Apathy in older people living with a major neurocognitive disorder in long-term care homes: A scoping review protocol

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Abstract

Background: Apathy has major consequences for older people (e.g., deconditioning), their family care partners and formal caregivers. Although systematic reviews have been conducted, they have focused on the effectiveness of interventions to reduce this behaviour. Furthermore, they have not been specific to long-term care homes, despite studies conducted in that setting. However, older people in this setting have very different characteristics and more severe cognitive impairment than those in the community. For this reason, knowledge about existing interventions, causes, associated factors, and consequences of apathy is needed to choose or develop personalized interventions. Thus, this scoping review aims to map the state of knowledge about apathy in older people living in long-term care homes to develop personalized interventions. The Senses Framework, which provides a humanistic and relational perspective to examine apathy, will guide this review.

Methods: Levac, Colquhoun, and O'Brien (2010) scoping review methods will be used. Eleven databases (e.g., CINAHL, MedLine, PsycINFO, Web of Science, Grey Literature Report) will be searched for literature using a combination of keywords and descriptors. Other data sources will be used to identify non-indexed literature or unpublished results (e.g., article references, journal tables of content, contact with key authors). The literature will be selected if it concerns older people, aged 65 or older, with a major neurocognitive disorder who exhibit apathy and live in long-term care homes. Data will be extracted using standardized extraction grids. A quality assessment of the literature will be done to consider this aspect in the data synthesis. A content analysis will be used to synthesize the results, as well as tables and graphs.

Discussion: No scoping review has been found on apathy in older people living with a major neurocognitive disorder in long-term care homes. The results of this review will help identify the needs for further research and clinical and training development on this problem from a humanistic and relational perspective. It will also guide the development of personalized interventions.

Keywords: Alzheimer's disease, behavioural and psychological symptoms, aged, geriatrics, cognition disorders, dementia, systematic review, causes, factors, consequences, interventions

Background

Apathy is the most common behavioural symptom associated with a major neurocognitive disorder (NCD). Based on a recent meta-analysis of 13 studies about the prevalence of symptoms manifested by people living with an NCD, the pooled prevalence of apathy was 54%, with ranges across studies varying from 24% to 89% (Leung et al., 2021). This prevalence also appears consistent across severity stages of an NCD, although some studies suggest that apathy is more prevalent in moderate and severe stages (Fuh et al., 2005; Kazui et al., 2016; Zhao et al., 2016).

Many definitions have been proposed, some presenting apathy as a behaviour (Landes et al., 2001; Levy & Dubois, 2006; Massimo et al., 2018), a syndrome (Chow et al., 2009; Cipriani et al., 2014; Marin, 1991; Pagonabarraga et al., 2015; Robert et al., 2009), or a symptom (International Psychogeriatric Association, 2012). It is often defined as a lack of motivation that has affective/emotional, behavioural and/or cognitive dimensions (Chow et al., 2009; Cipriani et al., 2014; Lanctot et al., 2017; Robert et al., 2009). However, this definition can be problematic as motivation is not directly observable, and apathy is itself a behaviour. Therefore, we adopted Levy and Dubois's (2006) definition of apathy: "a quantitative reduction of voluntary, goal-directed behaviours" (p. 916). These authors describe three subtypes of apathy that are coherent with various dimensions mentioned in other definitions and are based on the underlying mechanisms responsible for the behaviour, i.e., disruption of emotional-affective, cognitive, and auto-activation processing. The subtype of emotional-affective apathy is associated with emotional blunting or loss of interest. The cognitive subtype refers to apathy associated with difficulty planning and slowness after stimulation. And the subtype of auto-activation is related to a lack of activation of thoughts or behaviours unrelated to an emotional or cognitive disruption (Levy & Dubois, 2006). Multiple concurrent subtypes are possible as they have different underlying cerebral mechanisms. Also, apathy may or may not be concurrent with depression, but it is clinically and pathologically considered distinct.

Regardless of the subtype, apathy has significant consequences for older people, their family care partners and formal caregivers. For older people, it can lead to physical deconditioning, decrease their capacity to participate in their activities of daily living, create social isolation or trigger uncooperativeness (Massimo et al., 2018; Politis et al., 2004; Villar et al., 2021). It can also increase their mortality (Ishii et al., 2009; Kolanowski et al., 2017; Massimo et al., 2018; Nijsten et al., 2017; Villar et al., 2021), and it is associated with a reduced quality of life in the ones with less cognitive impairment (Gerritsen et al., 2005; Ishii et al., 2009). Apathy can also affect their nutritional status (Benoit et al., 2008; Ishii et al., 2009) and increase the number of psychotropic prescriptions (Benoit et al., 2008). For family care partners, apathy is associated with an increased burden (Benoit et al., 2008; Ishii et al., 2009; Kolanowski et al., 2017) and a higher level of depression (Kolanowski et al., 2017). Finally, in formal caregivers, it exacerbates work dissatisfaction and distress (Politis et al., 2004).

