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Relationship-Centered Care and Humanitude: A Narrative Review on Reducing Care Refusal in People Living with Dementia

João Partel Araújo

Nursing School of Coimbra, UICISA: E - Health Sciences Research Unit: Nursing/Doctoral Program in Nursing. Coimbra, Portugal.

ORCID:0000-0003-0037-9383

Helena Luz

Center for Interdisciplinary Studies - CEIS20 - University of Coimbra, Faculty of Psychology and Educational Sciences of the University of Coimbra.

ORCID: 0000-0003-1592-0953

Rosa Melo

Nursing School of Coimbra, UICISA: E - Health Sciences Research Unit: Nursing. Coimbra, Portugal.

ORCID: 0000-0002-0941-407X

Catherine Van Son

Washington State University-Vancouver.

ORCID: 0000-0002-0491-5748

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ABSTRACT

This narrative literature review investigates the efficacy of relationship-centered care approaches, particularly the Humanitude methodology, in reducing care refusal among people living with dementia (PLWD). With care refusal affecting up to 60% of PLWD, this phenomenon presents significant challenges to healthcare delivery, quality of life for care recipients, and caregiver well-being. The study synthesizes current evidence on the prevalence, causes, and consequences of care refusal; examines relationship-centered care approaches in nursing; and explores how Humanitude techniques can contribute to reducing care refusal.

Results indicate that relationship-centered care, especially Humanitude's focus on professionalizing gaze, speech, touch, and verticality, can significantly improve care quality, reduce neuropsychiatric symptoms, and alleviate caregiver burnout. Studies report a decrease in care refusal incidents, improved cooperation during care activities, and increased caregiver satisfaction following Humanitude implementation.

However, successful integration of these approaches requires overcoming challenges such as changes in organizational culture. The review emphasizes the need for comprehensive training programs, ongoing support, and integration into nursing education curricula.

Although promising, current research is limited by small-scale studies and heterogeneous implementation methods. Future research should focus on large-scale longitudinal studies across diverse healthcare settings to establish long-term efficacy and cost-effectiveness.

As the global prevalence of dementia increases, incorporating relationship-centered approaches like Humanitude into nursing practice and

education could revolutionize care quality for PLWD and significantly improve healthcare professionals' well-being.

Keywords: dementia; humanization of care; nursing; relationship-centered care; humanitude

1. INTRODUCTION

The global demographic landscape is undergoing a significant transformation, characterized by a rapidly aging population. According to the World Health Organization (2021), the proportion of the world's population over 60 years will nearly double from 12% to 22% between 2015 and 2050. This demographic shift brings with it an increased prevalence of age-related conditions, most notably major neurocognitive disorders like dementia. Current estimates suggest that over 55 million people live with dementia worldwide, with this number projected to rise to 78 million by 2030 and 139 million by 2050 (Alzheimer's Disease International, 2021).

As the number of people living with dementia (PLWD) grows, healthcare systems face mounting challenges in providing effective and dignified care. One of the most significant obstacles in dementia care is the phenomenon of care refusal. Studies indicate that PLWD with neuropsychiatric symptoms can refuse care in up to 60% of cases (Ishii et al., 2012). This high prevalence of care refusal not only compromises the quality and effectiveness of nursing care but also contributes to increased caregiver stress, reduced quality of life for PLWD, and elevated healthcare costs (Araujo et al, 2024).

In response to these challenges, there has been a growing emphasis on relationship-centered approaches in healthcare, particularly in nursing care for PLWD. Relationship-centered care recognizes that the interactions and relationships between care providers and care recipients are central to the care process and can significantly influence health outcomes (Beach et al., 2006). Within this paradigm, Humanitude has emerged as a promising care methodology. Developed by Yves Gineste and Rosette Marescotti, Humanitude comprises a care philosophy and a set of techniques designed to improve caregiver relational skills and enhance the quality of care interactions (Gineste & Pellissier, 2008, Melo et al., 2020a).

The integration of Humanitude into nursing practice represents a potential avenue for addressing the complex issue of care refusal in PLWD. By focusing on the professionalization of fundamental human interactions – gaze, speech, touch, and verticality – Humanitude offers a structured approach to building and maintaining caring relationships. This approach aligns closely with the core values of nursing, which emphasize compassionate, person-centered care that respects the dignity and autonomy of each individual (ICN, 2021)

The importance of this topic in nursing practice cannot be overstated. As the primary caregivers for PLWD in various healthcare settings, nurses are uniquely positioned to implement relationship-centered approaches and potentially reduce instances of care refusal. Moreover, by adopting methodologies like Humanitude, nurses can enhance their relational skills, improve care outcomes, and contribute to a more humane and effective healthcare system for PLWD (Fazio et al., 2018; Giang et al., 2023).

