

Comfort Theory in the Anticipatory Grief of Family Caregivers of People with Alzheimer's Disease: The Nurse's Role

Teoria do conforto no luto antecipatório de familiares de pessoas com Alzheimer: Atuação do Enfermeiro

Teoría del confort en el duelo anticipado de familiares de personas con Alzheimer: Actuación del enfermeiro

Jéssica Goretti da Silva¹, Vanessa de Paula Marangão², Zélia Marilda Rodrigues Resck³,
Silvana Maria Coelho Leite Fava⁴, Eliza Maria Rezende Dázio⁵

How to cite: Silva JG, Marangão VP, Resck ZMR, Fava SMCL, Dázio EMR. Comfort Theory in the Anticipatory Grief of Family Caregivers of People with Alzheimer's Disease: The Nurse's Role. REVISIA. 2025; 14(4): 1943-50. Doi: <https://doi.org/10.36239/revisa.v14.n4.p1943a1950>

REVISA

1. Federal University of Alfenas (UNIFAL-MG), School of Nursing, Main Campus, Graduate Program in Nursing, Brazil.
<https://orcid.org/0000-0002-3946-9119>

2. Federal University of Alfenas (UNIFAL-MG), School of Nursing, Main Campus, Graduate Program in Nursing, Brazil.
<https://orcid.org/0009-0008-1542-2747>

3. Federal University of Alfenas (UNIFAL-MG), School of Nursing, Main Campus, Graduate Program in Nursing, Brazil.
<https://orcid.org/0000-0002-3752-8381>

4. Federal University of Alfenas (UNIFAL-MG), School of Nursing, Main Campus, Graduate Program in Nursing, Brazil.
<https://orcid.org/0000-0003-3186-9596>

5. Federal University of Alfenas (UNIFAL-MG), School of Nursing, Main Campus, Graduate Program in Nursing, Brazil.
<https://orcid.org/0000-0001-9216-6283>

Received: 17/01/2024
Accepted: 17/03/2024

RESUMO

O luto antecipatório é um fenômeno recorrente entre familiares de pessoas com Doença de Alzheimer, caracterizado por sofrimento emocional contínuo diante da perda simbólica e progressiva da pessoa cuidada. Este estudo teórico-reflexivo, de abordagem qualitativa, foi desenvolvido durante uma disciplina do Programa de Pós-graduação em Enfermagem de uma universidade pública, com base na Teoria do Conforto de Katharine Kolcaba e na análise crítica de evidências científicas nacionais e internacionais. Reflete-se sobre o papel do Enfermeiro na identificação e acolhimento do sofrimento antecipado de familiares cuidadores, considerando as dimensões física, psicoespiritual, sociocultural e ambiental do conforto. As reflexões apontam que reconhecer o luto antecipado como parte do processo de cuidar é essencial para a qualificação da prática assistencial e para a promoção de um cuidado mais sensível, ético e humanizado.

Descritores: Cuidados de Enfermagem; Doença de Alzheimer; Luto antecipado; Cuidadores de Família; Teorias de Enfermagem.

ABSTRACT

Anticipatory grief is a recurring phenomenon among family caregivers of people with Alzheimer's disease, characterized by continuous emotional suffering in the face of the symbolic and progressive loss of the cared-for person. This theoretical-reflective study, with a qualitative approach, was developed during a course in the Graduate Program in Nursing at a public university, based on Katharine Kolcaba's Comfort Theory and on critical analysis of national and international scientific evidence. This reflection addresses the nurse's role in identifying and welcoming the anticipatory suffering of family caregivers, considering the physical, psycho-spiritual, sociocultural, and environmental dimensions of comfort. The reflections indicate that recognizing anticipatory grief as part of the care process is essential to qualify nursing practice and to promote more sensitive, ethical, and humanized care.

Descriptors: Nursing Care; Alzheimer Disease; Anticipatory Grief; Family Caregivers; Nursing Theory.

