# INPLASY

## Supporting the personhood, citizenship, and autonomy of people with dementia living at home: a scoping review protocol

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## ADMINISTRATIVE INFORMATION

## INTRODUCTION

**R**eview question / Objective To map the research evidence on strategies proposed by formal or community-based institutions to support the personhood, citizenship, and autonomy of people with dementia living at home. The questions for this scoping review are:

- How are autonomy, personhood, and citizenship of people with dementia living at home being supported through homecare and day care services? (e.g., protocols, activities, initiatives, etcetera)

- What are the indicators/attributes associated with supporting autonomy, personhood, and citizenship at the service level?

- What are the reported factors influencing the support of these values in home care/ support services?

**Background** The provision of healthcare for older people has increasingly focused on enabling them to stay at home for as long as possible (Donnelly et al., 2016; Gage et al., 2015). This is driven by various factors, ranging from cost-effectiveness (Gage et al., 2015; Kringos et al., 2015; Tucker et al., 2008) to the preference of older individuals themselves, including those with complex cognitive care needs such as dementia (Iwarsson et al., 2007; Tucker et al., 2008). Depending on the country, home care can encompass a broad range of services including home nursing, house cleaning, shopping, transport, day care, and home visits, among others. For this review we are including medical and non-medical support to people in their own homes, as defined by Low et al.(2015). By medical support we will refer to services provided by medical, nursing and generally health professionals, and by non-medical support, we mean community care or social care such as case management, integrated care, consumer directed care, and restorative care (Low et al., 2011; Low & Fletcher, 2015).

Dementia is a progressive neurodegenerative condition that significantly impacts on quality of life, as well as an individual's ability to continue living independently. It is the leading cause of disability in older populations and is a significant contributor to loss of independence, disability and care home placement (Prince et al., 2013).Furthermore, it presents a significant challenge globally, with over 55 million people currently living with dementia worldwide and projecting to reach 78 million by 2030 (Gauthier et al., 2021). In response, there is a growing emphasis in diverse countries on facilitating individuals with dementia to remain in their homes while sustaining independence in daily activities for as long as possible (Mazurek et al., 2019).

The paradigm shift in dementia care over recent decades has steered away from a predominantly biomedical approach towards a more person-centered perspective, catalyzed by the work of Kitwood (1997) on personhood. This value prioritizes the recognition and tailored response to the unique needs, values, and beliefs of individuals with dementia. Building upon Kitwood's framework, subsequent authors have broadened the scope of dementia care models, introducing elements such as autonomy and citizenship. In this context, autonomy is to be understood from McCormack 's (2001) definition, which describes two sides: (a) decisional autonomy, which refers to the ability and the freedom to make choices; (b) executional autonomy, referring to the ability and freedom to carry out and implement such choices. Citizenship is to be understood as a dynamic practice that happens at both macro and micro levels, and is enacted through a person's participation in everyday life (Nedlund & Nordh, 2018). These three values -personhood, autonomy and citizenship-have evolved towards a relationality and interdependency, whereby all agents involved in the process of care influence each other and the care outcomes through continuous interaction and time (Bartlett, 2022; Bartlett & O'Connor, 2010; Klein, 2022).

Despite the incorporation of these key values and person-centeredness being recognized as a synonymous with high standards of care in dementia (Bosco et al., 2019), there is still debate on how to better conceptualise and operationalise them in practice (Klein, 2022). Moreover, it has been noted that their recognition does not necessarily entail their promotion (Bosco et al., 2019). This review is interested in clarifying what are the mechanisms being utilized by diverse home-care services to support the autonomy, personhood and citizenship of people living with dementia at home.

**Rationale** Through a preliminary literature review on autonomy, personhood, and citizenship within the context of dementia care through PubMed, the Cochrane Database of Systematic Reviews and JBI Evidence Synthesis, we identified a range of scoping and systematic literature reviews aimed at conceptualizing these values (Baldwin & Greason, 2016; O'Connor et al., 2022), determining best practices to support them (Bosco et al., 2019; Boumans et al., 2019; Innes et al., 2021), and exploring their intersections with gender (Bartlett et al., 2018). However, our examination revealed that most of these reviews are focused on one value (e.g. citizenship but not autonomy or personhood) and predominantly include studies on the residential care setting, with limited evidence addressing the support of these values within home care/home support services.

Firstly, we argue that it is important to consider autonomy, personhood, and citizenship as key values in high-quality dementia home care and advocate for their more comprehensive integration into service protocols and strategies. Furthermore, we hypothesize that some strategies employed by home care/home support services likely encompass aspects of more than one of these values, yet no reviews have analyzed this aspect. Secondly, this review would contribute to better defining the attributes or indicators currently associated with these values at the service level, which can inform future research and practice on how to operationalize them and evaluate them in different stages of the care continuum.

