Strategies to promote the training of informal caregivers: a qualitative study

Estrategias para promover la formación de los cuidadores informales: un estudio cualitativo

Liliana Ferraz[1]

Marco Gonçalves[1]

António Ferreira[2]

Telma Vidinha[3]

António Marques[1]

[1]MSc., Escola Superior de Enfermagem de Coimbra, Coimbra, Portugal

[2]MSc., Centro de Investigação, Inovação e Desenvolvimento em Enfermagem de Lisboa (CIDNUR), Lisboa, Portugal

[3]MSc., Unidade de Cuidados na Comunidade Coimbra Saúde, Unidade Local de Saúde de Coimbra, Coimbra, Portugal

Abstract

Background: the complexity associated with the empowerment process of informal caregivers results in changes in family dynamics, often underestimated by healthcare professionals, with potential negative consequences. Nurses are key facilitators in the transition process for hospitalized individuals and their families. However, the lack of early and appropriate interventions may hinder the empowerment process and compromise the development of a healthy transition.
Objective: to identify strategies that facilitate the empowerment of informal caregivers.
Methodology: an exploratory and descriptive study with a qualitative approach, conducted at a central hospital in Portugal. Nine nurses participated in semi-structured interviews, with data analyzed using NVivo 10® software. All ethical principles were upheld.
Results: seven categories of facilitating strategies emerged, subdivided into various subcategories, focusing on both nurses (training, competence, coordination) and nursing care processes.
Conclusion: the identified strategies can improve nursing care, fostering effective transitions and promoting the well-being and satisfaction of individuals and their informal caregivers.

Keywords: family; nursing; caregivers; transitional care

Resumen

Marco contextual: la complejidad asociada al proceso de capacitación del cuidador informal resulta en un conjunto de cambios en las dinámicas familiares, frecuentemente subestimados por los profesionales de

salud y con posibles consecuencias negativas. Los enfermeros son facilitadores clave en la transición de personas hospitalizadas y sus familias. Sin embargo, la ausencia de intervenciones tempranas y adecuadas puede perjudicar el proceso de capacitación y comprometer el desarrollo de una transición saludable.

Objetivos: identificar estrategias que faciliten la promoción del rol del cuidador informal.

Metodología: estudio exploratorio y descriptivo, con un enfoque cualitativo, realizado en un hospital central de Portugal. Nueve enfermeros participaron en entrevistas semiestructuradas, y los datos fueron analizados mediante el software NVivo 10®. Se respetaron todos los principios éticos.

Resultados: surgieron siete categorías de estrategias facilitadoras, subdivididas en varias subcategorías, con un enfoque tanto en los enfermeros (formación, competencia, articulación) como en los procesos de atención de enfermería.

Conclusión: las estrategias identificadas pueden mejorar la atención de enfermería, facilitando transiciones eficaces y promoviendo el bienestar y la satisfacción de las personas y sus cuidadores informales.

Palabras clave: familia; enfermería; cuidadores; cuidado de transición

Introdution

The aging population and growing prevalence of chronic diseases are leading to an increase in the number of people with functional and cognitive disabilities, posing a challenge for family caregivers of dependent people (Koopman et al., 2020).

It is estimated that by 2030 there will be 21.5 million informal caregivers over the age of 25 in the European Union providing at least 20 hours of care per week and 10.9 million providing at least 35 hours of care per week (Teixeira et al., 2016).

This issue has become relevant in political, social, and research areas (Teixeira, 2015), making informal caregivers increasingly important in healthcare. The delivery of quality care involves the integration of the informal caregiver as a participant in the decision-making process within a philosophy of care centered on the patient and the informal caregiver, both of whom are undergoing transitions that can be facilitated by the nurse's intervention (Marques, 2015; Teixeira, 2015). However, a recent study shows that informal caregivers are often regarded as a resource to facilitate patient discharge from hospitals, rather than as recipients of individualized nursing interventions (Nunes et al., 2022).

Despite the recognition of this phenomenon, in which nurses avoid training informal caregivers and prioritize more practical tasks focused on the dependent person (Nunes et al., 2022; Vidinha et al., 2024), the training of caregivers should be continuous and systematic so that they feel capable of providing patient care of greater or lesser complexity. Therefore, nurses must provide the tools, training, and interventions to ensure that caregivers can fulfill their role.

