



Patient-Centered Care Models for Institutionalized Older Adults Requiring Palliative Care: A Systematic Review Protocol

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Abstract. Introduction: The increase of chronic diseases, multimorbidity, functioning changes and loss of autonomy, associated with the absence of caregiver and community support, lead to institutionalization of older adults who will require palliative care. The integration of accessible palliative care is currently a wide priority. This study aims to answer the question: What are the palliative care needs of the institutionalized older adults? So, the aim is to synthesize scientific evidence about Patient-Centered Care Models for institutionalized older adults requiring palliative care.

Methods and analysis: The protocol follows the methodology PRISMA and uses five databases, CINAHL Plus with Full Text, MedicLatina, MEDLINE with Full Text, Academic Search Complete and Psychology and Behavioral Sciences Collection. The search strategy includes the following MeSH or similar terms: “palliative care”, “end of life”, “palliative nursing”, “long term”, “nursing home”, “residential care”, person centered care”, “patient centered care” and “client centered care”. The search, analysis, extraction and synthesis of data is conducted by two independent reviewers and a third will solve disagreements. All studies written in English, Portuguese, Spanish or German conducted between December 2017 and August 2022 will be included regarding diagnostic evaluation, which identifies the need for palliative care, care planning and implementation of interventions.

Conclusion: It is hoped that this protocol will facilitate the systematic review and contribute to future studies within the scope of models of care centered on the institutionalized older adults with need of palliative care.

Keywords: “palliative care · “nursing home · person centered care

1 Introduction

The population aged 65 and over, on average, has almost doubled in OECD Countries. In the 38 member countries, more than 232 million were aged 65 or over in 2019, and

more than 62 million were at least 80 years old. In five countries (Portugal, Greece, Italy, Korea and Japan), the percentage could exceed one-third of the population by 2050 and more than one in eight people will be 80 or older [1, 2].

The population resident in nursing homes is increasingly composed of frail older adults with chronic and progressive diseases [3–6]. However, knowing the real needs of this population is a challenge given the lack of systematic studies that allow for the restructuring of organizational and health policies and care planning, bearing in mind the users' characteristics[7].

A study conducted in Portugal, with a sample of 586 subjects, 484 of whom were institutionalized, revealed a mean age of 85.79 years, with most of the sample being composed of women (69.6%). In the functional profile, the domain of self-care was the one that showed the worst results and 56.6% of the institutionalized participants had cognitive deterioration.[8] In another study, 68.2% of older adults had 2 or more nosological diagnoses, the most frequent being circulatory system diseases, followed by nervous system diseases (including dementias), musculoskeletal system, neoplasms, endocrine, nutritional, and metabolic diseases, and mental and behavioral disorders, and 70.12% had multimorbidity [3]. Underlying this reality is the worrying prevalence of chronic diseases that manifest themselves as multimorbidity [7]. Although it is still little consensual, multimorbidity is usually defined by the cooccurrence of several chronic diseases [8–10]. Reality that is accentuated with advancing age [11, 12], becoming a public health concern associated with increased health needs [9, 10, 12].

The literature shows that care in the Residential Structures for the Older Adults is predominantly provided by direct action assistants and auxiliaries, unqualified professionals with low levels of education [7, 13], factors that will contribute to the overload of the health systems, which highlights the hyperuse of emergency services [14]. Data confirmed by a study which sought to identify which components of care models influenced functionality and concluded that factors such as a good inter and transdisciplinary management, well-defined admission criteria, and individual care plans focused on the functioning improvement of the older person are essential components to adopt a care model promoting self-care in long-term care settings [15].

The suffering of the institutionalized person, associated with the presence of physical and psychological symptoms, resulting from the progression of multimorbidity and loss of functioning, [5, 6, 10, 16], and social and spiritual problems, associated with limitations in sharing feelings, loss of meaning in life itself, and breakdown of close ties [5, 16, 18] reveal the need to integrate palliative care as a way to ensure symptom relief and well-being in this phase of great vulnerability. The WHO estimates that only 1 in 10 people receive palliative care according to need [1]. Each year, it is estimated that more than 56.8 million people, including 25.7 million in the last year of life, require palliative care [2, 19].