A scoping review was chosen as the methodology for this study due to its ability to offer a comprehensive overview of existing literature within a specific field, encompassing its nature, features, and volume (Arksey & O'Malley, 2005). They serve to assess and comprehend the extent of knowledge within an emerging field, while also identifying, mapping, reporting, or discussing its characteristics or concepts (Peters et al., 2020). Therefore, we consider that a scoping review is well-suited for exploring the breadth of strategies and interventions being used to support the autonomy, personhood, and citizenship of people with dementia living at home, the challenges associated with this, and the indicators being used to evaluate such strategies. The results from this review may enhance the overall understanding of these values in the context of people with

dementia living at home and map the initiatives currently used to support them. Furthermore, it will contribute to the discussion on how to operationalize and evaluate the support of such broad concepts.

## METHODS

**Strategy of data synthesis** The review will adhere to the PRISMA-ScR guidelines to ensure consistency in data extraction, reporting procedures, and outcomes. A comprehensive search will be conducted across electronic databases including Medline, Scopus, EBSCO (including Academic Search Complete, AgeLine, APA PsycInfo, APA PsycArticles, CINAHL Complete), and Web of Science. To develop the search strategy, an initial exploration of PubMed was conducted to identify pertinent articles. Keywords and index terms extracted from relevant titles and abstracts were utilized to formulate the complete search strategy for this review. For a detailed outline of the full search strategy, refer to Table 1.

**Eligibility criteria** This scoping review will focus on the peer-reviewed literature. Therefore, it will include published and peer-reviewed sources of quantitative, qualitative, or mixed method studies encompassing any type of study designs. The reference list of all included sources of evidence will be screened for hand-picking additional studies, following the guidelines of Arksey and O'Malley (2005). Systematic reviews, meta-analyses, unpublished studies, and grey literature sources (e.g. reports and conference abstracts) will be excluded from this review. The search strategy will encompass 2000-2024, to reflect the impact of the work of Kitwood (1997) on the recognition of personhood and the introduction of person-centred care as key elements of dementia care.

The inclusion criteria for this review are based on the Person-Concept-Context (PCC) framework recommended by JBI for conducting scoping reviews as a guide to construct a clear inclusion criteria (Peters et al., 2020):

Population: This scoping review will consider all studies that include older people with dementia (65 years or more), of all stages, living at home. However, we will exclude studies only focusing on early onset dementia, since the support of autonomy, personhood and citizenship will probably be operationalised through different strategies. All ethnicities and genders will be included.

Concept: This review will consider studies that explore the support of autonomy and/or personhood, and/or citizenship of people with dementia living at home. Studies will be excluded when not clearly reporting on these concepts.

Context: This review will consider studies of older people with dementia residing at home or in the community, independently of the country.

**Source of evidence screening and selection** The records sourced from database searches will be gathered and organized within Zotero, eliminating any duplicates. Subsequently, citations will be imported into ASReview LAB (Version v1.3) for examination. The reviewer will evaluate titles and abstracts to ascertain compliance with inclusion criteria. Studies with unclear abstracts or uncertain relevance will undergo full-text screening. Potentially eligible studies will then undergo thorough assessment against inclusion criteria. Full-text studies failing to meet inclusion criteria will be excluded. Finally, reference lists of included articles will be scrutinized for additional pertinent citations, as proposed by (Arksey & O'Malley, 2005). The results of the search and the study inclusion/exclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (Tricco et al., 2018).

**Data management** Data will be extracted using the data extraction tool developed by the reviewer (see Table 3 for a draft of such tool). Such data will include details about the author, year of publication, country of origin, study aims, methods, type of participants, and key findings relevant to the review questions.

The data extraction tool was developed based on the 'JBI template source of evidence details, characteristics, and results extraction instrument' (Aromataris & Munn, 2020). Throughout the process of extracting data from the evidence sources, the tool will be refined as deemed necessary. Any modifications will be documented as part of the scoping review methods. In instances where data are absent in the extracted studies, the authors will be contacted for supplementary information. The extracted data will be organized into a single Microsoft Excel spreadsheet.

**Reporting results / Analysis of the evidence** After the all the data from the included studies have been tabulated in the main data extraction excel sheet, the data will be categorised and summarised. For quantitative results, we will a)

report the number and proportion of studies using each method/strategy used to support autonomy, personhood, or citizenship; b) report on the indicators/attributes linked with the key values and the frequency with which they are mentioned; and c) report on the factors affecting the support of these values in the home care setting.

For qualitative results, we will report on the indicators/attributes, strategies, and evaluation methods identified will be categorized under "autonomy", "personhood" or "citizenship" depending on the value(s) they are supporting. Furthermore, we will report on strategies supporting more than one value, which can help to broaden the definition of high-quality care for people with dementia. To increase the quality of the analysis, these findings will be validated through a triangulation process with academic experts on the topic.