Systematic reviews have been conducted about apathy in people living with an NCD. They focused on pharmacological (Drijgers et al., 2009; Harrison et al., 2016; Ruthirakuhan et al., 2018; Sepehry et al., 2017) or non-pharmacological interventions to reduce apathy (Brodaty & Burns, 2012; Goris et al., 2016; Theleritis et al., 2018; Verkaik et al., 2005). However, these reviews were not specific to older people living in a long-term care home (LTCH), even though they manifest more advanced NCD (Fagundes et al., 2021; Gonzalez-Colaco Harmand et al., 2014) that may alter the prevalence of apathy. In addition, the findings do not distinguish between interventions that can be implemented in LTCH from those in home care, despite their significant differences. These reviews also did not consider factors influencing the manifestation of apathy (i.e., something that contributes or is associated with apathy, for example, environmental or relational aspects), its causes (i.e., something that directly brings about apathy as an effect, for example, a biological mechanism), or its consequences on people living with an NCD, their family care partners and formal caregivers.

Still, some studies have been found regarding interventions for apathy specific to LTCH (Leone et al., 2013; Politis et al., 2004). Others are not specific about apathy but include this behaviour as a secondary outcome in this same context (D'Cunha et al., 2021; Husebo et al., 2014; Tsoi et al., 2018). Finally, few studies focused on factors associated with apathy in the context of LTCHs (Ellis et al., 2016; Leontjevas et al., 2018; Mouriz-Corbelle et al., 2021; Volicer et al., 2013).

To our knowledge, a review examining apathy in LTCHs has yet to be published despite some recent studies. As such, it is unclear whether the interventions included in the published reviews apply to LTCHs. Moreover, the causes, associated factors, and consequences of apathy are not addressed in reviews regarding apathy, even in other settings, when these should be considered in developing interventions.

To establish the current state of knowledge on apathy in LTCHs that could guide the development of personalized interventions, our systematic scoping review will consider its causes, associated factors, and consequences, as well as existing interventions specific to older people living with an NCD in LTCHs. To this end, our scoping review will be conducted systematically to map the state of knowledge of apathy in older adults with NCD living in this setting. This type of review allows the extensive identification, analysis, and synthesis of knowledge in a literature domain by considering many publication types and is not limited to intervention studies (Paré et al., 2015). In this way, additional elements for developing personalized interventions can be explored. Four questions will guide this scoping review about apathy in older people living with an NCD in LTCH:
1) What is known about the factors associated with apathy?
2) What is known about the causes of apathy?
3) What is known about the consequences of apathy on the various stakeholders involved (including older people, their family care partners and formal caregivers)?

4) What is known about interventions to prevent and/or manage apathy?

The Senses Framework will guide this review (Nolan et al., 2004). This framework describes the importance of mutual relationships between older people, family care partners and formal caregivers in providing humane care. It also indicates that everyone's needs must be considered to promote collective well-being. It will be used to guide data extraction as each publication will be examined to assess if and how the relationships between those stakeholders are addressed. This will be done for the results of each research question. These data will allow us to draw conclusions on which aspects should be considered in developing personalized interventions.

Methods

The scoping review methods suggested by Levac, Colquhoun, and 'O'Brien (2010) will be used to map the state of knowledge on apathy in older people living with an NCD in an LTCH. These methods follow six stages: identify the review questions; identify the literature; select the literature; extract the data; present the results; and consult knowledge users. The scoping review will be conducted iteratively to adjust and refine the method throughout the study. This protocol will therefore serve as a basis for highlighting and documenting the changes made. It is consistent with the items proposed by the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) (Moher et al., 2016; Shamseer et al., 2015). Some items (1b, 2, 4, 13, 14, 15a, 15b, 15c, 16, 17) were not included as they are not adapted to a scoping review or this project (Peters et al., 2022). This protocol is not registered since the International Prospective Register of Systematic Review (PROSPERO) does not yet allow this type of systematic review registration. However, the protocol will be made available on an open-access online research platform to ensure transparency in our process (Allers et al., 2018; Moher et al., 2009).