RESUMEN

El duelo anticipado es un fenómeno recurrente entre familiares de personas con enfermedad de Alzheimer, caracterizado por un sufrimiento emocional continuo ante la pérdida simbólica y progresiva del ser querido. Este estudio teórico-reflexivo, de enfoque cualitativo, fue desarrollado durante una asignatura del Programa de Posgrado en Enfermería de una universidad pública, con base en la Teoría del Confort de Katharine Kolcaba y en el análisis crítico de evidencias científicas nacionales e internacionales. Se reflexiona sobre el papel del enfermero en la identificación y acogida del sufrimiento anticipado de los familiares cuidadores, considerando las dimensiones física, psicoespiritual, sociocultural y ambiental del confort. Las reflexiones señalan que reconocer el duelo anticipado como parte del proceso de cuidado es esencial para la cualificación de la práctica asistencial y para la promoción de una atención más sensible, ética y humanizada.

Descritores: Cuidados de Enfermería; Enfermedad de Alzheimer; Duelo anticipado; Cuidadores familiares; Teorías de Enfermería.

Introduction

Alzheimer's Disease is characterized as a neurodegenerative disorder of progressive evolution, whose impact significantly affects cognitive functions, especially memory and the person's identity, affecting not only those who live with the diagnosis, but also their network of affective bonds. The process of loss occurs gradually, causing family members and caregivers to experience continuous pain prior to biological death. This phenomenon, called anticipatory grief, is characterized by the early manifestation of feelings of loss, sadness and emotional suffering⁽¹⁾.

The diagnosis of Alzheimer's Disease marks, for many families, the beginning of a process of continuous and silent loss. The physical presence of the person contrasts with the progressive absence of their identity, language and affectivity, as the condition progresses. This experience, still little recognized in the social imaginary, is called anticipatory grief and is characterized by the early manifestation of emotions typical of grief, such as sadness, anger and guilt, even before the biological death of the loved one⁽²⁾. It is a pain that escapes the traditional rituals of farewell and, therefore, often remains without institutional shelter or adequate emotional support. When this grief is ignored, there is a risk of naturalizing the burden and silencing a legitimate pain, aggravating the suffering of caregivers. This phenomenon is reinforced by the fact that anticipatory grief in dementia is not socially sanctioned, lacking collective spaces for expression and generating silence and isolation among family members⁽³⁾.

Recent studies show that this type of grief is prevalent among family caregivers of people with Alzheimer's, especially spouses, but also daughters and sons, who experience an emotional alternation between denial and acceptance. This is associated with physical and psychological overload, depressive symptoms and social isolation, with greater intensity observed as the disease progresses⁽⁴⁾.

In the context of long-term care, nurses are often the professionals closest to family members. However, it is observed that the focus of attention still falls mostly on the patient, to the detriment of the caregiver's emotional needs. This gap evidences the need to broaden the view of nursing practice, recognizing that the suffering of family members also requires therapeutic interventions, guidance and qualified listening⁽⁵⁾.

Compared to caregivers of people in cancer care, family members who accompany people with Alzheimer's experience forms of anticipatory grief that are often more prolonged, intense, and silent. Although the prevalence of anticipated grief is similar between both groups, caregivers of people with dementia report greater emotional overload, marked by gradual and continuous losses, such as cognitive and behavioral decline of the loved one, in addition to facing an experience that is less socially recognized, which deepens subjective suffering and isolation⁽⁶⁾.

In this scenario, the importance of rethinking the role of nurses is highlighted, not only in caring for the sick person, but also in welcoming the emotional pain of family members. The Comfort Theory, proposed by Katharine Kolcaba, offers a sensitive and applicable reference to the care of family members who experience anticipatory grief, by proposing that comfort should be promoted in four fundamental dimensions: physical, psychospiritual, sociocultural and environmental⁽⁷⁾.

This approach allows nurses to understand caregiver suffering in a broad and integrated way, recognizing its multiple expressions and needs. With this, nursing expands its performance beyond technical procedures, assuming a therapeutic role capable of generating relief, receptiveness and meaning in the midst of anticipated pain.