The OECD, and the Strategic Plan for the Development of Palliative Care (PEDCP), recognizes the relief of suffering (physical, psychological, social, or spiritual), as a global ethical responsibility, highlighting the relevance of the integration of palliative care in all care settings (home, Palliative Care, CCI, HSC, PHC) as a crucial part of integrated and person-centered health services [1, 2, 20]. Person-centered care can be understood as the provision of health care that respects the individual preferences and needs of patients.

The patient's life history, values and beliefs are considered, and the person starts to take an active role in their clinical decision-making process [21, 22].

Objective:

To synthesize the scientific evidence about models of care centred on the institutionalized older adults with need of palliative care.

Review Question:

This review will be undertaken to answer the following question: Which models of care/interventions focused on the institutionalised older person recognise/consider and answer the need for palliative care?

2 Methods and Analysis

This protocol was developed in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and was registered in the International prospective register of systematic reviews (PROSPERO) under registration number: CRD42022373388.

Considering that the scope of this study is very specific and still understudied, we chose to include in this review primary empirical quantitative studies: cross-sectional, longitudinal, observational, or experimental studies.

This protocol was developed in September 2022. We will start data analysis in December 2022 and will completed the systematic review by the end of April 2023.

2.1 Eligibility Criteria

The inclusion criteria are adult patients aged 60 years and over, institutionalised in nursing homes, receiving palliative actions. For example, all studies involving participants, institutionalised, targeted by palliative interventions will be included. The aim is to collect as much information as possible, as such reviews are still scarce in the scientific literature.

2.1.1 Intervention

The review will include studies on person-centred interventions aimed at minimising symptomatology, relieving suffering, promoting quality of life and respecting the dignity of older adults institutionalised in care homes, in any geographical area.

2.1.2 Comparison

This review will include studies with or without a comparison group.

2.1.3 Primary Outcome

The main objective will be to synthesise the data on strategies for diagnostic assessment, care planning and implementation of interventions with an impact on the quality of life and relief of suffering of the institutionalised older person, that is, on the care process in this context.

2.1.4 Study Design

This review should include primary empirical quantitative studies: cross-section, longitudinal, observational or experimental.

2.1.5 Context

All studies related to diagnostic assessment, care planning or intervention strategies focused on adults aged 60 years or older, with uncontrolled symptoms and/or suffering, only in institutionalised nursing homes, will be included in this review.

2.2 Search Strategy

2.2.1 Data Sources

In the research strategy, the aim is to carry out a broad literature search and the databases to be consulted will be: CINAHL Plus with Full Text, MedicLatina, MEDLINE with Full Text, Academic Search Complete and Psychology and Behavioral Sciences Collection

2.2.2 Search Terms

The research will include the combination of three key concepts according to Medical Subject Headings (MeSH) terms: (“palliative care”) OR (“end of life care”) OR (“palliative nursing”) AND (“long term”) OR (“nursing home”) OR (“residential care”) AND (“person centered care”) OR (“patient centered care”) OR (“client centered care”). The strategy will be adapted according to each database and will be restricted to the period between December 2017 and September 2022, in English, Portuguese, Spanish.

The employed search terms and the search strategy used for each database are specified in the Supplementary Materials.

2.3 Data Collection and Analysis

2.3.1 Selection of Studies

The studies resulting from the search in each database will be exported to Mendeley and duplicates will be removed.

3 Conclusion

Given the change in care that occurs in older adults who live in nursing homes, it has become a priority to identify the models of care that accurately respond to this population regarding palliative care. This kind of identification will allow us to clarify which the needed model components are, making it possible to build indicators centered in the person and its well-being.

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