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Palliative Care in the Home Environment: The Burden of the Informal Carer in Palliative Care

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ABSTRACT

This article derives from work developed within the scope of clinical teaching in the Nursing course, with the aim of fostering the development of professional skills and stimulating critical reflection on care practice. The experience reported focuses on the care provided by informal carers and the relationship established with the person being cared for, using as a theoretical and methodological reference the reflective cycle proposed by Graham Gibbs, published in 1988 in the book "Learning by Doing". Although the model consists of five distinct stages, the reflection presented adopts an integrated approach, allowing for an understanding of the process as a whole. This work was developed in the context of Clinical Teaching of Continuing and Palliative Care, constituting a pedagogical strategy aimed at promoting meaningful learning based on the practical experience of nursing students. The experience presented in this article is a student's informed reflection on her clinical teaching journey in the field of home palliative care and highlights the difficulties encountered in linking theory and practice.

Keywords

Informal Caregiver, Sick Person, Family, Informal Caregiver Burden (ICB), Evidence-Based Practice (EBP).

Introduction

People's homes seem to me to be the ideal setting for reflecting on their health. I am privileged in this regard, as I am developing my clinical teaching skills in a team of nurses who provide home care. When I talk about home, I am not referring to its most common meaning, that of an architectural structure, but rather to the social dynamics, spiritual energy and interpersonal environment that inhabit it, a metaphysical, immaterial home. A space where the spirit of protection, family life and personal achievements coexist. A home is the main setting for the most intimate relationships and all family dynamics. For me, as an outside observer, entering a patient's home is as rich, if not richer, than examining them physically in their entirety. There are houses and houses, there are houses that have a patient, there are houses that are, as a human dynamic, a patient. I encountered a house that constitutes, as a whole, a patient, and I chose to reflect on it.

The experience took place during Clinical Teaching in Continuing and Palliative Care, while accompanying the Home Palliative Care Team. The critical situation involved Mrs A., aged 68, who was providing long-term care for her husband, Mr J., aged 70, who had advanced Chronic Obstructive Pulmonary Disease (COPD) and was receiving palliative care.

Development

It was the third home visit of the day and, as usual, we parked the van near the patient's house, put on our gloves and headed for the door. As a fourth-year nursing student, I know that I will face a clinically or socially delicate situation when my clinical supervisor prepares me in advance for a particular context. Mr. J. is the patient and Mrs. A. is his wife and carer. We were welcomed by the carer, Mrs. A.

During this routine visit, as a nursing student focused on controlling Mr. J.'s dyspnoea and managing his medication, I noticed that Mrs. A. showed clear signs of exhaustion: physical fatigue, tearfulness, irritability, and an unkempt appearance. When asked about her own rest and nutrition, Mrs A. dismissed it, saying, ‘I can handle it, Nurse. He is the priority.’ She hurried the conversation back to her husband's symptoms, demonstrating a difficulty in focusing on her own needs. I quickly thought, who was caring for whom? Who needed care more at that moment?

At the time of observation, I felt a deep sense of anxiety and some helplessness. I felt frustrated by the lack of time and Mrs A.'s reluctance to verbalise her suffering. I thought: ‘I'm failing. I know she's at risk of burnout, but my intervention is too focused on the technical side and not on the relational side. How can I help?’

The reduced focus on the family, historically rooted in strict hospital rules and the belief that only the healthcare team has the power to make decisions, often leads the family to take a passive stance. This distancing and disregard for their opinions and values erodes the relationship of trust, compromising the quality of life of the whole family. In the home setting, which should be the ideal environment for applying the philosophy of palliative care centred on the person-family unit, the family unfortunately continues to be treated as a secondary focus, underestimating the impact of caregiver overload.

Upon returning to the health unit, among the various concerns raised by the care context, interest emerged in reflecting a little on the situation of the caregiver, Mrs. A., and on the relationship between the informal caregiver and the person being cared for – Mr. B. – particularly in the context of palliative and continuing care. Initially, it was considered essential to understand the characteristics necessary for an individual to acquire the status of informal caregiver. In this sense, when consulting the Practical Guide to the Status of Informal Caregivers, the following requirement was highlighted: “to be in adequate health to provide care to the person being cared for and to be available to provide such care”.