Reflecting on anticipatory grief in the light of this theory contributes to qualify professional practice, integrating emotional suffering as a legitimate and indispensable dimension of care.

In view of this scenario, this article aims to reflect on the role of nurses in the anticipatory grief of family members of people with Alzheimer's in the light of Katharine Kolcaba's Comfort Theory.

Method

This is a theoretical-reflective study, with a qualitative approach, developed in the context of the discipline "Philosophical, epistemological, theoretical and methodological foundations of research in the care process" of the *Stricto Sensu* Graduate Program in Nursing of a Brazilian public university in the first semester of 2025.

The construction of the manuscript was based on Katharine Kolcaba's Comfort Theory (2003) and on the national and international literature on nurses' support in relation to the anticipatory grief of family members of people with Alzheimer's disease. The analyzed publications were selected through directed searches and critical reading in indexed information sources, such as SciELO (Scientific Electronic Library Online), PubMed and Virtual Health Library (VHL). In addition, theoretical works and academic productions obtained through manual search in institutional repositories and virtual libraries were included, in order to enrich the discussion with relevant and updated conceptual references.

Priority was given to articles published in the last five years, in Portuguese and English, that addressed the phenomenon of anticipatory grief and the role of nurses in the context of dementia. In addition, classical theoretical references and productions prior to this period were included, whose conceptual relevance is recognized for the deepening of reflective analysis.

The elaboration of the text followed criteria of theoretical rigor, argumentative cohesion and articulation between practice, science and ethics. Because it does not contemplate data collection directly from human beings, the present study is exempt from evaluation by the Research Ethics Committee, in accordance with the guidelines established by Resolutions No. 510/2016 and No. 674/2022 of the National Health Council.

Results and Discussion

Anticipatory grief manifests itself as an intense, silent and continuous emotional experience. As cognitive and functional deterioration worsens, the family caregiver is confronted with a symbolic loss of the person they knew, although their physical presence remains. This is a process described as "death in life", in which identity, communication and affective bonds are progressively undone⁽²⁾. As this subjective absence is consolidated, the caregiver is confronted with a deep emotional paradox, which weakens their mental health and intensifies the experience of affective disconnection⁽⁸⁾.

Anticipatory grief is particularly common among caregivers with direct affective bonds, children and spouses, who closely follow the advance of dementia. Feelings such as persistent sadness, guilt, emotional ambivalence, and physical and psychic exhaustion are frequent. Compared to caregivers of people with cancer, those who care

for people with Alzheimer's experience a longer, emotionally dense and less socially validated grief⁽⁹⁾.

From the perspective of the Comfort Theory, this suffering reflects gaps in the psychospiritual dimension. Nurses can contribute significantly by offering therapeutic presence, qualified listening and coping strategies that promote emotional relief, resignification and serenity. Recognizing anticipated grief as a legitimate experience is essential to welcome the caregiver and preserve their subjective integrity.

In the context of care for people with Alzheimer's, the nurse's work is strategic in identifying and welcoming the suffering of family caregivers. However, it is observed that the focus of care is still primarily on the sick person, relegating the caregiver's suffering to invisibility. A recent integrative review shows that the application of the Comfort Theory, when considering the physical, psychospiritual, sociocultural and environmental dimensions of comfort, favors an expanded model of care, capable of integrating science, sensitivity and relational ethics⁽¹⁰⁾.

By recognizing the family as a subject of care, nurses can offer emotional support, educational guidance and relational mediation, favoring coping with anticipatory grief. Such strategies are especially necessary in a scenario where the caregiver's suffering is often made invisible by emotional, cultural and institutional barriers, which hinder the verbalization of pain and access to structured support networks⁽⁸⁾.

