Identification of people for palliative care in primary health care: integrative review

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Abstract  This article aims to analyze the evidence available in the literature on the process of identifying adults and elderly people who can benefit from palliative care (PC) in primary health care (PHC). This is an integrative literature review carried out in PubMed, CINAHL, LILACS, Web of Science, and Embase. Eight studies were selected, in which different instruments and methods were distinguished with the purpose of identifying people who can benefit from PC in the context of PHC. The incorporation of these instruments into clinical practice is urgent in order to increase the reach and effectiveness of the services offered by health professionals, considering the current demographic and epidemiological profile that points to the increase of people with a potential need for PC. Different instruments have been successfully used to identify PC in the context of PHC. However, some have weaknesses, such as the fact that they only allow the identification of people with oncological diseases, leaving out other health conditions, which reinforces the need for further studies on this topic.

Key words Palliative care, Primary health care, Comprehensive health care, Health policy, Review

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Introduction

In Brazil, the palliative care movement has been growing and gaining notoriety due to the demographic and epidemiological transition, characterized by the increase in the adult and elderly population and, consequently, change in clinical processes, leading to a gradual increase in chronic and complex diseases that affect multiple organs, which often threaten the continuity of life.

Palliative care (PC) is defined as active holistic care provided to people who are confronting intense suffering related to health, resulting from severe diseases, especially for individuals in the final stages of life. This type of care seeks to improve the quality of life of the patients, family, and caretakers. What is recommended is the adoption of the aforementioned definition and its use as a model in the construction of health policies and educational initiatives.

Considering the intense demographic and epidemiological transition occurring in Brazil, one can observe a gradual increase in users of the Brazilian Unified Health System (SUS) in the sense of PC, highlighting the inherent need for the reorganization of health services to attend to this demand.

Primary health care (PHC) has been considered the highest level of health care to provide and coordinate PC due to the geographic and cultural proximity and to the connection of health professionals who work in these units with the population that may eventually contribute to a more humanized form of health care.

It can be said that both PC and the PHC are focused on providing complete health care to people and expand this care to the personal and family contexts in an attempt to positively influence patients’ health conditions and quality of life, developing education, treatment, and complete care actions, even in the cases in which there is no possible cure. This study also observed the fact that people with PC needs are present in the PHC context; however, the identification of these people is a challenge for health care.

As it involves clinical conditions and different social contexts that directly affect one’s quality of life, the definition of patients undergoing PC is not well defined. In this light, a systematic review, which sought to propose minimal characteristics that define a patient in PC, identified a variety of definitions for this population in studies on PC. Faced with this scenario, the authors recommended the following criteria: i) the identification of health conditions that threaten life, such as progressive diseases or conditions with no possibility of remission; ii) the inclusion cannot be limited to only one type of disease; and iii) the identification of conditions with the need for different types of care due to the presence of multiple symptoms.

In the literature, evidence can be found indicating that most health professionals tend to associate this type of care to the final moments of life and imminent death, contributing, in many cases, to a scenario in which the health professionals find it difficult to provide an early identification of people with a potential need for PC and who do not fit into this terminal stage of life.

It is also important to highlight the significance of resorting to a systematized manner in which to help health professionals to provide an early identification of the people who need follow-up under the philosophy of PC. The studies on these forms are rare, in both the national and international scenarios.

Considering that presented above, studies geared toward the debate surrounding PC in PHC are warranted in order to cooperate in the planning and formulation of actions that contribute to overcoming these challenges. In this light, the following question arose: How have PHC professionals identified adult and elderly people with a potential need for PC actions? It is important to note that investigating the manner in which the identification has been conducted by the PHC is of utmost importance for the incorporation of methods and tools that have been proven effective, especially in health services that still do not use them, as well as the recognition of barriers that should be overcome so that the identification of these people can occur in such a way as to guarantee complete and high-quality health care. Therefore, the present study aimed to analyze the evidence available in the literature regarding the identification of adult and elderly individuals who can benefit from PC in PHC.

Method

This study is an integrative review and was conducted according to the following stages: drafting of the research question, search in the literature, categorization of the studies, critical evaluation, interpretation of results, and presentation of integrative review. Part of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses was used to develop the review. This review’s protocol was registered on the Open Science
The PICo strategy was used to construct the question and to search for primary studies, in which P = patient, I = intervention, and Co = context. Thus, the defined question was: what evidence is available in the literature about the process of identification of adult and elderly people in PC in PHC? For the element “P”, “adult and elderly people” were considered; for “I”, the identification of people who can benefit from PC”; and “Co”, “PHC”.

The following inclusion criteria were applied to select the studies: primary studies that treated the identification of adult and elderly people in PC in the realm of PHC, in English, Spanish, and Portuguese, published in the past four years. The definition of the time period is justified by the publication of the National Primary Care Policy (PNAB, in Portuguese), which, in its main document, presents this care as part of the services to be offered in PHC in Brazil, aiming to guarantee access to the entire Brazilian population, by means of Decree 2436, of September 21, 2017. Publications in the form of editorials, letters to the editor, theses, dissertations, experience reports, and case studies, as well as studies with pediatric patients, were excluded.

