2020) indicate that around 65.3% of informal carers have insufficient levels of health literacy. The lack of knowledge is associated with the burden felt by informal carers. The study by Dixe and Querido (2020) shows that increased training/information for carers reduces feelings of burden and increases the quality of the services they provide

(Dixe & Querido, 2020). The work of Ángel-García and his collaborators (2020) corroborates the idea that there is a negative correlation between the low skills of the informal carer and the burden felt by them (Ángel-Garcia et al., 2020).

Taking on the role of carer is a challenging and demanding experience, implying a set of requirements and the consideration of countless variables, with a view to the needs of the dependent person (Nunes et al., 2024).

In light of the transitions model by Meleis and colleagues (2000), taking on the role of a carer refers to a situational transition with the possibility of multidimensional and complex patterns, which are not always experienced exclusively. Like all transitions, it is an individual experience with the recognition of what has changed and the reorganization of the new role over time. The level of involvement of the carer in this new role determines the degree of their commitment to the process (Meleis et al., 2000).

In this adaptation, the caregiver uses adaptive mechanisms that allow them to get closer to performing the new role, known as coping strategies, allowing the family carer to deal with threatening/challenging situations (Melo et al., 2021). According to Sequeira (2018), the strategies used by carers are related to their level of education, cognitive ability, knowledge, life experiences, social skills, social support, motivation, health, personality factors, self-concept, and self-esteem (Sequeira, 2018). Recently, it has been identified that carers use strategies such as active coping, planning, and religion more regularly (Melo et al., 2021). These may or may not be effective, so they can be understood by professionals as indicators of the transition process.

The family often plays the role of carer. And situations in which the family is faced with the need to look after one of its dependent members, especially in prolonged situations, are a potential crisis scenario (Petronilho, 2007). It is, therefore, crucial to identify factors related to the overload felt by carers. It is not uncommon for this overload, which generates stress, to be related to a lack of preparation for these carers to fulfill their role (Dixe & Querido, 2020). The moment of hospitalization, whether due to exacerbation or caregiver rest, can be interpreted as a critical event that promotes change. The moment of hospitalization is the caregiver's preparation (Dixe & Querido, 2020). Lacerda and his team corroborate the importance of nursing professionals in empowering carers but stress that turnover among professionals is cited by carers as a factor of dissatisfaction (Lacerda et al., 2021). However, nurses should not only focus on empowering carers but also on their emotional well-being (Melo et al., 2021). In 2019, stress was defined by the ICN, as the feeling of being under pressure and anxiety to the point of being unable to function adequately physically and mentally, feeling of discomfort associated with unpleasant experiences associated with pain, feeling of being physically and mentally tired, disturbance of the mental and physicalstate of the carer (ICN, 2019). Performing the role of carer can be time-consuming and exhausting, generating negative consequences associated with caring (Melo et al., 2021).

The aim of this study is to assess the perception of a group of nurses specializing in medical-surgical nursing about the role of the caregiver in a hospital setting. It is hoped that this process will improve the quality of care provided in the preparation and/or support of caregivers in this context.

Methodology

The present study is based on the paradigm of an exploratory and descriptive qualitative study, following the criteria recommended by the Consolidated Criteria for Reporting Qualitative Studies (COREQ) (Tong et al., 2007). It is intended to answer the following research question: Which nursing domains are relevant in the training of the care provider?

As a data collection technique, a focus group was used. For the composition of the groups, the number, homogeneity, and heterogeneity of the participants were taken into account (Henriques et al., 2021). Thus, the sample was intentional and composed of 13 nurse participants (EEEMC) with functions in the provision of care. Nurses with exclusive management functions were excluded. The characterization of the sample is heterogeneous in the experiences of these specialist nurses, as they represent miscellaneous areas of intervention in hospital care. However, the objective was to obtain a greater representation of the specialty, in the various departments of the hospital unit. Thus, after the identification of the EEEMC of the hospital unit, professionals who met the inclusion criteria and who had more than five years of professional experience as specialist nurses in a hospital context.