This study aimed to contribute to the growing body of knowledge on relationship-centered care for PLWD and the contributions of Humanitude to the reduction of nursing care refusal by PLWD.

The objectives of this research were to:

1. Analyze current evidence on care refusal by PLWD, including its prevalence, causes, and consequences.
2. Examine the role of relationship-centered approaches in nursing care for PLWD.
3. Explore how Humanitude techniques may promote nurses' relational skills and potentially reduce care refusal by PLWD.
4. Discuss the implications of integrating Humanitude into nursing practice and education.

2. METHODS

This study followed a narrative literature review methodology to examine the current evidence on the following research question: How does the integration of relationship-centered care approaches, particularly the Humanitude methodology, influence care refusal behaviors in people living with dementia, and what are the implications for nursing practice?

We conducted searches in electronic databases including PubMed, CINAHL, and Google Scholar to identify relevant literature. The search was not exhaustive but focused on identifying key papers that addressed our research question. We used a combination of terms related to "dementia," "care refusal," "relationship-centered care," and "Humanitude."

Inclusion criteria were stablished in agreement, allowing for the selection of papers that provided significant insights into our topic of interest. We included both empirical studies and theoretical papers that contributed to our understanding of care refusal by PLWD and relationship-centered care approaches in nursing care.

The selection of papers was based on their relevance to the research question and their potential to provide meaningful insights. This approach allowed for the inclusion of seminal works and papers that offered unique perspectives on the topic.

We synthesized the findings using a narrative approach, organizing the results thematically to address the main aspects of our research question. This method allowed for the integration of diverse types of evidence and the development of a coherent narrative around care refusal by PLWD and the potential of relationship-centered approaches in nursing care, in particularly Humanitude care methodology (Aromataris et al., 2024).

3. RESULTS

3.1 Care Refusal in People Living with Dementia

Care refusal among PLWD is a widespread and challenging issue in various care settings. Studies have reported prevalence rates ranging up to 60%, depending on the care context and the specific type of care being refused (Volicer et al., 2007; Ishii et al., 2012). A large-scale study by Galik et al. (2017) found that approximately 35.8% of nursing home residents with dementia exhibited care-refusal behaviors during activities of daily living (ADLs).

The impact of care refusal is multifaceted, affecting not only the health and well-being of PLWD but also the care process and caregiver stress levels. Konno et al. (2014) reported that care refusal often leads to increased time spent on care tasks, heightened frustration among caregivers, and potentially suboptimal care delivery.

Several factors have been identified as determinants to care refusal in PLWD, like personal determinants (like cognitive impairment, communications difficulties or unmet needs); relational determinants (like the way caregivers

interact with the PLWD); environmental determinants (noise, lighting, layout and decoration); and organizational determinants like inflexible routines, understaffing and poor interdisciplinary collaboration.

Care refusal can have severe consequences like compromised health outcomes; compromised care provision and exacerbation of neuropsychiatric symptoms (Araujo et al., 2024)

Understanding these determinants is crucial for developing effective strategies to address care refusal and improve the overall care quality for PLWD.

3.2 Relationship-Centered Approaches in Nursing Care

Relationship-centered care (RCC) has emerged as a significant approach in healthcare delivery, particularly in the context of dementia care. As defined by Beach et al. (2006), RCC emphasizes the importance of relationships in the care process, recognizing that interactions between care providers, people receiving care, and families are central to high-quality care. The core principles of RCC, as outlined by Soklaridis et al. (2016), encompass personhood, affect and emotion, reciprocal influence, and the moral value of relationships.

In the care for people living with dementia, the reported benefits of RCC were improved quality of life for people living with dementia (PLWD), reduced agitation and behavioral symptoms, and increased satisfaction among both patients and caregivers (Edvardsson et al. (2008; and Li & Porock, 2014). Fazio et al. (2018) also found that RCC interventions led to a significant 50% reduction in the use of antipsychotic medications in nursing home residents with dementia, highlighting the potential of this approach to minimize pharmacological interventions.

The application of RCC in current nursing practice takes various forms. Gilmore-Bykovskyi et al. (2015) described the implementation of personalized care planning, where care plans are tailored to individual preferences and life histories. Gaugler (2005) emphasized the importance of family involvement, actively engaging family members in care decisions and delivery. Castle (2011) discussed the practice of consistent assignment, ensuring continuity of care by assigning the same caregivers to patients over time. Environmental modifications also play a crucial role in RCC, with Chaudhury et al. (2018) demonstrating how creating homelike environments can support relationships and social interaction. Additionally, Spector et al. (2013) highlighted the significance of staff education, focusing on training nursing staff in communication techniques and empathy-building to enhance relationship-centered care.

