INPLASY

Care Refusal in Older Adults with Dementia Receiving Professional Care: A Scoping Review Protocol

Corresponding author:
JOAO ARAUJO

joaopartelaraujo@gmail.com

Author Affiliation:
University of Coimbra.

Partel Araujo, JP[1]; Melo, R[2]; Amaro da Luz, H[3]; Van Son, C[4]; Giang, TA[5]; Henriques, L[6].

ADMINISTRATIVE INFORMATION

INTRODUCTION

Review question / Objective This scoping review aims to comprehensively map the existing literature on the determinants and effects of care refusal behaviors exhibited by older adults aged 65 and above with dementia who receive professional care in institutional settings. The specific review questions are: 1) What are the determinants of care refusal behaviors in older adults aged 65 years and above with dementia who are receiving professional care in healthcare settings? 2) What are the effects associated with care refusal behaviors in older adults aged 65 years and above with dementia who are receiving professional care in institutional settings?

Rationale Dementia is a progressive neurocognitive disorder affecting over 55 million people globally (Livingston et al., 2020; WHO, 2021). Caring for those with dementia poses increasing challenges exacerbated by disease progression and cognitive impairment (Volicer,

2018). One such challenge is care refusal, defined as behaviors to resist a caregiver's assistance (Mahoney et al., 1999). Referred to by varied terminology, care refusal by older adults living with dementia is complex, subjective, and an underreported and understudied phenomenon (Konno et al., 2014; Featherston et al., 2019). Care refusal occurs across settings, and its prevalence estimates range widely from 9% (Volicer et al., 2007) to 59.8% (Fauth et al., 2015). Ultimately, care refusals compromise the well-being and safety of both the care provider and care recipient, leading to worse health outcomes and caregiver stress and burnout (Backhouse et al., 2020; Mortensen et al., 2021; Konno et al., 2014; Pizzicalla et al., 2015; Volicer & Hurley, 2003).

Despite being an important issue in dementia care, synthesis of evidence on care refusal has been limited (Backhouse et al., 2020; Featherston et al., 2019; Konno et al., 2014). Existing reviews have a narrow focus on management strategies while overlooking their determinants and effects (Backhouse et al., 2020; Gjellestad et al., 2022;

Ishii et al., 2012; Konno et al., 2014). A comprehensive understanding of this complex phenomenon is needed to inform care practices and research (Galik et al., 2017; Spiegelmyer et al., 2018). This scoping review will map the extent and nature of research on care refusal in older adults living with dementia, clarifying the determinants and effects of this phenomenon to guide evidence-based practices and future research (Arksey & O'Malley, 2005).

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Condition being studied The interest of this research arises from understanding care refusal as a common but complex behavior among older adults with dementia receiving professional care. As dementia progresses, neuropsychiatric symptoms often emerge, complicating care and limiting the understanding and cooperation of the person living with dementia (Volicer, 2018). Care refusal manifests in various forms - verbally through vocal refusal, physically through resistance, or passively through nonresponsiveness (Backhouse et al., 2023; Volicer, 2020). Prevalence estimates range widely due to subjective interpretations and inconsistencies in terminology and reporting (Ishii et al., 2012; Konno et al., 2014; Spiegelmyer et al., 2018). Nonetheless, care refusal is prevalent across all healthcare settings and care relationships for older adults with dementia, compromising safety, health outcomes, and quality of care (Backhouse et al., 2020; Galik et al., 2017; Konno et al., 2014; Pizzicalla et al., 2015).
Several factors likely contribute to care refusal in this population, among them: (i) unmet physical needs triggering refusal behaviors (Mast et al., 2022); (ii) cognitive impairments (Backhouse et al., 2020; Gjellestad et al., 2022); and (iii) environmental factors (Goodwin et al., 2023). This review aims to elucidate such determinants of care refusal among older adults living with dementia in care institutions and map the effects of care refusal on this population. A comprehensive understanding of this complex yet important phenomenon is needed to inform ethical, professional and person-centered approaches to dementia care and guide further research.

METHODS

Search strategy The following databases will be searched systematically from inception onwards: MEDLINE, CINAHL, MEDLINE, CINAHL, Web of Science, Scopus, and SciELO, using both commonly used keywords and database-specific terminology (i.e. MeSH terms). Reference lists of included studies will be hand-searched to find additional relevant studies.

Participant or population Institutionalized older adults aged 65 years and above with a dementia (of any type and severity) who are receiving professional care in a healthcare setting. People receiving informal care or in a home-care setting will be excluded.

Intervention Not applicable.

Comparator Not applicable.

Study designs to be included This scoping review will include primary research (quantitative, qualitative, mixed studies) and secondary research sources (systematic reviews). The search strategy will follow Arksey and O'Malley (2005). All sources will undergo screening for relevance to the topic and research questions. Both primary and secondary sources will be documented and cited appropriately. In data extraction and synthesis, quantitative analysis may summarize evidence from primary vs. secondary sources separately to avoid over-representing particular studies.