**Presentation of the results** The findings of the study will then be presented according to the PRISMA-ScR checklist. A PRISMA flow chart will be used to present the methodological process in detail, and the results of included studies will be grouped according to the concept(s) (autonomy/ personhood/ citizenship) they report on. Furthermore, they will be categorised based on the type of strategy used to support the values, population (type and stage of dementia) and method of assessment used to evaluate the strategy. Gaps in literature will be discussed, and areas for further research will be identified and reported.

**Language restriction** Only studies in English, Spanish or French will be included.

**Country(ies) involved** Italy.

**Keywords** Dementia, Home care, Home support, Autonomy, Personhood, Citizenship.

**Contributions of each author**
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**Table 1. Search strategy for Scopus**

| | Query |
|---|---|
| #1 | Dement* OR Alzheimer*or lewy |
| #2 | "home care" OR homecare OR "home care service*" OR "community health*" OR "independent living" OR "aging in place" OR "community dwelling" OR "social support" OR "senior center*" OR "social work*" OR "family care*" OR "day center*" |

| #3 | autonom* OR freewill OR "free will" OR "free-will" OR selfdetermination OR "self determination" OR "self-determination" OR citizen* OR "human right*" OR personhood OR "person hood" OR selfhood OR "self hood" OR "self-hood" OR *identity OR dignity OR respect OR "self concept" OR selfconcept OR "sense of self" |
|---|---|
| | #1 AND #2 AND #3<br><br>Limits:<br>- Title, Abstract, Keywords<br>- After year 2000<br>- Only English, Spanish and French language |

*Table 2 Inclusion and exclusion criteria based on the Population, Concept and Context (PCC) framework*

| | Inclusion criteria | Exclusion criteria |
|---|---|---|
| Population<br>People with dementia living at home | Studies are included if they:<br>• Included people with a diagnosis of dementia.<br>• Includes all ethnicities and genders. | • The population does not have a diagnosis of dementia.<br>• If the study does not mention older adults explicitly or describe their population as adults aged 65 or above.<br>• If the study only involves people with early onset dementia. |
| Concept<br>Support of autonomy, personhood, and citizenship for people with dementia living at home | Studies are included if they:<br>• Explicitly mention these values in the context of dementia care for people living at home.<br>• Mention the intent to support one or more of these values in dementia care services. | • Do not mention any of these values or key words associated with them. |
| Context<br>Home setting | Studies are included if they:<br>• Include participants living in their homes/ in the community.<br>• Includes those who are living in the community and using day care and home care services.<br>• Includes all countries. | Focus exclusively on:<br>• Experiences of people with dementia in care and residential homes, inpatient settings, or hospitals. |

| Study design | Studies are included if they:<br>• Are published and peer reviewed.<br>• Are quantitative, qualitative, or mixed method studies encompassing any types of study designs.<br>• Identified to be relevant from the reference list of included sources. | Studies are excluded if they:<br>• Are systematic reviews or meta-analyses.<br>• Are unpublished studies and grey literature sources (e.g. reports and conference abstracts). |
| --- | --- | --- |
| Year of publishing | Studies from 2000-2024 will be included | Studies conducted before 2000 |

*Table 3: Data extraction tool*

| Scoping Review Details | |
| --- | --- |
| Scoping Review title: | Supporting the personhood, citizenship, and autonomy of people with dementia living at home: a scoping review protocol |
| Review objective/s: | To map the research evidence on strategies/initiatives proposed by formal or community-based institutions to support the personhood, citizenship, and autonomy of people with dementia living at home. |
| Review question/s: | • How are autonomy, personhood, and citizenship of people with dementia living at home being supported through homecare and day care services? (e.g., protocols, activities, initiatives, etcetera)<br><br>• What are the indicators/attributes associated with supporting autonomy, personhood, and citizenship at the service level?<br><br>• What are the reported factors influencing the support of these values in home care/support services? |
| Inclusion / Exclusion Criteria | |
| Population | Inclusion:<br>- People living at home, diagnosed with any stage of dementia, regardless of ethnicity or gender.<br><br>Exclusion:<br>- Institutionalised individuals |
| Concept | This review will consider studies that explore the support of autonomy, citizenship, and personhood of people with dementia living at home |
| Context | This review will consider studies on community-dwelling or people with dementia living at home, not limited by countries. |

| | |
|---|---|
| Types of evidence source | This scoping review will include quantitative, qualitative, or mixed method studies encompassing any types of methods and study designs. |
| **Evidence source Details and Characteristics** | |
| Author(s) | |
| Year of publication | |
| Origin (where study was conducted) | |
| Aims | |
| Value(s) they are focusing on (autonomy and/or personhood and/or citizenship) | |
| Population and sample size | |
| Study methods | |
| Results | |
| Method/strategy used to support the key values | |
| Attributes/indicators associated with the key values | |
| Evaluation methods of implemented strategies | |