Identify the Literature

Information sources

As suggested by Cooper (2010), four categories of sources will be targeted to identify the literature. First, many databases will be searched: Cumulative Index to Nursing and Allied Health Literature (CINAHL Complete, EBSCOhost), MEDLINE (Ovid), Embase (Ovid), APA PsycINFO (Ovid), EBM Reviews - Cochrane Database of Systematic Reviews (Ovid), Web of Science, Trip, Dissertations & These Global (ProQuest), Epistemonikos, Social Services Abstract (ProQuest), and Social Work Abstract (EBSCO). The reference list of included literature will be examined, and a prospective citation search of key literature will be carried out in Google Scholar. Second, governmental and organizational websites will be explored (e.g., National Institute for Health and Care Excellence, Alzheimer's Society, Alzheimer's Association, Registered Nurses and Gerontological Associations). Finally, key authors on apathy will be contacted to identify non-indexed or additional relevant literature.

For the database search, initial keywords and descriptors will be determined by a research assistant and the principal investigator (PI), with the help of a librarian, for the following four concepts (see Table 1): 1) apathy; 2) older people; 3) neurocognitive disorder; and 4) long-term care home. In collaboration with the librarian, the research assistant will do an initial round of searching in CINAHL and MEDLINE to refine the keywords and descriptors iteratively. Once the PI and the librarian judge the search strategy as sensitive enough, a search with these refined keywords and descriptors will be carried out in the other databases and websites mentioned above.

Table 1. Major concepts and related initial keywords that will be used to build the search strategy.

Concept 1	Concept 2	Concept 3	Concept 4
Apathy	*Older people*	*Neurocognitive disorder*	*Long-term care home*
Apath*	Aged	Alzheimer*	Aged care establishment*
	Elder* adult	Cognit* afflict*	Aged care facilit*
	Elder* people	Cognit* condition*	Aged care home*
	Elder* person	Cognit* decline*	Aged care residence*
	Elder patient	Cognit* disabilit*	Extended care cent*
	Elderly	Cognit* disease*	Extended care establishment*
	elders	Cognit* disorder*	Extended care facilit*
	Geriatric*	Cognit* dysfunction*	Extended care home*
	Gerontolog*	Cognit* handic*	Extended care residence*
	Older adult*	Cognit* impairment*	Long term care cent*
	Older people	Cognit* issue*	Long term care establishment*
	Older person*	Cognit* limit*	Long term care facilit*
	Older patient	Cognit* problem*	Long term care home*
	Senior*	Cognit* syndrom*	Long term care residence*
	Centenarian*	Cognit* trouble*	Nursing home*
	Nonagenarian*	Dementia	Residential and long-term care cent*
	Octogenarian*	Lewy Bod*	Residential care cent*
		Neurocognit* afflict*	Residential care establishment*
		Neurocognit* condition*	Residential care facility*
		Neurocognit* decline*	
		Neurocognit* disabilit*	
		Neurocognit* disease*	
		Neurocognit* disorder*	

		Neurocognit* dysfunction* Neurocognit* handic* Neurocognit* impairment* Neurocognit* issue* Neurocognit* limt* Neurocognit* problem* Neurocognit* syndrom* Neurocognit* trouble*	Residential care home* Residential care residence* Skilled nursing cent* Skilled nursing establishment* Skilled nursing facilit* Skilled nursing home* Skilled nursing residence*

Data Management

The literature from the different data sources will be imported into EndNote™ 20. A research assistant will remove duplicates using an automatic built-in function integrated into this software, and the remaining ones will be removed manually. References will then be imported into the Covidence web application for the literature selection and data extraction stages, both conducted by two independent persons.

Select the Literature

Eligibility Criteria

To meet the aim of this scoping review, the literature that meets the following population-concept-context (PCC) criteria will be included in the review.

Population. The review will include literature on humans aged 65 and older (or with an average or median age of 65 and older) with a mild, moderate or severe NCD, as defined by the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5-TR; American Psychiatric Association, 2022). For example, this includes Alzheimer's disease, frontotemporal lobar degeneration, Lewy body disease, vascular disease, and mixed disease. Based on the Senses Framework (Nolan et al., 2004), literature about family care partners or formal caregivers of that population will also be included if it answers the research questions. Literature on people in a vegetative state or a coma will be excluded.

Concept. The core concept of this scoping review is apathy (defined in the background section). Literature on a group of behaviours will be included if it allows us to clearly distinguish the findings regarding apathy based on the title or abstract. Literature about factors associated with the apathy of older people living with NCD, the causes of this behaviour, and its consequences on different stakeholders (e.g., older persons, family care partners, formal caregivers) will be included. Literature on interventions to prevent and/or manage apathy will also be included.

