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# The Construction of Care with Nurses and People at the End of Life: An Integrative Qualitative Analysis from the Perspective of the Sick Person

Cidália Frias[1]*, José Carlos Lopes[1], Ana Cristina Dias[1]

1. Professor at the University of the Azores-School of Health Sciences.

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***Address for correspondence:** Cidália Frias, Professor at the University of the Azores-School of Health Sciences.

**Email:** cidalia.lc.frias@uac.pt

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## Abstract

**Introduction:** Caring for people at the end of life poses ethical, emotional and relational challenges for nursing, requiring practices centred on the person and human dignity.

**Objective:** To analyse the construction of nursing care from the perspective of people at the end of life, based on an integrative qualitative analysis.

**Methods:** Integrative analysis of a qualitative case study based on an interview with a person at the end of life, with inductive thematic analysis supported by NVivo software.

**Results:** Four central themes emerged: experiencing terminality between hope and resignation; loneliness associated with family denial; vulnerability and concerns about future care; and nursing care as a source of comfort and dignity.

**Conclusion:** End-of-life care is a process of relational co-construction, in which the therapeutic presence and authentic communication of the nurse are fundamental to mitigating existential suffering and promoting a dignified death.

**Keywords:** palliative care; end of life; nursing; care humanisation of care; helping relationship

## Introduction

Caring for people at the end of life is one of the greatest challenges for nursing, requiring scientific, technical and, above all, human competence. With the progressive transfer of death from the home to the hospital, the unique needs of people at the end of life and their families dictate the need for differentiated interventions.

The World Health Organisation [WHO] defines palliative care as care that aims to improve the quality of life of patients and families facing problems arising from life-threatening illnesses, through the prevention and relief of suffering. In this context, the construction of care is seen as a dynamic process, often conceptualised as an 'encounter of bodies' between the nurse and the person at the end of life. This process is shaped by the context, knowledge and experiences of both, resulting in individualised nursing care built around each specific situation.

Studies highlight the importance of identifying the needs of people at the end of life and promoting their active participation in the development of care. However, denial of the dying process by the patient or family is a reality that hinders the provision of care.

This article aims to describe and analyse the experience of care from the perspective of a person at the end of life who is hospitalised, focusing on their experiences, concerns and perceptions of the support received. It is based on Frias' doctoral thesis [2010].

## Theoretical Framework

A person at the end of life who is hospitalised experiences a transition process that profoundly affects their self, their perception of change, and their adaptation to a new reality. The development of nursing care is a dynamic and complex process that begins with understanding and identifying the needs of the person and their family and seeking answers together.

## The Care Paradigm and the Depersonalisation of Care

The construction of nursing care is seen as a process that begins with identifying the needs of the person at the end of life and their family, seeking the best way to respond to them together.

However, the hospital environment, historically focused on disease and technique [Collière, 2003], tends to view the person as a 'number' or 'bed x,' devaluing the way the person at the end of life experiences their situation.
This culture, marked by routines, lack of time, and lack of privacy, creates difficulties in the interaction between nurses and people at the end of life and hinders the personalisation of care.
The transfer of the person at the end of life from home to the acute hospital [which is an unsuitable environment for the end of life] intensifies their vulnerability and dependence on others to meet their basic needs, which can aggravate their adjustment.

### The Helping Relationship and the Personal Dimensions of the Nurse

Nurses can only help people at the end of life if they themselves cultivate feelings of adequacy and well-being, maintaining essential personal dimensions in the relationship: empathy, human warmth, availability, and acceptance [Twycross, 2003].
These dimensions are crucial and aim to help people at the end of life to understand themselves, to favour their choice, control and self-determination, and to preserve their dignity. so that people at the end-of-life life understand their situation, exercise choice and self-determination, and preserve their dignity.
People at the end of life find themselves in a situation of extreme dependence and vulnerability, often afraid of 'bothering' others. It is crucial that nurses are able to predict, assess, and interpret the signs that reveal their multiple needs (biological, psychological, social, and spiritual).

