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Study Protocol

Public Policies for the Development of Palliative Care: Scope Review Protocol

Políticas públicas para o desenvolvimento de Cuidados Paliativos: Protocolo de Revisão de Escopo

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ABSTRACT

Introduction: Public policies are essential for palliative care development, but they vary between countries.

Objective: To present a Scoping Review Protocol to explore how and which components have been considered in the development of public policies in palliative care.

Method: A search strategy will be carried out in scientific bibliographic databases (PubMed, Web of Science, PsycINFO/Ovid, ScienceDirect and CINAHL/EBSCO) and grey literature databases (BASE and OpenGrey) with association of terms related to "Public policy" and "Palliative care", without limitation of language or period. A Joanna Briggs Institute framework will be considered to define the review structure and PRISMA-ScR checklist will be applied to present the results. A librarian perform the search strategy, and two reviewers will evaluate the results. The review will consider World Health Organization's public policy model for the development of palliative care to investigate how it is developed worldwide and what components are used in its formulation.

Keywords: Healthcare System; Palliative Care; Public Policy; Public Health.

RESUMO

Introdução: As políticas públicas são essenciais para o desenvolvimento dos cuidados paliativos, mas podem variar entre países.

Objetivo: Apresentar um Protocolo de Revisão de Escopo para explorar como e quais componentes são considerados no desenvolvimento de políticas públicas em cuidados paliativos.

Método: Será realizada uma busca em bases de dados bibliográficas científicas (PubMed, Web of Science, PsycINFO/Ovid, ScienceDirect e CINAHL/EBSCO) e de literatura cinzenta (BASE e OpenGrey) com associação dos termos relacionados com "Public policy" e "Palliative care", sem limitação de idioma ou período. O referencial do Joanna Briggs Institute será considerada para definir a estrutura de revisão e a PRISMA-ScR será aplicada para apresentar os resultados. Um bibliotecário executará a estratégia de pesquisa e dois revisores avaliarão os resultados. A análise considerará o modelo de política pública para o desenvolvimento de cuidados paliativos da Organização Mundial da Saúde para investigar como ele é desenvolvido ao redor do mundo e quais componentes são utilizados em sua formulação.

Palavras-chave: Sistema de Saúde; Cuidados Paliativos; Políticas Públicas; Saúde Pública.

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INTRODUCTION

Yearly, around sixty million people experience severe health-related suffering (SHS) worldwide which can be alleviated with palliative care (PC), and this number tends to increase[1,2]. However, the World Health Organization (WHO) estimates that only 14% of the people in need have access to palliative care services, most of them concentrated in high income nations[3]. This unequal development has been reported in the scientific literature, as by the Lancet Commission on Palliative Care and Pain Relief and the Global Atlas of Palliative Care[2–4].

PC is the active holistic care of individuals affected by SHS of all ages due to severe illnesses that compromise physical, social, spiritual, and emotional functioning and, especially those near end-of-life. It aims to improve the quality of life of patients, their families', and their caregivers'. Additionally, its integration in the healthcare system generates benefits for society with cost reduction and less use of hospital setting[4].

The WHO proposed in the '90s a public health model for PC integrated provision, which was corroborated by the 67th World Health Assembly resolution in 2014 (WHA67.19)[5]. According to this "umbrella model" health policies represent the cover for all other fundamental components, until it has been replaced by the "house model" in which health policies are one of the ground foundations for other structures such as education and training, use of essential medicine, service provision of PC, and scientific research, which is depicted in Figure 1.[6]

The health public policy component refers to the political commitment and leadership expressed in governance structures and policies to achieve an outcome or implement an action. It encompasses the development of legal framework, regulations, stated strategies, standard settings and guidelines to ensure the development and access to palliative care support in a national or regional healthcare system[7]. By promoting and implementation laws, regulations, and practices that influence the development of systems, as well as organizational and behavioral changes, policies have an effect on health and care. Public health policies are shaped by historical, cultural, political, and socio-economic aspects and therefore vary from country to country and may have different approaches to the provision of PC services[7,8].

A preliminary search of the PubMed, PROSPERO and Cochrane Library databases was performed using the terms "Palliative care" and "Public policy" to identify existing systematic reviews on the subject or review protocols in progress. One scoping review protocol, one systematic review protocol and two systematic reviews were considered associated[9,10,11,12].

Source: Reproduced from WHO. Assessing the development of palliative care worldwide: A set of actionable indicators. Geneva: World Health Organization; 2021, p. 14. Available from: https://www.who.int/publications/i/item/9789240033351.

Figure 1. Palliative Care development model for healthcare system.