Considering that the training of informal caregivers requires the maximum availability, proximity, and systematic work of nurses, the main objective of this study is to identify facilitating strategies to promote the training of informal caregivers.

Background

Caregiver education programs should be a priority in health policies. These initiatives should include nurse-led strategies aimed at training caregivers. However, in the Portuguese health system, there are still

shortcomings in the solutions adopted by health institutions and in the social support provided to family caregivers. Policies remain too focused on the patient, neglecting family caregivers and their needs. There is also a lack of interventions that nurses can implement (Marques, 2015), as evidenced by a study conducted in a hospital setting that found that informal caregiver training was avoided in discharge planning (Vidinha et al., 2024). In a study carried out by França et al. (2023), which included the creation and implementation of a family caregiver support model, the authors concluded that professionals and institutions should invest more in informal caregiver training.

Nunes et al. (2022) revealed the complexity of the training process and the importance of nurses offering caregivers educational opportunities to improve competence, autonomy, and confidence. Caregivers who were more involved in hospital discharge planning reported better health and greater acceptance of their role (Bull et al., 2000).

Marques (2015) sought to understand informal caregivers' perspectives on whether nurse-led training during the hospitalization of a person with a stroke contributed to caregiver training. This study found that what nurses perceive as valid does not correspond to the informal caregivers' perspectives. Informal caregivers believe that their needs, abilities, previous experiences, and motivation are not taken into account, that training focused on instrumental care, and that teaching methodologies varied according to the nurse and not according to the caregivers' skills. They also perceive that, although nurses' understanding and availability were in line with the fundamental skills for the teaching-learning process, nurses also demonstrated contrary attitudes, such as haste and lack of interest. From the informal caregivers' perspective, training was very important, but insufficient.

Hui et al. (2022) explored the stressors and coping strategies of caregivers of people with dementia, concluding that health professionals should recognize these factors and consider the individual sociocultural needs of caregivers to safeguard their psychosocial well-being. The approach used in training caregivers should consider their specific needs, as well as help them with difficulties and understand the strategies they use (Chen et al., 2023).

Given the complex context of healthcare systems, where multiple factors influence the quality of care (Albsoul et al., 2021), it is essential to study this complexity and identify strategies that facilitate caregiver training. This requires an adaptive and holistic nursing intervention capable of addressing the challenges of caregivers and health professionals, promoting dynamic, contextualized, and sustainable solutions that make the caregiver training process more efficient.

This study aims to identify strategies that can respond to these needs, offering grounded solutions that contribute to improving caregiver training in the Portuguese health system.

Methodology

In order to answer the research question "What are the strategies for promoting the training of informal caregivers?", an exploratory study with a qualitative approach was conducted in a central hospital in central Portugal.

All the ethical assumptions were met, and a favorable opinion was obtained from the Ethics Committee (OBS.SF.116/2022).

The participants selected were nurses specialized in the field of nursing information and documentation systems and clinical practice, given that they could have a critical and comprehensive view of the phenomenon under study. Data saturation was reached with a sample of nine nurses.

Exploratory interviews were carried out using a semi-structured script developed by the researchers. The interviews were audio-recorded by two researchers, after written informed consent from the participants, and then transcribed verbatim. The audios were eliminated after transcription.

Data were analyzed using the method of questioning and systematic comparison using NVivo 10® software. Initially, coding was carried out, assigning preliminary codes to the relevant text segments. Subsequently, the categories were refined, and subcategories emerged from the comparative analysis. Triangulation was used to validate the categories and ensure the consistency of the findings.

Results

From this exploratory study, seven categories emerged regarding the strategies to be used by nurses to promote informal caregiver training. These categories and their subcategories are shown in table 1.

