INPLASY PROTOCOL

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Conflicts of interest: None declared. Mealtime difficulties in dementia: a scoping review protocol about the impacts of interventions on people with dementia, care staff and care context/ environment

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Background: Dementia is a syndrome characterized by the deterioration of cognitive function and the ability to perform daily activities, beyond the expected in primary ageing. In advanced stages, people with dementia may experience mealtime/feeding difficulties, usually manifested by oropharyngeal dysphagia, low food/fluids intake, refusal to eat, aversive behaviours, among others. These difficulties could lead to inadequate oral intake, weight loss, malnutrition and dehydration, dysphagia, pulmonary aspiration and respiratory problems, infections, weakness, fatigue, and reduced functionality in activities of daily living. Maintaining nutritional status becomes a challenge to family members, caregivers, and health professionals, who often need to decide on an alternative diet/hydration route. However international scientific societies do not recommend tube feeding for people in the late stages of dementia and suggest offer an adapted and careful oral hand feeding. Frequently, institutional care focuses only on performing tasks (offering lunch, for example), reducing several other components that caring involves. Managing the feeding difficulties from a socio-ecological perspective implies involving people with dementia, caregivers and also the environment where mealtime takes place. A care staff aware of feeding difficulties, and an environment that meets the residents' needs tend to improve the mealtime experience and consequently improve the nutrition and hydration of institutionalized people with dementia.

INPLASY registration number: This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 04 August 2021 and was last updated on 04 August 2021 (registration number INPLASY202180015).

INTRODUCTION

Review question / Objective: Review question: How do interventions on feeding difficulties for older people with dementia impact people with dementia, care staff, and care context/environment (according to nursing home administrators' perspectives)? Objective: To identify and summarize available research literature about mealtime/feeding difficulties interventions for people with dementia, and its impacts on institutionalized older people with dementia, care staff and care context/ environment.

Background: Dementia is a syndrome characterized by the deterioration of cognitive function and the ability to perform daily activities, beyond the expected in primary ageing. In advanced stages, people with dementia may experience mealtime/feeding difficulties, usually manifested by oropharyngeal dysphagia, low food/fluids intake, refusal to eat, aversive behaviours, among others. These difficulties could lead to inadequate oral intake, weight loss, malnutrition and dehydration, dysphagia, pulmonary aspiration and respiratory problems, infections, weakness, fatigue, and reduced functionality in activities of daily living. Maintaining nutritional status becomes a challenge to family members, caregivers, and health professionals, who often need to decide on an alternative diet/hydration route. However international scientific societies do not recommend tube feeding for people in the late stages of dementia and suggest offer an adapted and careful oral hand feeding. Frequently, institutional care focuses only on performing tasks (offering lunch, for example), reducing several other components that caring involves. Managing the feeding difficulties from a socio-ecological perspective implies involving people with dementia, caregivers and also the environment where mealtime takes place. A care staff aware of feeding difficulties, and an environment that meets the residents' needs tend to improve the mealtime experience and consequently improve the nutrition and hydration of institutionalized people with dementia.

Rationale: The feeding difficulties developed by people with dementia have been the subject of studies in recent decades. The causes and factors associated are already well known, thus allowing the development of preventive and intervention strategies to improve or reduce feeding difficulties. The literature already has some intervention studies with people with dementia, mainly in long-term care context, that describe the effectiveness of the actions taken having as the main outcome measures nutritional status, amount of food eaten, and the person with dementia's behaviour. Few more recent studies include the role of care staff in intervention programs, evaluating the impact on their skills, well-being, and job satisfaction. However, knowledge about the impacts of these interventions on care staff remains scarce and, to the best of our knowledge, there is a lack of studies focusing on the perspective of institutional managers about the impacts of these interventions on the care context/ environment. Thus, the authors propose in this protocol to carry out a scoping review on the impact of interventions in feeding difficulties on the triad: person with dementia, caregiver, and care context/ environment.