In this sense, the application of the Comfort Theory allows nurses to develop therapeutic interventions aimed at the integral reception of the family. This includes: empathetic listening, validation of ambivalent feelings, adaptation of the environment for security and tranquility, encouragement of shared care with the support network and educational actions about the trajectory of dementia⁽⁷⁾.

Therapeutic listening emerges as a central tool to access the caregiver's subjective suffering. When the nurse is willing to listen, without judgment, he opens space for contained emotions to be verbalized and resignified. Often, the simple act of naming the pain is already an important step towards emotional relief. Attentive and empathetic listening, in this scenario, transcends technique and approaches relational ethical care, reaffirming nursing's commitment to the dignity of those who care.

Sociocultural comfort is manifested when the caregiver feels recognized in his or her life history, in the relationships he or she has built and in the values he or she supports, while environmental comfort is related to the creation of physical and symbolic spaces that provide welcoming, silence, rest and existential meaning^(8,7). By incorporating these dimensions into care practice, in the light of the Comfort Theory, nurses expand their field of action beyond biomedical demands, favoring the emotional strengthening of family caregivers and contributing to the continuity of care. More than promoting punctual relief, this approach reaffirms the ethical commitment of nurses to human dignity, recognizing the invisible suffering of those who care as a legitimate experience that also deserves listening, presence and care.

The nurse's performance is not limited to the execution of technical procedures, it also implies recognizing and welcoming the suffering that is often silenced. Anticipatory grief can remain hidden, disguised by feelings of guilt, shame, denial or by the naturalization of the overload in prolonged care. Validating these emotions is part of an ethical, sensitive and humanized practice, contributing to the recognition of suffering as legitimate⁽⁷⁾.

The importance of systematically evaluating anticipatory grief in family caregivers of people with dementia is highlighted, as these experiential processes directly impact mental health, quality of care, and continuity of care. It was evidenced

that institutional recognition and clinical support for anticipated suffering are decisive factors in mitigating the emotional exhaustion of these caregivers⁽¹¹⁾.

The silence that surrounds the caregiver, permeated by ambiguous and often unconfessable feelings, reveals not only emotional suffering, but also a lack of meaning in the face of the experience of loss lived in life. It is at this point that the importance of looking at the spiritual dimension of care as a possibility of resignification becomes evident. When the caregiver's feelings remain unspoken, due to fear, guilt or emotional exhaustion, what is lost is the chance to transform pain into meaning.

To this symbolic suffering is added the spiritual dimension, often forgotten, but essential when it comes to resignifying the experience of progressive loss. Recent studies reveal that spiritual well-being acts as a mediator between psychic suffering and the ability to find meaning in the trajectory of care, even in the midst of pain⁽¹²⁾. This implies recognizing that spirituality is not restricted to religiosity, but involves values, purposes, personal rituals, and the desire to reconnect with what gives meaning to life. Therefore, creating spaces for the caregiver to manifest this dimension is a therapeutic practice.

The absence of public policies and care protocols aimed at the emotional and spiritual health of caregivers is still a challenge in clinical practice. By neglecting subjective suffering, the health system contributes to the chronicity of conditions such as depression and burnout among family caregivers. The proactive performance of nurses, in this context, can represent an important counterpoint, creating welcoming networks and instituting practices that humanize the trajectory of care.

In this sense, it reinforces that emotional overload and anticipatory grief are interconnected, especially when the family caregiver does not receive structured support. Research indicates that, in contexts of lack of support, there is a higher prevalence of severe psychological suffering, suggesting that care for family caregivers should be a priority in public policies and in the clinical performance of nurses⁽¹³⁾.

By promoting small adaptations in the environment, such as offering a space reserved for rest, reorganizing care routines in a lighter way, or encouraging moments of self-care, nurses directly contribute to the permanence of home care and to the preservation of the caregiver's health. Simple but intentionally planned actions generate physical and emotional comfort and demonstrate the attentive and individualized view of nursing⁽¹⁴⁾.