Sallnow et al.[11] conducted a systematic review ten years ago examining the impact of a public health approach to end-of-life care, specifically efforts to strengthen community action, and found some evidence on the impact of the involvement of such personal and community support on wellbeing and social isolation in end-of-life care. However, none of these references take into account the recent reformulations of the WHO model for integrated PC, nor recent advances in its development around the world. In this regard, more attention should be paid to specific public policies and their contents. To explore and map how public policies have included PC in healthcare system of different countries, what specific elements have been defined in their implementation and what gaps exist for the integration of PC, we will conduct this scoping review.

METHODS

The proposed scoping review will be guided by Joanna Briggs Institute (JBI) framework for defining the structure of the review[13]. Scoping review is an approach to broadly examine the literature for key concepts in a thematic field, identify recommendations for practice, and map scientific evidence, taking into account a period of time, different locations and sources. We will use the Population-Concept-Context (PCC) framework for formulating the review question and defining the search strategy. I) The Population of this study is the people who might have benefits from PC; II) The Concept is public policy; and III) the Context is the different countries of the world.

The review question is: "How PC public policies are developed around the world?". Specific questions are:

i) Are the components of the WHO conceptual model for PC development used to formulate public policies in different countries and regions? and,

ii) Are there other components or gaps to consider in PC public policies beyond the WHO model?

Conceptual frameworks, experimental and quasi-experimental studies (such as randomized controlled trials, non-randomized controlled trials, descriptive observational before and after studies, interrupted time-series studies and descriptive cross-sectional studies), qualitative studies, systematic reviews and official government documents that meet the criteria according to the thematic focus (Chart 1) will be considered for inclusion in this exploratory review.

Exclusion criteria will be references to journal editorials, abstracts, book reviews, newspapers, personal opinion articles and studies with undefined method or with incomplete information.

Search strategy

An initial limited search in PubMed database was conducted to identify the index terms used to describe the articles in order to develop the full search strategy. The terms related with Palliative care (including "Hospice care", "End-of-life care" and "Terminal care") proposed by Rietjens et al. (14) will be associated with the term "Public policy". Boolean operators (such as AND) will be used to fine-tune the search terms**.** A university librarian will adapt the search strategy as necessary and apply it to the databases.

The scientific databases considered for bibliographic search are PubMed, Web of Science, PsycINFO/Ovid, ScienceDirect and CINAHL/EBSCO. Grey literature searches will also

Chart 1. The Population-Concept-Context (PCC) framework for eligibility of studies and search strategy.

Framework	Inclusion criteria	Exclusion criteria
P (Population/ Participant)	Terms: Palliative care, Hospice, Hospice Care, End of life, Terminal care.	Euthanasia, organ donation, specific disease policies.
C (Concept)	Terms: Public Policy, Public Policies.	
C (Context)	Any country. Any language.	
Period:	Any period.	
Type of publication:	Experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, descriptive observational before and after studies, interrupted time-series studies, descriptive cross-sectional studies; Conceptual framework; Qualitative studies; Systematic reviews; Official government documents.	Journal editorial, summaries, book review, newspaper, personal opinion articles and studies with undefined method or with incomplete information.

be conducted using the following online databases: Bielefeld Academic Search Engine (BASE) (https://www.base-search.net/) and OpenGrey (http://www.opengrey.eu/). There will be no language or time restrictions. The proposed period for this research is the first half of 2024. Reference management software (Endnote/Clarivate Inc.) will be used to organize and eliminate duplicates references.

The first screening step will set a preliminary filter by titles and abstract analysis by two independent reviewers. Sources that meet the eligibility criteria and answer the secondary questions will have their citation details imported and will be grouped and uploaded for full-text analysis. Reviewers will evaluate the full text of selected citations in detail according to the inclusion criteria. Reasons for excluding sources of evidence in the full text that do not meet the inclusion criteria will be recorded.

A secondary analysis will consider the health policy conceptual health policy model for the integration of PC into the healthcare system promoted by WHO, to investigate the components involved in the development of public policies for PC in different countries and regions. Additional studies can be found in the references of the selected articles.

Data Extraction and Analysis

Data will be extracted from the documents included in the scoping analysis using an Excel spreadsheet (Microsoft Corporation) to establish information on the authors of the publication, the year of publication, the type of study, the related country or region, and identification of public policies and detailed components according to the WHO conceptual framework. Modifications will be detailed in the full scoping review. Any disagreements between reviewers will be resolved through discussion with an additional reviewer. If appropriate, authors of the articles will be contacted to request missing or additional data where necessary.

A basic qualitative content analysis approach will be used for scoping reviews, consisting of three phases: i) preparation, ii) organization, and iii) reporting[13]. The analysis will consider the public health policy model for PC integration into the healthcare system promoted by the World Health Organization to investigate the components involved in its development.

For a transparent presentation of the results and writing of the manuscript, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR)[15] will be used as supporting material.

The search results and study inclusion process will be communicated in the full scoping review. The protocol will be registered and made available online for consultation (https://osf.io/9upwf/files/).

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