The moments of data collection were previously prepared and organized. They took place at two different times with different participants (between April and May 2022), in a university hospital in the north of Portugal. In the moments of contact with the EEEMC, semi-structured interviews were used, guided by classified terminology, whose organization reflected the result of the literature consulted. These interviews followed the organization expressed in the planned proposal and were conducted by the moderator. A rapporteur was also involved to ensure compliance with all the guidelines for the success of the interviews. At the end of both moments, the moderator summarized the central points of discussion. Reinforcing the validation of the data collected, an online questionnaire was subsequently sent to all participants. Subsequently, the thematic-categorical content analysis was carried out, consisting of three chronological poles: pre-analysis, exploration of the material and treatment of the results, inference, and interpretation (Bardin, 2013). Given the objective of the study, categories and subcategories were defined and the information was organized through the registration units. In the final step, the results were interpreted to answer the research question.

Participants freely expressed their contribution based on their experiences and knowledge, guided by the organization of the interview. All ethical assumptions inherent to the research process were safeguarded. The present study has received approval by the ethics committee of the hospital unit where it is integrated with the reference: 2023.188(157-DEFI/149-CE).

Results

The EEEMC sample used had in common the direct provision of care, although in different hospital services: Medical hospitalization, cardiology, intensive care, nephrology, neurosurgery, vascular surgery, general surgery, neurology, urology, emergency service, and surgical clinic. Their ages ranged from 30 to 50 years, and their professional experience was more than a decade, as can be seen in table 1.

Table 1 Sample characterization

Age group	**Number**	**Year of expertise**	**Number**
30 – 40 years	8	≤ 10 years	0
41 – 50 years	3	10-20 years	9
≥ 51 years	2	≥ 20 years	4
Total	13	Total	13

Regarding the data collected, there was initially a discussion about the moment of evaluation of the care provider. In compliance with the hospital standard, it was unanimous that the care provider should be identified upon admission to the hospital unit, with a stay of more than 48 hours, in the "initial assessment" of the computer system in use.

However, even "during hospitalization, the patient's condition may change and therefore the need for a caregiver may arise" (P8). There are also situations in which "the provider has to be replaced either due to physical or mental weaknesses" (P5). However, "the condition of the user himself may vary and needs may arise that did not exist before" (P1). In this way, it was established from the outset that the care provider and, subsequently the beginning of the clinical path, would be at the time of admission to the hospital unit with a stay of more than 48 hours, but also, whenever the user's condition changes. These conditions were designated as mandatory conditions, for the beginning of the clinical path.

After content analysis, the results were organized into categories and subcategories, as shown in table 2.

Table 2 Schematic representation of categories and subcategories

CATEGORIES	**SUBCATEGORIES**	**Data validation**	
		Number of participants	**Percentage**
Care Provider Role		13	100%
Caregiver stress			
Potential to take care	Knowledge to take care of		
	Ability to take care		
Family process			
Support			
Continuity of care			

The caregiver role category is considered by all participants to be key to understanding the carer's willingness to take care. With the evaluation of this domain, "it is quickly understood whether or not the person identified for the role of provider is oriented to the function" (P6). There are many cases in which the "person accepts to be a care provider, but has no real notion of what this implies, having a moment of confrontation is important to sensitize the caregiver" (P3). However, this moment of confrontation can be stressful. "The psychological condition of the provider is essential to determine the future of care; the person may not be well, but with support, whether from professionals or peers, he or she may be able to remain a provider" (P10). The categories of support and continuity of care were enunciated by several elements at the time of the discussion of the stress category. Another relevant aspect to highlight is the consistency of the participants in defining that the categories role of caregiver and stress of caregiver only make sense if there is previous experience in the performance of caregiver functions.

If the provider is starting the process, the participants considered that it would make sense to understand the potential of the provider to take care of it, "we have to understand what he knows or even if he has the skills" (P9). Often, "the caregiver says he knows and does, but when he is evaluated by a nurse we realize that it will not be so much" (P7). Again, in the discussion of this category, the reference to the category of support and continuity of care is widely raised. Transversally to the categories mentioned above, there is also the reference to the family and affective bond of the care provider to the hospitalized person. "Not all caregivers are family, but when they are, it is important to understand if there are other close family members who can also support" (P3), thus the family process category emerges.