The sociocultural dimension of care also needs to be respected. When the caregiver realizes that their life history, their choices and their values are recognized by the nurse, there is a sense of belonging and validation that contributes to their emotional balance. Such recognition sustains the bond between caregiver and team, and reinforces the perception that their pain is legitimate and worthy of care^(7,3).

The Comfort Theory, in this context, provides a robust theoretical basis for understanding care as an ethical, relational and integrative practice. By recognizing the family member as a subject of care, nurses expand their work beyond the physical body, acting on the symbolic, affective and spiritual dimensions of anticipated pain. Evaluative tools such as overload scales, feelings records or reflective listening circles are viable and effective strategies to access and intervene in this invisible suffering⁽⁹⁾.

When anticipatory grief is not recognized or validated, suffering tends to be internalized, which favors the emergence of anxiety, depression, and Burnout Syndrome. By using the Comfort Theory as a guide, nurses transform care into a therapeutic space, where suffering is not denied, but welcomed, understood and resignified with dignity, empathy and ethical presence.

The experience of anticipatory grief, when understood and welcomed, is no longer just a source of suffering and also becomes an opportunity to humanize care for both those who leave and those who remain.

Final considerations

The anticipatory grief experienced by family members of people with Alzheimer's disease is a subjective, complex experience that is often made invisible in health services. It is a suffering that is established while still alive, fed by the gradual loss of identity and affective relationship with the loved one, in a process marked by emotional ambivalence, exhaustion and lack of social recognition.

By reflecting on this experience in the light of the Comfort Theory, it was evidenced that the nurse's performance can and should go beyond the boundaries of technical care, assuming a therapeutic, relational and humanized role, which values the physical, psychospiritual, sociocultural and environmental dimensions of comfort. Empathetic listening, validation of ambiguous feelings, support for spirituality, and the creation of welcoming environments are essential strategies for the emotional strengthening of the caregiver.

Recognizing the caregiver as a subject of care is an ethical and political act, which repositions the nurse as a profession committed to human dignity in all its expressions. When nurses welcome anticipated grief as a legitimate experience and intervene intentionally, they contribute not only to the relief of suffering, but also to the resignification of pain and the continuity of home care in a more sustainable and compassionate way.

It is essential, therefore, that care practices and public policies incorporate the recognition of anticipatory grief as a real dimension of mental and emotional health care. This includes investing in professional training, strengthening interprofessional support networks, and institutionalizing practices that promote comfort and meaning to the trajectory of those who care.

Acknowledgments

The study was funded by the authors themselves.

References

1. Rice A, Schwarzkopf M, Galvin JE, Keys K, Schilling K, Lingler JH, et al. *Anticipatory grief among family caregivers of persons with Alzheimer's disease and related disorders: predictors, correlates, and clinical implications* [Internet]. *Am J Alzheimers Dis Other Dement.* 2021 [cited 2025 Jun 27];36:1–10. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8506937/>
2. Rocha DV, Liotti DM, Marcial LSD, Novaes LF, Salles RJ. *O luto antecipatório em cuidadoras de idosos com Alzheimer avançado* [Internet]. *Fam Ciclos Vida Saúde Contexto Soc.* 2023 Jan-Mar [cited 2025 Jun 27];11(1):1–16. Available from: <https://seer.uftm.edu.br/revistaelectronica/index.php/refacs/article/download/6778/6938/38937>