Context. Literature concerning explicitly LTCH or similar settings (e.g., skilled nursing facilities) will be included if they offer the presence of nurses 24h a day. Publication about other types of settings offering mainly personal assistance (e.g., assisted living facilities) will be excluded. In publications that include various types of settings, only the ones with most of the sample being from an LTCH will be included. Literature from all countries will be included.

Type of Records. The search strategy will be limited to English, French or Spanish literature. No year's limit will be used. All types of literature will be considered. This includes, for instance, primary studies (e.g., quasi-experimental, experimental, qualitative, and mixed-method designs), literature reviews (e.g., narrative reviews, meta-analysis, systematic reviews), grey literature (e.g., governmental reports, theses), as well as theoretical articles. To focus on scientific and clinical literature with sufficient content to help answer our questions, the following will be excluded: conference abstracts or proceedings, protocols, editorials, expert opinions, commentaries, letters, summaries of an article, book reviews, books, book chapters, magazines, publications without an author, personal story, personal blogs, media, and social media.

Screening Process
First, the literature will be screened based on the title and abstract of identified references with the eligibility criteria and the review questions. The literature will be organized as relevant (included) or non-relevant (excluded). The publications deemed relevant or of uncertain relevancy at this stage will be read in full to validate their eligibility. Reasons for exclusions will be documented at the full-text review stage. Two independent persons will carry out the screening and full-text review in duplicate, one of them always being the research assistant (CP) or the PI (AB). Conflicts between two screeners will be discussed between the research assistant and the PI to reach a consensus. The other research team members will be involved, if needed, to resolve the remaining conflicts and iteratively adjust the protocol, as expected in a scoping review (Levac et al., 2010).

Before starting the screening based on titles and abstracts and the one based on the full-text review, a calibration process using at least 10 documents will be undertaken. The results of the calibration processes will be discussed with all team members. After screening a certain number of publications (100 for the screening with abstracts and 20 with full-text), the research team will meet to discuss if adjustments are needed to the eligibility criteria. If needed, this step will be repeated with another number of publications until the screening process is clear.

Extract the Data
Once the screening and full-text review processes are completed, two independent team members will independently extract the data in duplicate. One of the extractors will resolve the consensus with the research assistant or PI. If there are more than 20 documents to be

extracted, the first 20 will be extracted independently by two people in duplicate, and the following ones will be done by only one person with uncertainties tagged for discussion and resolution by consensus with the research assistant or PI. This is justified by the little additional value of independent extraction after many documents have been extracted. As Levac et al. (2010) recommend extracting only five to ten documents independently, our proposed protocol is more stringent to ensure similar extraction between extractors. Also, a calibration process using 4 documents will be undertaken before starting data extraction. The results of the calibration processes will be discussed with all team members.

Using tables built in Covidence, the following data will be extracted from the selected literature and will be influenced by the Senses Framework (Nolan et al., 2004) for the extracted data:

1. General data: title, year of study publication, first author surname, the discipline of the first author, country of the first author's affiliation, type of literature (i.e., primary study, literature review and its type, grey literature, theoretical article), aim/research questions of the study;
2. Theoretical data: explicit use of a framework to identify relevant variables, guide the design or development of an intervention, guide the conduct of the study, or explain the relationship between variables, if mentioned;
3. Methodological data (if an empirical study): research design (i.e., randomized trial, quasi-experimental study, cohort study, descriptive study, correlational study, qualitative study, mixed-methods study, case study, case report, case series, case-control study, action research, other), number of participants recruited, participants' characteristics (i.e., mean, [and standard deviation] or median [and interquartile range]) age of participants, the proportion of female participants (versus male), frequency and proportion of neurocognitive disorder diagnosis in participants (i.e., Alzheimer's disease, frontotemporal lobar degeneration, Lewy body disease, vascular disease, mixed disease, other), the severity of cognitive impairment as measured in the study, name of data collection tools and measures timing;
4. Results data: results on factors, causes, consequences, or interventions (nature of the intervention based on the following items of the TIDieR checklist, i.e., name, procedure, provider, modes of delivery, number of times it was administered [Hoffman et al., 2014], as well as its effects) associated with the apathy of older people living with a neurocognitive disorder in a long-term care home, whether these results consider the relationship between the older person, their family care partners and formal caregivers and, if so, how.