Despite its proven benefits, the implementation of RCC faces several challenges. McCormack et al. (2010) identified time constraints, organizational culture, and lack of resources as primary barriers to effective RCC implementation. However, their research also suggested that overcoming these obstacles can lead to improved outcomes for PLWD and increased job satisfaction among nursing staff, underscoring the value of persevering in the face of these challenges.

Relationship-centered approaches in nursing care offer a promising framework for improving the quality of care for PLWD. As the field of dementia care continues to evolve, the principles and practices of RCC may play an increasingly important role in shaping effective and compassionate care strategies.

3.3 Humanitude Care Methodology

Humanitude, developed by Yves Gineste and Rosette Marescotti in the 1970s, is a relationship-

centered care methodology that has gained increasing attention in the field of dementia care. This approach is rooted in the philosophy that recognizes the fundamental human need for connection and recognition and emphasizes the importance of preserving dignity and autonomy in care interactions (Gineste & Pellissier, 2008). Humanitude techniques are designed to enhance caregiver-care recipient relationships and improve the quality of care, particularly for individuals with cognitive impairments who may exhibit care-refusal behaviors.

At the core of Humanitude are four key pillars: gaze, speech, touch, and verticality. These elements are carefully integrated into care interactions to create a positive and proficient care relationship.

Evidence supporting the effectiveness of Humanitude in reducing care refusal has been accumulating. A study by Melo et al. (2020b) reported that after Humanitude training, caregivers experienced a decrease in the frequency and intensity of resistance to care among people living with advanced dementia. Honda et al. (2016) conducted a case series in an acute care hospital, demonstrating that the application of Humanitude led to reduced behavioral and psychological symptoms of dementia (BPSD) and improved cooperation during care activities. Both researchers noted particular success in situations that typically provoked strong resistance, such as bathing and medication administration.

A systematic review by Giang et al. (2023) synthesized findings from multiple studies and concluded that Humanitude shows promise in improving the quality of care interactions, reducing agitation and aggression, and enhancing overall well-being for people living with dementia. The review also highlighted the positive impact on caregiver satisfaction and reduced burnout rates among staff trained in Humanitude techniques.

Despite these encouraging results, it's important to note that research on Humanitude is still evolving. Some studies have pointed out challenges in implementation, including the need for sustained training and organizational support to fully integrate Humanitude principles into daily care practices (Celich et al., 2022a). Additionally, while the majority of studies report positive outcomes, the strength of evidence varies, and more large-scale, controlled studies are needed to firmly establish the efficacy of Humanitude across diverse care settings. Nevertheless, as research continues to accumulate, Humanitude may become an increasingly valuable tool in the repertoire of evidence-based approaches for dementia care.

3.4 Integration of Humanitude into Nursing Practice

The integration of Humanitude methodology into nursing practice represents a significant opportunity to enhance the quality of care for people living with dementia (PLWD), particularly in addressing issues of care refusal. As nursing professionals increasingly recognize the value of relationship-centered approaches, Humanitude offers a structured yet flexible framework to improve care outcomes, through the professionalization of care relationships.

Potential benefits of integrating Humanitude into nursing practice are multifaceted. Melo et al. (2019, 2020) reported that nursing students trained in Humanitude techniques demonstrated improved communication skills and greater empathy in their interactions with PLWD. This enhanced relational capacity led to a reduction in neuropsychiatric symptoms observed during care activities and increased patient cooperation. Furthermore, Giang et al. (2023) found that nurses

practicing Humanitude reported lower levels of burnout, indicating that the benefits extend to caregivers as well.

Despite these promising outcomes, the integration of Humanitude into nursing practice is not without challenges. As Henriques et al. (2019) noted that the successful integration of Humanitude requires a shift in organizational culture towards prioritizing relationship-centered care, which can be a complex and time-consuming process.

Training and skill development play crucial roles in the effective integration of Humanitude into nursing practice. Fukuyasu et al. (2021) advocated for a combination of theoretical instruction and hands-on practice, allowing healthcare professionals to refine their skills in a supportive environment before applying them in real care situations.

Ongoing education and support are equally important in maintaining and enhancing Humanitude skills over time. Some institutions have implemented mentoring systems, where experienced practitioners of Humanitude guide and support their colleagues in applying the methodology consistently and effectively (Celich et al., 2022b).

The integration of Humanitude into nursing education curricula is another avenue being explored to ensure new nurses enter the field equipped with these valuable skills. Melo et al. (2020b) suggested that incorporating Humanitude principles into foundational nursing courses could help cultivate a new generation of nurses well-versed in relationship-centered care approaches from the outset of their careers. In the long run, creating a positive spiral effect, this may lead healthcare institutions and nursing schools to recognize the value of adopting this approach to enhance the quality of care for PLWD and support the well-being of nursing professionals.

4. DISCUSSION

This review has explored the complex issue of care refusal in people living with dementia (PLWD), the potential of relationship-centered approaches in nursing care, and the specific contributions of the Humanitude methodology in addressing this challenge.