3. Costa BS. *Luto antecipatório em familiares de pacientes com doença de Alzheimer: revisão integrativa* [Internet]. Salvador: Escola Bahiana de Medicina e Saúde Pública; 2024 Jun [cited 2025 Jun 27]. Available from: <https://repositorio.bahiana.edu.br/jspui/handle/bahiana/8862>
4. Crawley S, Sampson EL, Moore KJ, Kupeli N, West E. *Grief in family carers of people living with dementia: a systematic review* [Internet]. *Int Psychogeriatr*. 2022 [cited 2025 Jun 27];34(1):1-32. Available from: <https://doi.org/10.1017/S1041610221002787>
5. Cabral LAM, Guedes ECS, Dantas ED, Araújo ES, Saraiva AKA de C, Costa BHS, et al. *Assistência de enfermagem frente ao luto antecipatório de familiares de pacientes em cuidados paliativos: revisão integrativa* [Internet]. *Contrib Cienc Soc*. 2024 [cited 2025 Jun 27];17(10):1-19. Available from: https://www.researchgate.net/publication/385050966_Assistencia_de_enfermagem_frente_ao_luto_antecipatorio_de_familiares_de_pacientes_em_cuidados_paliativos
6. Meyer RM, Trembl JL, Tate JA, Yang Y, Bialek K, Belyea MJ, et al. *Comparing anticipatory grief and caregiver burden in dementia and hematologic cancer: a dyadic study* [Internet]. *J Acad Consult Liaison Psychiatry*. 2025 [cited 2025 Jun 27];66:100-8. Available from: <https://doi.org/10.1016/j.jaclp.2025.04.003>
7. Kolcaba K. *Comfort theory and practice: a vision for holistic health care and research*. New York: Springer Publishing Company; 2003
8. Dekker NL. *Anticipatory grief in dementia: an ethnographic study of loss and connection* [Internet]. *Cult Med Psychiatry*. 2023 Sep [cited 2025 Jun 27];47(3):701-21. Available from: <https://doi.org/10.1007/s11013-022-09792-3>
9. Souza Alves LC, Monteiro DQ, Bento SR, Hayashi VD, Pelegrini LNC, Vale FAC. *Burnout syndrome in informal caregivers of older adults with dementia: a systematic review* [Internet]. *Dement Neuropsychol*. 2019 Dec [cited 2025 Jun 27];13(4):415-21. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6907708/>
10. Freire PC, Silva RM, Oliveira LGS, Santos AC, Almeida FCM, Costa LCF, et al. *Cuidados de enfermagem para a pessoa idosa com doença de Alzheimer fundamentados na Teoria do Conforto de Kolcaba: revisão integrativa* [Internet]. *Braz J Implant Health Sci*. 2025 Apr [cited 2025 Jun 27];7(4):1468-82. Available from: <https://doi.org/10.36557/2674-8169.2025v7n4p1468-1482>
11. Dehpour N, Koffman J. *Anticipatory grief in informal caregivers of people with dementia: a scoping review* [Internet]. *BMC Palliat Care*. 2023 [cited 2025 Jun 27];22(1):1-18. Available from: <https://doi.org/10.1186/s12904-023-01231-z>
12. Lou Q, Liu F, Jiang Z, Zhang L. *The chain mediating effect of spiritual well-being and anticipatory grief between benefit finding and meaning in life of patients with advanced lung cancer: empirical research quantitative* [Internet]. *Nurs Open*. 2024 Jul [cited 2025 Jun 27];11(7):e2179. Available from: <https://doi.org/10.1002/nop2.2179>

Silva JG, Marangão VP, Resck ZMR, Fava SMCL, Dázio EMR

13. Janssen AL, Gaugler JE, Lingler JH, Mitchell AM, Gilmore-Bykovskyi AL, McDarby M, et al. *Caregiver burden and anticipatory grief in dementia caregiving: a systematic review* [Internet]. *J Aging Health*. 2023 [cited 2025 Jun 27];35(2):167–87. Available from: <https://doi.org/10.1177/08982643221100179>

14. Lin Y, Zhou Y, Chen C, Yan C, Gu J. *Application of Kolcaba's Comfort Theory in healthcare: mapping review* [Internet]. *BMJ Open*. 2024 [cited 2025 Jun 27];14:e077810. Available from: <https://doi.org/10.1136/bmjopen-2023-077810>

Correspondent Author

Jéssica Goretti da Silva
Célia Maria da Conceição Alve Street, 190 -
Jardim Alvorada. ZIP: 37160-000, Campos
Gerais, Minas Gerais, Brazil.
jessykasilva_cangere@yahoo.com.br