METHODS

Strategy of data synthesis: The proposed scoping review will be conducted following Joanna Briggs Institute (JBI) methodology. A search strategy will be developed to identify published and unpublished studies. First, a limited search was carried out in MedLine (via PubMed) to identify relevant articles on the topic and extract MESH terms and other relevant words and expressions contained in the titles, abstracts, and keywords to build a full search strategy. The following electronic databases will be searched: MedLine (via PubMed), Web of Science, Scopus, ScienceDirect, CINAHL Complete (via EBSCO) and SciELO. The search syntax will be composed by: ((dement* OR alzheimer*) AND ("older people" OR "old* person" OR elderly OR aged OR senior)) OR (caregiv* OR "formal caregiver" OR "direct care worker*" OR staff* OR nurs*) OR (manager* OR "health manager" OR administrator OR "nurse administrator" OR "nursing home administrator" OR "ALF administrator" OR "assisted living administrator") AND ((intervention* OR train* OR program*) AND ("feeding difficult*" OR "eating difficult*"

OR "mealtime difficult*" OR "mealtime challenge*" OR "mealtime management")) AND ("nursing home*" OR "long term care" OR "care home*" OR "residential facility" OR "home* for aged" OR "residential home" OR "elderly care" OR "residential care" OR "assisted living facility"). For each chosen database, the search syntax will be adapted to fit the requirements. The reference lists of articles included in the review will be screened for additional papers. A manual search for systematic review articles in the databases Cochrane, JBI and PROSPERO will be undertaken to identify additional papers of interest. The search on grey literature will include DART-Europe, OpenGrey, and RCAAP. Studies published in English, French, Portuguese or Spanish, from 1990 onward, will be considered for inclusion.

Eligibility criteria: Participants: This scoping review will consider all studies that included people with dementia (all types or degrees/stages), 60 years or over, nursing homes care staff and administrators. Studies with people with dementia in tube feeding (exclusive or not) will be excluded. Concept: This scoping review will include studies that focus on intervention in the feeding/mealtime difficulties of people with dementia. Context: This scoping review will consider interventions implemented and evaluated in long-term care (people with dementia must be institutionalized) and be designed exclusively for feeding/mealtime difficulties. Interventions designed for hospitalized or in community people with dementia will be excluded, as well as those with the participation of informal caregivers. Studies in which interventions are merely nutritional or pharmacological will also be excluded. Types of sources: This scoping review will consider quantitative, qualitative, and mixed-method studies. Quantitative designs involve any experimental studies, as randomized or non-randomized controlled trials and quasi-experimental (before and after studies), and observational studies, like descriptive, cohort, cross-sectional and case studies. Qualitative designs include studies that focus on qualitative data, such as but not limited to, explorative,

phenomenology, grounded theory, and ethnography designs.

Source of evidence screening and selection: The first author will perform the databases search and include all the references into Mendeley V1.19.8 (Mendeley Ltd., Elsevier, Netherlands) and duplicates removed. Then, two independent reviewers (LP and JT) will screen titles and abstracts against inclusion criteria. Studies that can meet the inclusion criteria will be retrieved in full text and assessed in detail against the inclusion criteria. They will be read entirety and those that do not meet the inclusion criteria will be excluded, and reasons for exclusion will be provided in an appendix in the final manuscript of the scoping review. Any disagreements between the reviewers will be resolved by discussion until consensus is reached, and if it is necessary a third reviewer (DF) will be involved to facilitate the process.

Data management: Two reviewers will extract data from the included studies: authors and year of publication, country, study design, type and description of the intervention, sample size and demographics, outcomes (for people with dementia, care staff, and care context), and main results. Disagreements will be resolved by consensus between the reviewers or with a third reviewer. Data will be extracted using a charting table, as indicated by the methodology for scoping reviews developed by JBI.

Reporting results / Analysis of the evidence: The results of the search will be reported in full in the final manuscript and presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) flow diagram.

Presentation of the results: A descriptive summary will complement the charted results and will explain how the results relate to the review's objective and question. Language: Eligible studies will be required to be published in English, French, Portuguese or Spanish language.

Countries involved: Portugal.

Keywords: Dementia; Interventions; Feeding difficulties; Mealtime difficulties; Older people; Nursing homes; Long-term care; Caregiver; Nursing assistants; Nursing home administrator; Care context.

Dissemination plans: Once the data analysis is completed, results will be published in a peer-reviewed journal and presented in relevant scientific conferences.

Contributions of each author:

Author 1 - Lígia Passos - The author created and developed this protocol. The author will select the studies, extract and analyse data, and also will write the manuscript for this scoping review.

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Author 2 - João Tavares - The author supported the preparation and development of the protocol and checked the search methodology. The author will participate in the selection of studies based on the inclusion criteria, as well as the critical review of the scoping review manuscript.

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Author 3 - Daniela Figueiredo - The author supported the preparation and development of the protocol and checked the search methodology. The author will participate in the checking of the data extraction for accuracy and detail, as well as the critical review of the scoping review manuscript.

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