Still, on knowledge and skills, it is relevant to underline that the participants pointed out, that the assessment of these domains is essential in care providers with and without experience. However, as a care provider with previous experience, the evaluation orientation should be according to the dependence of the hospitalized person. In the case of caregivers with experience it is necessary to evaluate "for each self-care that the user has compromised" (P9).

At the time of the review, it was noticed that the participants consider the following categories: role of caregiver, stress of caregiver, and potential to take care of as categories of greater importance. However, they do not discard the importance of the categories: family process, support, and continuity of care. The triangulation between the data obtained, the literature review carried out, and the use of classified language, a flowchart was designed in order to improve the understanding of the results (figure 1).

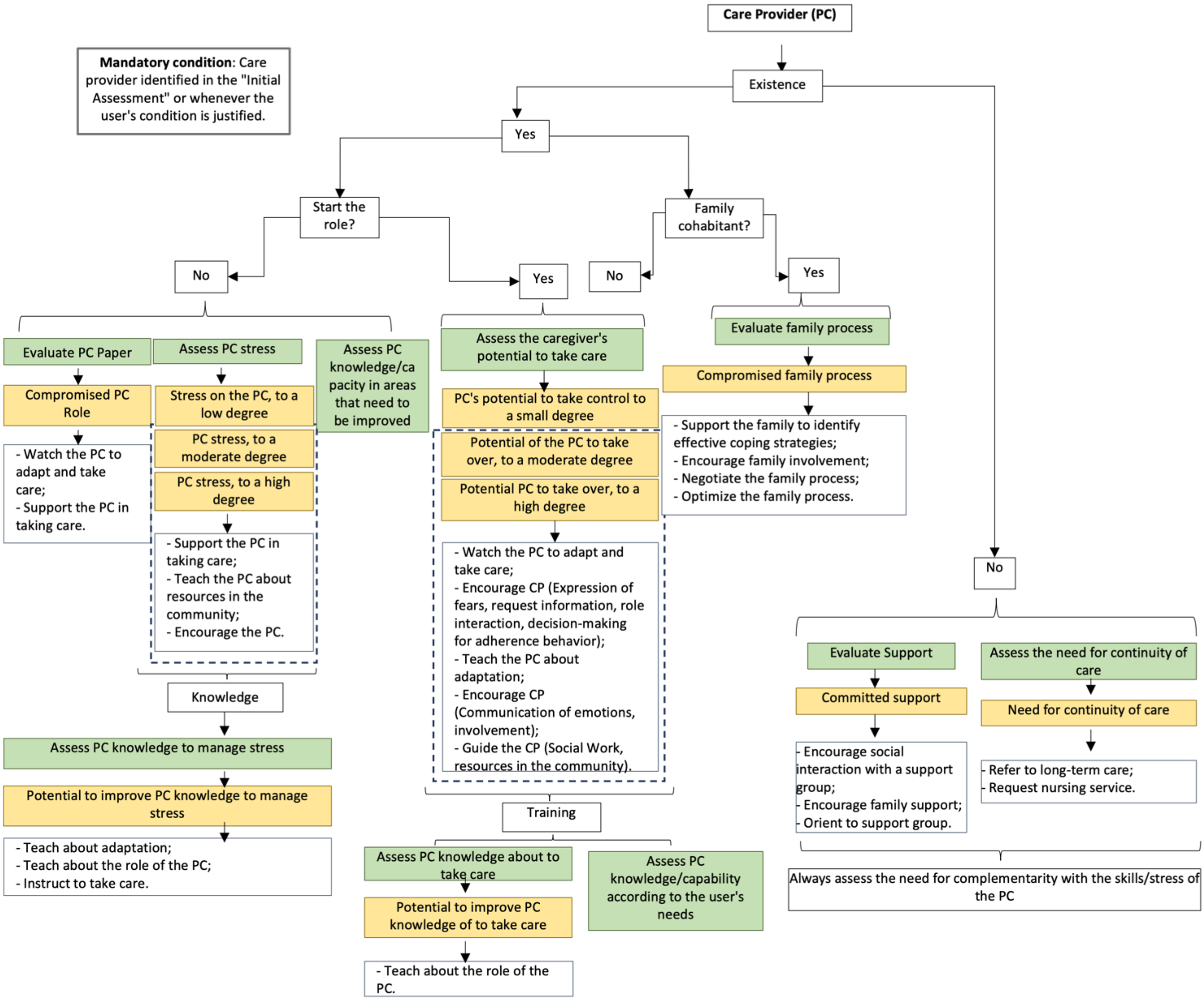

Figure 1 Clinical pathway

Discussion

For the nursing professionals who participated in this study, the consideration of the care provider was unanimous, and their effort to ensure the best care for the patient hospitalized at home was evidenced. The role of the caregiver requires total surrender and physical, emotional, and cognitive availability. Thinking of their role only as executors of instrumental and physical tasks such as food and hygiene is reductive (Martins, 2006). However, the demand for care and the costs of support services can overload and impair the performance of the caregiver (Lacerda et al., 2021; Sequeira, 2018). Regarding overload, we know that there may be a correlation with a decrease in skills (Melo et al., 2021). Thus, the need for training care providers becomes evident, giving them tools, for their reality of care.

The way carers provide care to their dependent family members is a reflection of their fears, uncertainties, and lack of knowledge and skills. Weaknesses that are reflected in greater overload (Petronilho, 2007). This overload translates into maladjustments in the care provided to the person with dependency. And, inevitably, this scenario culminates in a reduction in the quality of care (Sequeira, 2018). However, there is also a reduction in the caregiver's self-care. It would be important for them to understand their role and find strategies to strengthen their self-care, as well as finding ways of relief: social activities, turnover among family members, and spiritual activities (Nascimento et al., 2021). In this line of thought, the domains of family process and support stand out as support elements.