Table 1 Summary of the strategies used by nurses to promote informal caregiver training

CATEGORIES	SUBCATEGORIES
Systematization of the informal caregiver training process	Method for identifying the informal caregiver Family assessment of the dependent person Planning the return home Inclusion of the topic in the shift handover Operationalizing the informal caregiver training process Identifying the nurse's gains and motivation
Organization of nursing care by a liaison nurse	Identification and assessment of the informal caregiver's needs Responsibility for discharge planning Appreciation and timely preparation for discharge Closer nurse/patient/informal caregiver relationship Ensuring continuity of care
Training on the role of informal caregiver	Based on scientific evidence Reports from informal caregivers
Acquisition of communication skills for complex situations	
Need for specialist nurses to advise generalist nurses	
Importance of leadership in processes	Nurse leadership and empowerment Leaders who promote the process Leadership and resource allocation
Coordination with primary health care teams	

Six subcategories emerged from the systematization of the categories related to the informal caregiver training process: method for identifying the informal caregiver; family assessment of the dependent person; planning the return home; inclusion of the topic in the shift handover; operationalizing the informal caregiver training process; and identifying the nurse's gains and motivation.

The participants believe that the caregiver training process should be planned and included in the nurse's work plan. It should not be contextual and depend on chance: "the plan should be well-designed, well-defined, and the organizational methodologies, the method rather, should include this moment" (I1); "and be correctly included in the work plan, just like any other time for care delivery, so that it is not avoided" (I4).

A method should be used to identify the person who will take on the caregiver role to facilitate the process: "define a methodology for identification (of the provider) and how the caregiver is identified" (I1).

Once the informal caregiver has been identified, it is important to assess their conditions for taking on this role and to gain a thorough understanding of the family process. The nurse often has to deal with difficulties shared by the family member. This aspect should be worked on to facilitate their involvement: "to start preparing is at least to know more than just the internal structure. It's knowing how that family is organized" (I3).

"I think the first step should be to explore whether the person wants to become a caregiver and whether they have taken on or want to take on the role or not, and then, if they have taken it, explore what the person needs, and whether it is the right time to take on this role and in what areas" (I4).

The caregiver training process should occur early and promptly throughout the hospital stay, rather than close to the time of discharge, which is why it is critical to define time horizons.

"From a methodological point of view, there are a number of possibilities here (...) to create minimum time horizons, where the return home is in fact targeted (...) so that the intervention takes place as early as possible" (I1).

Another strategy identified by the interviewees was to address the process at shift handover, which allows the team to share difficulties and identify situations that can be resolved in the short term: "Because preparing for the return home is not on the agenda (...) it should be a mandatory item at the shift handover" (I9).

Regarding the operationalization of the informal caregiver training, the participants acknowledged the importance of creating formal and specific moments for this purpose to raise the family's awareness and prepare them for the transition after discharge.

"We must create the conditions with formal moments to really train this person. That's why I'm talking about the organization of care and the individual role (...) nurses set up interviews, call these people (...) to make sure that the conditions are in place for the person to take on this role or not" (I1).

According to the interviewees, the systematization of the informal caregiver training process might be easier if the nurses involved could see the benefits of their role in the process recognized by the institutions, increasing their professional motivation: "the systematization of these areas would also be important, if the areas to be trained, the areas to be developed, were properly systematized, and gains were well evaluated, then the professionals would feel more that their work is valued" (I5).

The category "Organization of nursing care by a liaison nurse" was subdivided into five subcategories: Identification and assessment of the informal caregiver's needs, Responsibility for discharge planning, Appreciation and timely preparation for discharge, Closer nurse/patient/informal caregiver relationship, and Ensuring continuity of care.

In general, the nurses interviewed consider the organization of nursing care by a liaison nurse to be the most appropriate at all levels, particularly in preparing the informal caregiver, as it allows for a closer relationship between the nurse and the family, facilitating the creation of a bond and a relationship of trust.

"We need a different method of organizing care, one that lets me know that I'm responsible for that family and for preparing that caregiver, and some attachment from the caregiver as well (...) having a liaison person, which is one of the criteria for a good indicator of a healthy transition, caregivers feeling connected to health professionals" (I3).

Several benefits have been attributed to the liaison nurse method. On the one hand, it allows for better identification of the caregivers and their needs: "a change in care methodology or switching to the liaison nurse, where we can immediately identify the informal caregiver and have a different perspective" (I6); and "we can identify caregivers' needs from the very first contact we have with them" (I6).

On the other hand, as mentioned above, it improves the relationship between the nurse and the family, making them accountable to a certain extent: "the relationship is also better (...) when there was no liaison nurse, one day it was one nurse, the other day it was another, when we trained, one day it was one nurse, the other day it was another, and there was no liaison person for the informal caregiver to talk to (...) In the past, we probably neglected it... no one was really responsible for identifying the informal caregiver, and now there is this concern" (I6).