Although it is not required in a scoping review (Levac et al., 2010), we will assess the quality of the literature during the data extraction process and present the results. As the goal is to consider the quality of the knowledge available, publications will not be excluded based on this appraisal. Each publication will be judged as having good, moderate, or poor methodological quality. The critical appraisal tools developed by the Joanna Briggs Institute

(JBI) will be used. These tools are based on the type of research design and were approved by the JBI Scientific Committee following extensive peer review. They include questions (between 6 and 13) that allow for an overall judgment on the quality. For each type of document or study, the following critical appraisal checklists will be used:

- If randomized/experimental study: checklist for randomized controlled trials (Tufanaru et al., 2020);
- If quasi-experimental or non-randomized quantitative intervention study: checklist for quasi-experimental studies (Tufanaru et al., 2020);
- If qualitative study: checklist for qualitative research (Lockwood et al., 2015);
- If a review (with or without meta-analysis) : checklist for systematic reviews and research synthesis (Aromataris et al., 2015);
- If cross-sectional, quantitative descriptive or correlational study: checklist for analytical cross-sectional studies (Moola et al., 2020);
- If cohort or longitudinal study: checklist for cohort studies (Moola et al., 2020);
- If case series (tracks subjects with a known exposure): checklist for case series (Munn et al., 2020);
- If case reports or report of clinical case(s): checklist for case reports (Moola et al., 2020);
- If case-control study: checklist for case-control studies (Moola et al., 2020);
- If discussion, professional, clinical or other type of literature: checklist for text and opinion (McArthur et al., 2015).

As the JBI does not offer a critical appraisal checklist for mixed studies, these studies will be appraised using the checklist for qualitative research and the one corresponding to the quantitative design in addition to the five questions specific to mixed studies (section 5) of the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018; Pace et al., 2012). If the study is a action research, the checklist corresponding to the type of assessment will be chosen.

Results Presentation by Data Synthesis
Extracted data will be processed using content analysis techniques inspired by Miles et al. (2014). This data analysis method involves three steps: 1) data condensation; 2) data display of similarities and differences; and 3) drawing and verifying conclusions (noting themes and subthemes). Based on the review questions, results will also be presented in a narrative form with tables and graphs. They will be presented in adherence to the Preferred Reporting Items for Systematic Review and Meta-Analysis extension for scoping reviews (PRISMA-ScR) (Tricco et al., 2018).

Consult Knowledge Users
We will consult two clinicians (a psychogeriatrian and a geriatric psychologist) and a family care partner/advocate with expertise on the topic for this scoping review. Based on the reference

list of extracted data and the eligibility criteria that we will share to them, they will be invited to propose additional literature that might be missing from the selected literature, especially grey literature. Also, once a first version of the results and recommendations for research and the development or implementation of personalized interventions is available, two clinicians and one care partner/advocate, that were identified to act as consultants, will be invited to comment on the results based on their experience to help us refine our findings and to identify critical areas that should be discussed. A synthesis of the main results will be sent to them, and they will be asked questions in writing or, if they prefer, by discussing with the research assistant or the PI. Those questions will focus on what the clinicians and care partner/advocate perceive as being the most relevant results to guide the development or implementation of personalized interventions in LTCH and the missing aspects that should be considered. Their answers will guide the interpretation of the results and orient the discussion.

Discussion

The rationale for this project is the high prevalence of apathy in older people living with NCD in LTCH. As those behaviours are less disruptive to staff than other behaviours (i.e., vocal or aggressive behaviours), they might go unnoticed or not be prioritized even though they can have important consequences for the well-being of older people and their family care partners. So far, no systematic review seems to have determined the state of knowledge of the causes, associated factors, consequences, and interventions for this type of behaviour in the context of LTCHs. This scoping review will identify needs for further research by considering various aspects that could influence the development of relevant interventions in the context of LTCHs. By rigorously assessing the quality of the literature, the resulting research agenda will also reflect the quality and relevance of existing knowledge. This assessment also remedies some of the criticisms about the steps of scoping reviews that do not necessarily include consideration for the quality of studies (Brien et al., 2010; Grant & Booth, 2009; Paré et al., 2015). This additional step will also allow the findings from this scoping review to guide clinical practice, continuing education, and care organizations in LTCHs. This is particularly important since apathy is hardly ever discussed in the gerontology and mental health practice textbooks that clinicians often refer to. Moreover, because this review is guided by the Senses Framework (Nolan et al., 2004), it will allow describing the state of knowledge regarding the relationships between older people, family care partners and formal caregivers and its implications for the provision of humane care in the context of apathy. In conclusion, our scoping review will guide the development of a research agenda, clinical knowledge, and training on the best practices to assess, prevent, and intervene when older persons with NCD manifest apathy in LTCHs.

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