### Challenges in Interaction and the Need for Humanisation

The interaction between nurses and people at the end of life is a delicate encounter between two people who need to build care in a timely manner. Studies [Frias, 2008] highlight the difficulties nurses face in this process, which manifest themselves in tension, emotional involvement, and discomfort when faced with the patient's existential questions ['when am I going to die?'].
Care provision is often restricted to symptom control [physical and emotional pain of patients and family members] due to hospital culture. Lack of time, team coordination, and guidelines [Jacobs et al., 2002] contribute to this process being experienced with discontent and frustration by nurses.
Overcoming these difficulties requires 'lots of conversation and lots of affection' [Thompson et al., 2006], the development of relational skills, and a focus on the essential characteristics of interaction: interest, attention, sensitivity, and communication [Pagliuca et al., 2006]. Touch, protection, comfort, and the self for therapeutic purposes [Shatell, 2004] are critical components of interactive care.

### The New Perspective

There is a growing movement to move away from the disease-centred model and value the overall perspective of the person, their potential and the preservation of their identity at the end of life.
The goal is for the patient to 'die without pain and with dignity,' with nurse/patient interaction facilitating the development of 'holistic care' [Fahy and Dowling, 2009].

## Methodology

An integrative, qualitative, exploratory, and descriptive study was conducted through the analysis of an individual interview with a person at the end of life, referred to as Mrs. Guida. The interview was conducted while she was hospitalised in Room 8 of a hospital ward. The participant was aware of her diagnosis and the progressive worsening of her condition.
Data collection was carried out through a narrative interview. Data analysis consisted of coding text segments using NVivo 7 software, a technique used in inductive approaches. The results presented are based on the categorisation of codes [experiences and interpretations] extracted directly from the participant's discourse.

## Presentation and Analysis of Results

The analysis of the interview with Mrs Guida identified four central themes that characterise her experience and the process of building care.

| Axes | Interview segments |
|---|---|
| Experiencing Terminal Illness: Between Hope and Resignation | The experience of the disease was marked by a 'bipolar experiential alternation' between 'good days and bad days.' The good days were filled with 'hope that nothing was happening' and appreciation for 'small everyday things' (absence of symptoms, seeing grand daughters, watching television). The bad days represented'despair', where 'death is already tomorrow'.<br>At the time of the interview, the patient's speech reveals an ongoing process of acceptance, driven by the worsening of symptoms: 'I feel that this struggle will end' and 'she begins to detach herself from life'. The |

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|---|---|
| | patient expresses a progressive resignation, stating: 'I have to accept it! This will be here and a few days at home.' Her strength, which she seeks 'I don't know where,' translates into short-term life goals: 'to see my granddaughters get married,' 'to see a granddaughter,' which, once fulfilled, facilitate the process of detachment. |
| **The Loneliness of Dialogue and Family Denial** | A central source of suffering for Mrs Guida is the difficulty in sharing her awareness of her imminent death with her husband and daughters. The patient feels the need for her husband to 'sit down with me so we can talk about my near future', but he 'gets up', 'avoids talking about the illness' and 'runs away from everything'.<br>The patient interprets her husband's refusal to talk as an escape to 'protect himself' or her, but it creates a feeling of loneliness in her. The person at the end<br>of life expresses her right to be accompanied at this time, feeling that her husband 'has an obligation to help/accompany me, but has not yet realised or does not want to realise'. This family denial, where the husband lives in the 'illusion/hope that she will recover from her illness', reverses reality and intensifies the patient's "tension" and 'suffering'. |
| **Vulnerability and Concerns about Future Care** | The loneliness of knowing that life is coming to an end is accompanied by practical concerns about 'who will take care of me in my final days?' The patient wonders about her carers, recognising her dependence on others to take care of 'certain things' at home. Her vulnerability is exacerbated by concerns about the lack of healthcare resources in her homeland (São Jorge) and the perception that money could mobilise better help: 'If I had money, Santa Casa would take me in, but since I don't have any...'. |
| **Nursing Care as a Source of Comfort and Dignity** | Despite difficulties with her family, sharing her feelings with healthcare professionals proved to be a source of 'relief'. The patient reports having spoken to 'two assistants about "things like this" and I cried, I cried (...) but I felt relieved'.<br>The presence and affection of nurses and assistants are valued. Mrs Guida believes that nurses comfort her with gestures and concern 'about activities of daily living', such as when 'one comes and tidies my clothes, looks at me, asks if the food is good, and if not, can it be changed'. These simple gestures demonstrate the meaning of care in the process of dying. |