Studies show that there is a need to invest even more in the empowerment of caregivers, investing in more training throughout the hospitalization, thus reducing their burden and improving the care provided. The moment of hospitalization is important for the preparation of caregivers to perform their role (Melo et al., 2021). However, it is also necessary to ensure the proper passage of information between professionals, prioritizing the continuity of care outside the hospital (Dixe & Querido, 2020). This concern is mirrored in the domain: of continuity of care.

However, the structured support of health institutions is still punctual, a fact that conditions the training of caregivers, although it is evident that to ensure the quality of their performance, greater investment is needed (Sequeira, 2018). The trend will increasingly be to keep the person with dependence at home, with the support of care providers (informal caregivers) and to complement this care with formal health responses. However, the training of care providers is essential (Li et al., 2020; Melo et al., 2021; Kong et al., 2021; Zarzycki et al., 2023).

Conclusion

The relevance of the theme under analysis was adequate, current, and with an impact on the life and quality of life, both of the dependent person and their caregiver. Healthcare institutions have within their reach the promotion of strategies and interventions that drive the improvement of care provided by care-providers at in the home. context by care providers.

Many theoretical studies support the evidence of the domains necessary for training care providers, but few are those that reflect the real and effective practice of nurses. With this work, it was possible to realize that the EEEMCs primarily value the domains: role of the caregiver, stress of the caregiver, and potential to take care. However, they reinforce that the domains of family process, support, and continuity of care, will be complementary in the effective provision of care.

It is suggested that the development of studies that reflect clinical practice and promote change should be continued. The biggest limitation of this work is that it is exclusive to only one context, however, it can be replicated. Also, the sampling may not be representative.

Knowledge about nurses' perception of this theme, using classified language, also contributes to the standardization of nursing care documentation in a hospital context. The results obtained are easily framed in the computer system currently used in the hospital unit, and after the integration of these other implementations, follow-up studies may arise. Thus, the ambition is to achieve continuous improvement in quality standards.

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