This condition, however, proves to be incomplete if we disregard the psycho-emotional dimension of health and interpret “availability” only in terms of time. In the case observed, Mrs. A. had a profound lack of mental health and emotional availability, which highlights the limitation of a narrow interpretation of this requirement.

In the same document, the Specific Intervention Plan for Caregivers establishes that it must include actions for ‘training, continuous education, and information that informal caregivers must attend and consult.’ However, in practice, informal carers are not adequately prepared to deal with the mental exhaustion resulting from caregiving. This fails to recognise the carer as a user — a vulnerable individual who needs support and monitoring.

In the same document, the Specific Intervention Plan for Caregivers establishes that it must include actions for “training, continuous education and information that the informal caregiver must attend and consult”. However, in practice, informal carers are not adequately prepared to deal with the mental exhaustion resulting from the act of caring. Thus, there is a failure to recognise the carer as a user as well.

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However, this condition proves incomplete if we disregard the psycho-emotional dimension of health and interpret “availability” solely in terms of time. In the case observed, Mrs A. had profound mental health issues and a lack of emotional availability, which highlights the limitations of a narrow interpretation of this requirement.

In the same document, the Specific Intervention Plan for Caregivers establishes that it must include actions for ‘training, continuous education, and information that informal caregivers must attend and consult.’ However, in practice, informal carers are not adequately prepared to deal with the mental exhaustion resulting from caregiving. This fails to recognise the carer as a user — a vulnerable individual who needs support and monitoring.

According to Decree-Law No. 101/2006, Art. 3, which regulates the National Network for Integrated Continuing Care, this is defined as ‘the set of sequential health and/or social support interventions, resulting from a joint assessment, focused on overall recovery understood as the therapeutic and social support process, active and continuous, which aims to promote autonomy, improving the functionality of the person in a situation of dependency, through their rehabilitation, readaptation and family and social reintegration’.

This definition reinforces the cultural conception that the user is the central element in the dynamics of care, often perceived as the most vulnerable subject and least responsible for their condition of dependency. In contrast, the carer is assigned the duty of tolerating behaviours such as constant (often unnecessary) calls, emotional outbursts or manipulative attitudes resulting from frustration with the state of health of the person being cared for.

However, when discussing the humanisation of care, it is imperative to extend this principle to informal carers as well. These individuals, often without specific training or prior experience, are suddenly compelled to take responsibility for the comprehensive care of another person, even to the detriment of their own self-care. They are responsible for meeting basic needs, dealing with emotional outbursts and, in many cases, performing technical procedures with precision, without proper professional support.

Therefore, it is essential to recognise informal carers as users of the health system, with their own needs for support and monitoring. Ignoring the prioritisation of these needs indirectly contributes to increased hospitalisation rates, since physical and emotional overload leads to exhaustion and an inability to maintain home care. Such negligence not only exacerbates human suffering, but also has a negative impact on the healthcare system, increasing the costs of hospitalisations and institutionalisations.

The literature emphasises the need for a more humanised and integrated approach, where the continuous training of healthcare professionals and effective communication with the family are pillars for the provision of quality palliative care.

From this perspective, informal carers play an extremely important role in the community, constituting fundamental elements in maintaining the continuity and quality of healthcare. The appreciation and structured support of these carers not only promote better therapeutic outcomes for dependent people, but also represent an essential sustainability strategy for palliative and continuing care structures.

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Afterwards, the predominant feeling was guilt, because theoretical knowledge about “Caregiver Burden” — a priority nursing diagnosis in palliative care — did not translate into immediate and effective intervention. This experience created a tension within me between the theory I had learned and the complexity of practice in the home setting. However, I did not give up. After reflecting on what had happened, I realised that this moment further reinforced my motivation to be a nurse.

I highlight, as positive aspects, the early recognition of risk — by identifying signs of overload in Mrs. A. —, the empathetic communication established with her, expressed in the validation of her tiredness, even in the face of her attempt to devalue her own experience, as well as the effectiveness of the measures implemented to control Mr. J.'s dyspnoea.