Care refusal among PLWD emerges as a multifaceted problem with significant implications for both person recving care and care providers. The prevalence rates of care refusal underscore the urgency of addressing this issue, as it compromises care quality. The identification of various determinants of care refusal, including personal, relational, environmental, and organizational factors (Araujo et al., 2024), provides a framework for developing comprehensive interventions and address these potentially modifiable factors.

Relationship-centered care (RCC) approaches, with their emphasis on the importance of human connections in healthcare, offer a promising solution for addressing care refusal. The reported benefits of RCC in improving quality of life for PLWD, reducing agitation, and increasing satisfaction among people receiving care and caregivers further support the potential of RCC to address behavioral symptoms without resorting to pharmacological interventions or other potentially harmful interventions, like restraints or coercive care (Möhler et al., 2012; Gjerberg, et al., 2013).

The Humanitude care methodology, as it operationalizes the relationship-centered care principles, shows particular promise in addressing care refusal. The structured yet flexible approach of Humanitude, focusing on gaze, speech, touch, and verticality, provides a practical framework for enhancing care interactions. The reported reductions in care refusal incidents (Henriques et al., 2019) and improvements in cooperation during care activities (Honda et al., 2016) suggest that

Humanitude techniques can be effective tools in managing and reducing care refusal behaviors.

These findings have significant implications for nursing practice and education. The integration of relationship-centered approaches, particularly Humanitude, into nursing care routines could lead to improved health outcomes and increased job satisfaction among nursing staff. However, the challenges in implementation identified by Celich et al. (2022a), including resistance to change, highlight the need for comprehensive training programs and organizational support, in both healthcare organizations and nursing education programs.

The current research, while promising, has limitations that must be acknowledged. Many studies on Humanitude and relationship-centered care in dementia settings have been conducted on a relatively small scale or in specific cultural contexts. The variability in care settings, populations, and implementation methods makes it challenging to generalize findings across all healthcare contexts. Additionally, the long-term effects of these approaches and their impact on health outcomes require further investigation.

Future research directions should focus on addressing these limitations. Large-scale, longitudinal studies across diverse healthcare settings would provide more robust evidence of the effectiveness of relationship-centered approaches and Humanitude in reducing care refusal. Investigation into the cost-effectiveness of implementing these approaches, considering both immediate care outcomes and long-term health impacts, would be valuable for healthcare policy and resource allocation decisions. Furthermore, research into the optimal methods for training and supporting healthcare staff in these approaches could facilitate more effective implementation.

5. CONCLUSION

This comprehensive review explored the potential of relationship-centered care, particularly the Humanitude methodology, in addressing the phenomena of care refusal by PLWD.

The key findings of this study underscore the prevalence and impact of care refusal among PLWD. This phenomenon highlights the urgent need for effective interventions. Relationship-centered care (RCC) emerges as a promising framework for improving the quality of care for PLWD. The evidence suggests that RCC can lead to improved quality of care, but it requires further research.

Humanitude, as a specific methodology within the broader framework of relationship-centered care, offers a set of techniques to professionalize care relationships and reduce care refusal. The potential of Humanitude to reduce neuropsychiatric symptoms, improve cooperation during care activities, and decrease caregiver burnout suggests that its wider adoption could lead to substantial improvements in health outcomes for PLWD.

As the global population ages and the prevalence of dementia increases, the need for effective care approaches becomes ever more critical. Relationship-centered practices align closely with the core values of nursing and have the potential to significantly improve both the quality of care and the well-being of people receiving care and caregivers.

Considering these findings, it would be appropriate to integrate of relationship-centered approaches, particularly Humanitude, into nursing practice and education. Healthcare organizations should prioritize the implementation of these approaches, providing comprehensive training programs and ongoing support for staff. Nursing education institutions should consider incorporating relationship-centered care principles

and Humanitude techniques into their curricula, preparing the next generation of nurses to provide compassionate, person-centered care from the outset of their careers.

While challenges in implementation exist and further research is needed to fully establish the long-term efficacy of these approaches across diverse healthcare settings, the potential benefits for both PLWD and healthcare providers are too significant to ignore.

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CORRESPONDING AUTHOR
João Pärtel Araújo
joao.araujo@esenfc.pt

NOTES

AUTHORSHIP CONTRIBUTION

Conception of the study: Araújo JP

Data collection: Araújo JP, Melo R, Luz H, Van Son C.

Data analysis and interpretation: Araújo JP, Melo R, Luz H, Van Son C.

Discussion of results: Araújo JP, Melo R, Luz H, Van Son C.

Writing and/or critical revision of the content: Araújo JP, Melo R, Luz H, Van Son C.

Review and final approval of the final version: Araújo JP, Melo R, Luz H, Van Son C.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.