In addition, the interviewees believe that the methodology can provide more timely preparation, that is, before the patient is discharged, as well as contribute to the continuity of care at home. "And maybe you can prepare them better and earlier" (I6); and "really identify who is going to continue caring for that person" (I6).

Another benefit attributed to this method of organizing nursing care is a greater appreciation of the moment of discharge, which should be prepared in the best possible way.

"I think there's no delay... I don't know, sometimes we can let it go for a day or two, but then we have to train the informal caregiver so that the patient can go home" (I6).

Two subcategories were identified in the "Training on the role of caregiver" category: Based on scientific evidence and Reports from informal caregivers.

The nurses interviewed believe that there should be more appropriate training for informal caregivers. This training should be based on in-depth theoretical knowledge of care design and constant update: "This should be an area of professional training, and constant update, you don't just read it once and acquire it, because families are constantly changing" (I4).

Strategies suggested to operationalize this professional training included the use of research results and the inclusion of reports from caregivers to make it more realistic: "one of the issues could be to analyze these studies and discuss them, for example, in training sessions" (I9); and "share the testimony of someone who has been an informal caregiver" (I9).

Participants also mentioned the importance of communication skills for complex situations so that nurses can characterize and understand the various family processes and get closer to the different family dynamics: "we need nurses with better communication skills and more comfortable being close to family members" (I3).

Another strategy to be used by nurses in the caregiver training process was specialist nurses advising generalist nurses, applying their specific skills in the process with a greater understanding of family processes and awareness of the training and research areas: "The intervention of the specialist and generalist nurses is and must be decisive. And the specialist nurse should take the lead in terms of bringing the team together to achieve a goal" (I1).

Three subcategories emerged from the "Importance of leadership in the process" category: Nurse leadership and empowerment, Leaders who promote the process, and Leadership and resource allocation.

The content analysis revealed the important role that leaders must play within their teams in order to prepare them for solid and informed decision-making throughout the caregiver training process, with an active and proactive attitude in providing the necessary resources for the process, especially human resources: "those responsible for operational management should give power to the nurses so that they feel comfortable in making decisions" (I1); "we need leaders who also question and help their nurses prepare the return home of these patients" (I3); and "the management, the top management, must understand that this is a necessity and that is something that takes time and it needs enough professionals" (I4).

Finally, the need for coordination with primary health care teams was emphasized, so that they can follow the process of return home and monitor it, also with the possibility of analyzing and discussing aspects with hospital teams: "better coordination with primary health care" (I3).

Discussion

The analysis of the results highlights the need for greater systematization of the informal caregiver training process, especially in nurse-led interventions. The definition of structured planning is crucial to ensure that informal caregivers receive the necessary training and support throughout the hospitalization and in preparation for their return home. Studies suggest that systematizing the training process significantly improves health outcomes and reduces the burden and stress of informal caregivers, namely through the implementation of models or programs (Andrade, 2014).

This approach is aligned with the need to consider the complexity of health systems, where multiple factors directly influence the quality of care (Albsoul et al., 2021). Recognizing this complexity and adopting adaptive and holistic strategies are essential for effective intervention. The creation of models and programs can facilitate this process by, for example, advocating for the early identification of informal caregivers and the assessment of their conditions to understand and assume this role (Dixe et al., 2020). Early preparation for the return home, with the definition of time horizons, and addressing this topic in shift handovers are recommended practices.

For example, Dixe et al. (2020) developed the "Informal Caregiver Training Model for Dependent Care" as an educational model for informal caregivers of dependent people. It emphasizes the importance of providing resources, training, and ongoing support to caregivers, taking into account their specific needs, abilities, and context. The aim is to improve the quality of care and the well-being of the caregiver and the patient, with strategies that include personalized educational interventions and the creation of a collaborative supportive environment between health professionals and caregivers.

Arranging opportunities for getting to know, involving, and training the informal caregiver is necessary, such as phone calls, meetings, and opportunities for active participation in care (Bull et al., 2000). In addition, the identification of gains, with quality indicators in these areas, will increase nurses' motivation (Vidinha et al., 2024).