On the negative side, I identify unstructured intervention – the attempt at intervention was superficial–,unbalanced focus –I allowed the focus of the consultation to fall solely on the sick person and not on the person/family/carer unit –, lack of immediate coordination – I did not immediately coordinate the involvement of other members of the multidisciplinary team (psychologist/social worker), as provided for in the Regulations on the Competences of General Care Nurses of the Portuguese Nurses' Association. Palliative care should be provided by a multi- and interdisciplinary team. There should be a focus on the family and a holistic approach. Clear and empathetic communication between healthcare professionals and the family is crucial to align expectations and address issues related to diagnosis, prognosis and care. The family must be included as part of the care, with the need to intervene in the physical, emotional, social, and spiritual dimensions of the patient.

This experience highlights the challenge of translating theory into practice, particularly in the context of home care, where Informal Caregiver Overload is a highly prevalent and critical nursing diagnosis [1]. However, the shortage of human resources and the limited time available to provide comprehensive care to the person/family/caregiver unit, combined with the high number of home visits made daily, often mean that the time that one would like to devote to the family/caregiver is insufficient in view of their real needs.

It should be noted that Ms. A.'s situation (fatigue, irritability, neglect of her own needs) is clinically consistent with the results of systematic reviews on Informal Caregiver Burden in Palliative Care. Studies show that caring for a family member at the end of life results in significant physical, emotional, and social exhaustion, often associated with anxiety, depression, and poorer quality of life [2]. If left untreated, overload increases the risk of maladjustment in long-term grief [3].

The failure to intervene highlights a gap in the application of Evidence-Based Practice (EBP). Nurses working in palliative care play an essential role in identifying needs and training caregivers [4]. The support offered should be systematic and based on three pillars, as demonstrated in scoping reviews: emotional, physical and social support, in addition to health education, both on patient care and on self-care for the caregiver [5]. In the case in question, the intervention was superficial and failed to fully activate these pillars. This insufficiency is related to the scarcity of human resources and time, as well as, in this specific context, to the limited practical experience, as the nurse was still a nursing student.

In this situation, a family assessment model such as the Dynamic Model of Family Assessment and Intervention (MDAIF) should have been used. This type of theoretical-operational framework allows for the structuring of the assessment of the caregiver/ family subsystem and the definition of diagnoses in the functional dimension (such as Informal Caregiver Burden) and the Nursing Care Plan, enabling health gains to be achieved within the family [6]. The absence of a formal screening tool, such as the Zarit

Burden Inventory (which quantifies risk) [7], made it impossible to carry out rigorous intervention and share evidence with the interdisciplinary team, which is crucial in supporting the caregiver [8].

Clinical experience gained as a student cemented the understanding that proactivity in family and caregiver support is an essential skill in palliative care. Recognition and intervention in response to caregiver burden (CB) are insufficient in practice, a problem that reflects the lack of scientific literature. There are still few publications that consider the family as the focus of palliative care, and consequently, the ‘family’ dimension is often addressed as only a secondary point and not as the main focus.

Despite the small number of studies focusing on this topic, the literature shows that communication is the most effective way for healthcare professionals to build rapport and understanding with families in palliative care.

Healthcare professionals, particularly nurses, have an ethical and scientific duty to intervene systematically in cases of caregiver burden. The crucial lesson is that the caregiver's initial resistance must be overcome with assertiveness, evidence (through formal screening) and the establishment of a care contract focused on their needs. In the context of clinical teaching, the hesitation felt resulted in an incomplete intervention that can be overcome with prior planning of time allocated to the family/caregiver and effective communication.

In future similar situations, nursing intervention should be structured according to the principles of Evidence-Based Practice (EBP), in a systematic and multidimensional manner, covering the following steps:

1. Integration of Systematic Screening

We propose the systematic use of validated instruments, such as the Zarit Burden Inventory or the Caregiver Strain Index, in the initial and quarterly assessments of users in home palliative care. Quantifying the risk will enable the formalisation of the nursing diagnosis “Informal Caregiver Burden” and provide objective data to support and justify the implementation of specific interventions [7].

2. Development of a Caregiver Self-Care Plan

Nursing intervention should explicitly include education for self-care, stress management, and promotion of the informal caregiver's mental and physical health. This plan should be personalised, integrating coping strategies and emotional support, with the aim of preserving the caregiver's ability to care and reducing the risk of burnout [5]. Establishing partnerships between healthcare professionals and families is essential for successful family support.

