INPLASY PROTOCOL

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The role of behavioral and psychological symptoms of dementia (BPSD) in patient's autonomy. A scoping review protocol

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Review question / Objective: This scoping review study aims to identify, summarize, and appraise available literature regarding the role of (BPSD)/neuropsychiatric symptoms in patients' autonomy with all types of dementia diagnoses. To accomplish this objective, this scoping review will address the following question: What is the role of behavioral and psychological symptoms of dementia in the patient's autonomy? This review will comprise the terms capacity, functional abilities, and competence in the autonomy concept. **Background:** Dementia is a neurodegenerative syndrome characterized by the development of multiple cognitive deficits and behavioral changes that interferes with multiple aspects of life, including cognition, daily functioning, and behavioral. With the progress of the disease, the patients lose their capacity, functional abilities, competence, and autonomy (Barbas & Wilde, 2001; Darby & Dickerson, 2017; Irastorza, Corujo, & Bañuelos, 2011; Lee, Jang, & Chang, 2019; Marson, 2013).

INPLASY registration number: This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 02 May 2022 and was last updated on 02 May 2022 (registration number INPLASY202250008).

INTRODUCTION

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Background: Dementia is a neurodegenerative syndrome characterized by the development of multiple cognitive deficits and behavioral changes that interferes with multiple aspects of life, including cognition, daily functioning, and behavioral. With the progress of the disease, the patients lose their capacity, functional abilities, competence, and autonomy (Barbas & Wilde, 2001; Darby & Dickerson, 2017; Irastorza, Corujo, & Bañuelos, 2011; Lee, Jang, & Chang, 2019; Marson, 2013).

Rationale: The correlation between the disease progression and the BPSD was confirmed in the literature, and numerous negative clinical and social consequences for patients and their caregivers are well known. These consequences include: increased caregiver's burden; reduced functional abilities and interference in the patient's capacity (Torrisi et al., 2017; Bertrand et al., 2017; Kato et al., 2021). Despite some studies on the subject, there aren't scoping or systematic reviews concerning neuropsychiatric symptoms/ BPSD impacts in patient's autonomy. For this reason, the authors propose in their protocol to carry out a scoping review on the role of neuropsychiatric symptoms/ BPSD in the patient's autonomy, thinking in a perspective of the consequence of this relationship for patients, families, and caregivers.

METHODS

Strategy of data synthesis: The proposed scoping review will be conducted following the Arksey and O'Malley's methodological framework (Arksey & O'Malley, 2005), Joanna Briggs Institute's methodology for scoping reviews (MDJ et al., 2020), and PRISMA extension for scoping reviews (PRISMA-ScR) checklist (Tricco et al., 2018). According to these, the following steps will be performed: identification of the main objective/research questions; identification of relevant studies; study selection; data extraction; collating; summarizing and reporting the results; consultation of relevant aspects of the research question. First, a limited search was carried out in MEDLINE (by PubMed) to identify relevant studies on the topic and extract MESH terms and other relevant free-text words and expressions contained in the titles, abstracts, and keywords to construct a relevant research query. The research query was then built with the assistance of a professional librarian. The search syntax will be composed by: (dementia OR Alzheimer OR "Lewy body disease") AND (BPSD OR "Behavioural and psychological symptoms of dementia" OR "neuropsychiatric symptom*") AND (autonomy OR "functional abilit*" OR capacity OR competence). The following electronic databases will be searched: MedLine (by PubMed), Web of Science, Scopus and APA PscycArticles, APA **PsyInfo and Behavioral Sciences Collection** (by EBSCO) and search strategy was then adapted for each of these information sources.

Eligibility criteria: Participants or population: patients with a clinical diagnosis of any type of dementia. Concept: the relationship between the neuropsychiatric symptoms or BPSD and the patient's autonomy. Context: the progress of any type and stage of dementia. This scoping review will consider quantitative, qualitative, and mixed-method studies. Quantitative designs involve any prospective and retrospective observational cohort studies; controlled before-and-after studies; case-controlled studies; cross-sectional studies; case series. Narrative literature review, letters, and correspondence reports will be excluded.

Source of evidence screening and selection: The data screening and selection will involve two independent reviewers. The first author will perform the database search, including all references into Mendeley Desktop Version 1.19.8. The reference management will remove the duplicated studies. The first and the second author will screen titles and abstracts regarding the inclusion criteria. Studies will be selected for complete text analyses when they fit the eligible criteria. They will be read in their entirety, and the two reviewers will select the studies with scoping review eligible criteria. The authors will descript as the search decision process accompanied by the search decision flowchart as indicated PRISMA flow diagram for a scoping review process (MDJ et al., 2020).

Data management: The data management will implicate two independent reviewers in this process. . Data will be reported using an adapted chapter as the table indicated by the JBI methodology for scoping reviews. A summary of each article will include: authors, year of publication, study origin/country of origin, aims/purpose, study population and sample size (if applicable), etiology of dementia, features of autonomy involved in the study, neuropsychiatric symptoms/BPSD involved in the research, measures for the evaluation of neuropsychiatric symptoms/ BPSD, methodology/methods, intervention type and comparator (if applicable), outcomes and details of these, and key findings that relate to the review questions.

Reporting results / Analysis of the evidence: The results of the research will be described in integrality 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 (MDJ et al., 2020).

Presentation of the results: The extracted data will be presented in diagrammatic or tabular form. A descriptive summary will complement the tabulated results and will explain the relationship between the results and the review's objective and question.

Language: English, Portuguese, Italian, French and Spanish.

Countries involved: Portugal.

Keywords: Dementia; Alzheimer's disease; Levy body disease; BPSD; Behavioral and psychological symptoms of dementia; neuropsychiatric symptoms; autonomy; functional abilities; capacity; competence.

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

Contributions of each author:

Author 1 - Valeska Delineau - The author created the study design, prepared and developed the protocol, and checked the search methodology. The author will participate in selecting studies and the critical review of the scoping review manuscript.

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Author 2 - Ligia Passos - The author supported, prepared, and developed the protocol. The author will participate in the selection of studies and the critical review of the scoping review manuscript.

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