## Discussion

The results of this interview with Mrs Guida reveal the complexity of end-of-life care, illustrating the intersection between the individual's unique experiences, family dynamics and the professional response. The case validates the premise that palliative care, to be effective, must extend beyond the control of pain and physical symptoms [orthostasis approach], focusing on the relief of emotional, social, and existential suffering.

### Family Denial and the Loneliness of Dialogue

Mrs Guida's experience is marked by profound loneliness in the face of family denial. Her husband's refusal to discuss 'my approaching future' and his escape into the 'illusion/hope that I will recover from my illness' are common self-protection mechanisms in the context of terminal illness. However, this attitude, by inverting reality, imposes on the person at the end of life the burden of managing their own death without the most intimate support. The literature emphasises that the family is the unit of care in palliative care, and psychological support is crucial, given that the prevalence of anxiety and depression is high among informal carers. The construction of care, which ideally presupposes the active participation of patients and family members, is, in this case, compromised by the family's inability to accept reality.

The nurse thus emerges as the main facilitator of communication. Their willingness to listen, to 'be there' and allow the patient to express her feelings ['I cried and cried [...] but I felt relieved'] fills the gap left by the interrupted family dialogue. This is the essence of the helping relationship, which is realised by encouraging the patient to express themselves and welcoming their feelings.

### The Impact on Nurses and Preparation for Care

Providing quality care requires nurses to be prepared not only technically, but also emotionally. Several studies show that working with patients at the end of life can be stressful and trigger emotions such as fear, frustration, and anxiety. Ms Guida says she values simple gestures of comfort, but a lack of knowledge/training can be an obstacle to providing this kind of humanised care.

The fact that the patient finds relief in sharing with the healthcare assistants suggests that the human dimension and simple presence override technical intervention. The emotional overload inherent in palliative care requires healthcare teams to create coping mechanisms and emotional support, ensuring that the impact of terminality on the professional does not hinder the co-construction of care centred on the patient's needs.

### The Materialisation of Care: The 'Meeting of Bodies'

Nursing care, in the context of terminal illness, translates into gestures of comfort that Mrs Guida describes: 'she tucks me in, looks at me, asks if the food is good'. These basic acts are essential to maintaining well-being and dignity. Such interventions illustrate the central category of the 'Process of building nursing care/person at the end of life: meeting of bodies.' In this meeting, therapeutic intervention is not limited to the administration of medication, but rather to the sharing of bodies and the harmony that is strengthened throughout the process.

The fact that the patient expresses her vulnerability and concern about 'who will take care of me in my final days?', particularly in the context of limited resources [São Jorge region], highlights the need to reorganise care and invest in multidisciplinary teams. Humanised care also involves ensuring that the patient understands that 'they are not alone, that they continue to be important and that their care extends to the last moments of their life'.

In short, Mrs Guida's experience is a call for communication, family support and the affectionate presence of nursing staff to be prioritised as fundamental pillars for building dignified and shared care at the end of life.

## Conclusion

The process of building care for people at the end of life is a complex intertwining of individual experiences, family dynamics, and professional intervention.

Mrs Guida's perspective highlights the existential loneliness that comes from the awareness of death in the face of her spouse's denial, and her right to be accompanied and to have her grieving process validated. Nursing care, in this context, takes on a vital role of comfort and emotional relief, providing a safe space for dialogue and the expression of feelings.

The implementation of family support and mediation strategies, led by the nurse, is recommended so that denial does not compromise the right of the person at the end of life to experience their last days with authenticity, dignity and support.

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