The nurse liaison method has been suggested as a strategy for organizing care that allows for a more accurate identification of the informal caregiver, a stronger and closer relationship between nurse and family, and a more timely and continuous preparation of the informal caregiver. This method is also referred to in the literature as facilitating a smoother and more effective transition, enhancing the moment of discharge and promoting continuity of care at home (Chen et al., 2023; Parreira et al., 2021). It facilitates a more humanized approach that is less focused on the biomedical model, which is essential for the comprehensive training of caregivers (Parreira et al., 2021). However, the authors point out that this method relies heavily on nurses' qualifications and can cause greater emotional involvement and stress, requiring even more human resources.

Based on a comparative analysis with other care organization methods, this is the most complete method in terms of planning, autonomy, accountability, and continuity of care, promoting a high quality of care and satisfaction for both patients and their families/informal caregivers (Parreira et al., 2021).

This study also underlines the importance of ongoing enhancement of theoretical knowledge and constant updating of nurses for ensuring quality care, which is reinforced by the standards of the Portuguese Council of Nurses (Ordem dos Enfermeiros [OE]) and the Nursing Care Quality Standards (OE, 2001, 2015). Studies such as those by Meleis and Dean (2012) and Albsoul et al. (2021) reinforce the need for a solid theoretical basis for nursing practice, especially in complex contexts. Integrating research findings and practical examples, such as caregiver reports, can enrich training and professional practice, keeping nurses up to date and able to apply the latest knowledge in clinical practice (Teixeira et al., 2016).

Improving nurses' communication skills is also a key strategy for promoting the training of informal caregivers. Effective communication is often highlighted as a critical skill, particularly in complex contexts (Albsoul et al., 2021), and as a central component of the nursing process, with a direct impact on the caregiver training process. Studies and regulations advocate the need for communication training for nurses, as it is fundamental to improving the safety and quality of care, as well as the satisfaction of all those involved in care (Albsoul et al., 2021; Direção-Geral da Saúde [DGS], 2017; OE, 2015).

The intervention of specialist nurses is recognized as essential in advising generalist nurses. Specialization can promote a greater understanding of family processes and a greater awareness of critical areas such as training and research, ensuring a more holistic and grounded approach.

Nurse specialization has shown clear benefits in training caregivers. Studies have shown that appropriate education and support led by specialist nurses can significantly improve the physical and mental health of caregivers, as well as reducing the burden and stress associated with care (Tziaka et al., 2024).

Proactive and empowered leaders can, in turn, promote a work environment where nurses feel comfortable and supported in making clinical decisions, ensuring that the necessary human and material resources are available for effective training of informal caregivers. Cho et al. (2020) found that proactive nurse leaders who allocate resources appropriately contribute to a better quality of care and a lower incidence of missed care. In addition, strong leadership is associated with higher nurse satisfaction, which indirectly benefits caregivers (Koopman et al., 2020).

Coordination with Primary Health Care teams is vital for the continuity and monitoring of care after hospital discharge. Integrated policies and effective collaboration between health units can ensure that informal caregivers receive continuous and coordinated support, facilitating a safe and efficient transition to the home. Studies show that a close collaboration between different levels of care results in better continuity and coordination of care, improving patient outcomes and reducing informal caregiver burden (Nunes et al., 2022). Policies and guidelines that promote this integrative vision are needed to ensure an efficient and safe return home of hospitalized people (DGS, 2017).

Conclusion

This study identified several strategies to facilitate the training of informal caregivers, highlighting the importance of systematization and early structured planning of this process. The organization of nursing care through the nurse liaison method and continuous training are crucial to ensuring safe and efficient transitions. Effective communication, proactive leadership, and coordination with primary health care teams are key to ensuring continuity and quality of care, improving health outcomes for both the dependent person and their caregiver. Implementing these evidence-informed strategies contributes to a healthier transition, promoting patient satisfaction and well-being.

The results of this study highlight the need to develop and implement structured training programs for informal caregivers, which can be integrated into daily clinical nursing practice.

This study did not exhaust the strategies for training informal caregivers, and there are others that did not emerge from these data. Further and more comprehensive research should be conducted to better understand the dimension of the phenomenon of informal caregiver training at an institutional level. Future research should include larger and more diverse samples to validate and expand the results of this study.

Acknowledgments

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