3. Caregiver/Family-Focused Intervention Time Planning

In cases of positive screening for overload, immediate involvement of the multidisciplinary team's psychology and social work services is recommended. Informal Caregiver Burden is a complex phenomenon that requires an integrated approach, in which psychosocial support, activation of formal and informal support networks, and adequate management of social and community resources are fundamental to reducing burden [8].

4. Caregiver/Family-Focused Intervention Time Planning

During subsequent visits, a predetermined period of time — communicated in advance to the person/family/caregiver triad — should be set aside exclusively for the assessment and follow-up of the caregiver. This practice reinforces the role of the nurse as an advocate for the family, ensuring that the caregiver's needs are not neglected and that the approach to care remains comprehensive [6].

According to the Regulation on the Professional Practice of Nurses (Article 5, paragraph a), “nurses must be able to identify general health problems and nursing problems in particular in individuals, families, groups and communities”. This competence is particularly required in the context of home healthcare, which demands a broad understanding of the person and their social environment.

Nursing care, even when focused on a single patient, cannot be dissociated from a sociological perspective, since, according to the World Health Organisation (WHO), socialisation is one of the pillars of the concept of health. Therefore, understanding human relationships implies understanding human behaviour, and it is essential that nursing practice goes beyond clinical barriers and adopts a holistic approach, integrating biological, psychological, social and cultural dimensions.

In this sense, as recommended by the Code of Ethics for Nurses (CDE), in Article 100 — General Ethical Duties —, it is the responsibility of nurses to “ensure the continuous updating of their knowledge, namely through the attendance of professional qualification courses”. This ethical commitment reinforces the need for constant technical and scientific improvement to ensure a well-founded, reflective and humanised practice.

Conclusion

Providing care at home is an essential training opportunity for nursing students, raising awareness of the role of nurses in specific contexts, as well as the responsibilities and skills inherent in professional practice. Although certain knowledge can be acquired from books, other knowledge can only be fully understood and integrated through experience in real clinical practice contexts, a fundamental element in nursing training, in which half of the course is learned in a practical context through clinical teaching.

The incorporation of reflective thinking into the learning process favours the construction of more critical and informed reasoning, promoting more consistent future performance and supporting the development of the nurse's professional identity.

The clinical teaching experience reported was structured according to the phases of Gibbs' reflective cycle, which enabled a systematic reflection on practice, proving to be an effective methodology for recording and analysing highly complex situations. In addition, this reflective process made it possible to identify areas of the student's professional development that needed improvement, thus contributing to the improvement of the quality of nursing care provided to the family.

References

1. Choi YH, Seo HA. Family Caregivers' Burden in Palliative Care A Systematic Review. International Journal of Nursing Studies. 2019; 95: 100-110.
2. Caqueo-Urízar A. Sobrecarga no cuidar e suas repercussões nos cuidadores de pacientes em fim de vida Revisão sistemática da literatura. Ciência & Saúde Coletiva. 2014; 19: 4615-4626.
3. Ferrario LP. Caregiver burden and long-term grief adjustment in bereaved family caregivers of patients with advanced cancer. Journal of Pain and Symptom Management. 2020; 60: 513-520.
4. Santos C. Capacitação de cuidadores informais em cuidados paliativos: O papel essencial do enfermeiro. Jornal Enfermeiro. 2025.
5. Ferreira A, Pinho S. Intervenções de enfermagem destinadas ao cuidador informal da pessoa em cuidados paliativos: uma scoping review. Repositório Institucional. 2022.
6. Santos S. Ganhos em saúde na dimensão funcional da família da pessoa em condição paliativa Aplicação do Modelo Dinâmico de Avaliação e Intervenção Familiar (MDAIF). Revista de Investigação & Inovação em Saúde. 2022; 5: 241-253.
7. Costa JS. Validação Clínica do Diagnóstico de Enfermagem Sobrecarga do Cuidador Caregiver Role Strain em Cuidadores Familiares de Doentes Paliativos. Dissertação de Mestrado. Universidade Católica Portuguesa. 2018.
8. Alves M. Rede de cuidado formal e informal do familiar que cuida do paciente em cuidados paliativos oncológicos no domicílio. Revista Brasileira de Enfermagem. 2025; 75: e20210737.

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