Eligibility criteria The inclusion criteria for this scoping review will be based on the Population, Context, and Concept (PCC) (1) Population: institutionalized older adults, aged 65 years or more, who have a dementia (2) Context: in an acute or long-term care setting (Hospital, Nursing home, assisted living, memory care, etc.) (3) Concepts: Care refusal behaviors and associated determinant factors and effects (Peters et al., 2015). Studies that deviate from these criteria are not eligible, namely those in the context of homecare or receiving informal care. Studies that were not peer-reviewed will also be excluded (e.g., gray literature, letters to the editor, and abstracts published in proceedings). Studies published in English, Spanish, French, or Portuguese will be included.

Information sources A comprehensive search will be conducted using the following electronic databases: MEDLINE, CINAHL, Web of Science, Scopus, and SciELO. Search strategies will be developed for each database using both commonly used keywords and database-specific indexed terminology. The search will be limited to literature published in the past 10 years in order to capture the most recent relevant literature on the topic. Reference lists of included studies will also be hand-searched. If full-text versions of articles cannot be located, attempts will be made to contact the study authors to have access to

otherwise unreachable papers. The scoping review will follow the PRISMA 2020 guidelines (Page et al., 2021).

Main outcome(s) This scoping review will map and synthesize evidence on the determinants and effects associated with care refusal behaviors exhibited by older adults with dementia receiving professional care in institutional settings. The results will provide an overview of existing knowledge on factors contributing to and outcomes related to care refusals. It will elucidate key concepts, identify research gaps, and inform practice and policy to improve care for this population. These findings will be disseminated through a published paper reporting the scoping review methodology and results, as well as conference presentations to reach stakeholders in the healthcare field.

Additional outcome(s) Not applicable.

Data management The review will follow the PRISMA 2020 guidelines for scoping reviews (Page et al., 2021). Two reviewers will independently conduct title/abstract screening and study selection. References will be managed using Mendeley software (version 1.19.8), and before initial screening, duplicated documents will be deleted. Selected articles will be screened in full-text review by two independent reviewers and the data extracted will be exported into a standardized Excel spreadsheet (version 16.42). Each article's rationale for inclusion or exclusion will be documented, and any disagreements will be resolved through discussion or with a third reviewer. Extracted data from the included studies will be presented through numerical presentation, narrative descriptions, tables, diagrams, and the scoping review flowchart (PRISMA-ScR). Information extracted will include study details (author, year, country), geographical context, sample characteristics, study design/methods, instruments, results on determinants and effects of care refusal by institutionalized older adults aged 65 years and above with a dementia receiving professional care in a healthcare setting.

Quality assessment / Risk of bias analysis The methodological quality of included studies will be assessed using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). This tool evaluates risk of different types of bias, inconsistencies and data inaccuracy.

Strategy of data synthesis A thematic analysis will be conducted by three reviewers to synthesize findings. First, tables will be created to chart extracted data from the studies. Second, coding will be performed to identify analytical themes related to determinants and effects of care refusals. These themes will be described and interpreted through a narrative discussion of the results. Findings will be presented using diagrams, tables, and text to provide an overview of the available evidence.

Subgroup analysis Not applicable.

Sensitivity analysis Not applicable.

Language restriction Studies published in English, Spanish, French and Portuguese.

Country(ies) involved Portugal, United States of America, Singapore.

Keywords dementia, older adults, refusal of care, determinants, effects.

Dissemination plans The results of this scoping review will be published in a peer-reviewed journal article, presented at relevant academic conferences, and will be a component of a PhD dissertation.

Contributions of each author
Author 1 - Joao Partel Araujo - Joao Partel Araujo, as main author and PhD candidate, will take the lead role in all stages of the scoping review including protocol design, literature searching, screening, data extraction and charting, synthesis, and manuscript development.
Email: joaopartelaraujo@gmail.com
Author 2 - Rosa Melo - Will provide supervision and guidance as PhD tutor and committee member, and will assist with study screening, selection, data extraction and manuscript development.
Email: rosamelo@esenfc.pt
Author 3 - Helena Amaro da Luz - Will provide supervision and guidance as PhD tutor and committee member, and will assist with study screening, selection, data extraction and manuscript development.
Email: helenareis.luz@fpce.uc.pt
Author 4 - Catherine Van Son - Will provide supervision and guidance as PhD tutor and committee member, and will assist with study screening, selection, data extraction and manuscript development.
Email: vansonc@wsu.edu
Author 5 - Anh Giang - Will serve as research consultant to advise on methodology decisions and analytic approaches regarding the scoping

review, manuscript development and dissemination of findings.

Email: giang.thuy.anh@ktph.com.sg

Author 6 - Liliana Henriques - Will serve as research consultant to advise on methodology decisions and analytic approaches regarding the scoping review, manuscript development and dissemination of findings.

Email: lilianahenriques312@gmail.com