The search for primary studies was conducted in the following databases: PubMed, Cumulative Index to Nursing, and Allied Health Literature (CINAHL), Lilacs, Embase, and Web of Science. For this, the following controlled descriptors (vocabulary from the database itself) were selected: Medical Subject Heading (MeSH), CINAHL headings, Health Sciences Descriptors (DeCS), and Emtree, respectively. Please note that the Web of Science database does not have its own vocabulary. In addition to the controlled descriptors, alternative terms indicated by the databases were also adopted to formulate the search strategy, which was unique and adapted for each selected database. The Boolean operators AND and OR, as well as the truncation resource, were used. The search strategy proposed in this study was conducted on January 26, 2021, and exemplified by its use in the search for publications in PubMed, according to the following descriptions: (“Adult” [Mesh] OR “Adults” OR “Aged” [Mesh] OR “Aged” OR “Elderly” OR “Middle Aged” [Mesh] OR “Middle Aged” OR “Middle Age” OR “Young Adult” [Mesh] OR “Young Adult” OR “Young Adults” OR “Oldest Old” OR “Nonagenian$” OR “Octogenarian$” AND (“Palliative Care” [Mesh] OR “Palliative Care” OR “Palliative Treatment” OR “Palliative Treatments” OR “Palliative Therapy” OR “Palliative Supportive Care” OR “Palliative Surgery” OR “Palliative Care” OR “end-of-life” OR “end of life” OR “palliative patients” OR “Terminal Care” [Mesh: NoExp] OR “Terminal Care” OR “End of Life Care” OR “End Of Life Care” OR “End Of Life Cares”) AND (“Primary Health Care” [Mesh: NoExp] OR “Primary Health Care” OR “Primary Healthcare” OR “Primary Care” OR “primary care medicine”).

After the implementation of the search for primary studies in the selected databases, the identified registers were exported to the EndNote (version X7) references manager, where they were organized and duplicates were removed. Later, the registers were exported to the Rayyan web application, in which new identified duplicates were removed and two reviewers were included to select the studies by doing a blind reading of the title and abstracts. The divergences between the reviewers were resolved through a consensus meeting, together with a third reviewer. Next, the selected studies were read in full, following the same thoroughness of the previous stage, resulting in a final study selection stage which constructed the review sample. The references of the included studies were traced, resulting in the inclusion of one additional study.

After having selected the studies, the extraction of the main information, following the script, was carried out. The following information was recorded: title, author, year, aim, methodological design, results, and conclusions. This step was conducted by a reviewer and then revised by a second reviewer.

The Guideline Critical Review Form for Quantitative Studies, developed by McMaster University Occupational Therapy Evidence-Based Practice Research Group, was used to evaluate the methodological quality of the primary studies included in this review. The form was drafted to evaluate studies developed using the quantitative approach, with nine questions, and for studies conducted using the qualitative approach, with 12 questions. Each topic with a yes answer corresponds to the increase in the quality and methodological thoroughness of the study. The Mixed Methods Appraisal Tool (MMTA) tool was used to evaluate the methodological quality of the mixed studies, which contains five questions to evaluate the method, considering that with each positive answer, the quality of the method increases.
Finally, the level of evidence of each study was classified based on the ranking of evidence proposed by researchers. The evidence rankings were drafted according to the type of clinical question of the analyzed study, as follows: (1) clinical questions of intervention/treatment or diagnosis/diagnostic test, (2) clinical questions of prognosis/prediction or etiology, and (3) clinical question of meaning.

**Results**

Figure 1 presents the flow chart about the path taken during the primary study selection process, with a review sample comprised of eight questions.

As regards the year of publication, the number of studies in 2018 was (n = 4; 50%), and regarding the language, most of the studies were published in English (n = 6; 75%). The other studies were published in Spanish. As regards the country that developed the studies, an absence of Brazilian studies was observed, indicating a gap in the literature, especially when considering the new PNAB, which also clearly showed the responsibility of PHC upon people who need PC.

Chart 1 shows the main information of the studies included in the review, together with the level of classified evidence.

In the analysis of the methodological quality of the studies, in the only mixed study included in this review, weaknesses were found in two questions evaluated in the form, one referent to the integration of the qualitative and quantitative results, and the other about following all the quality criteria for the methods used in the review.

For the only qualitative study included here, of the 21 topics treated in the evaluation of methodological quality, only five were marked as “Not informed” and referred to the aspects related to the information about the saturation of the data; the description of the data collection was also not informed. Weaknesses were also observed where five topics were marked as “Not” and referred to the data analysis, as well as the absence of evidence about the reliability components (credibility/transferability/reliability/affirmability) and the conclusion, considered inadequate when considering the findings from the study.

Chart 2 presents the methodological quality analysis of the quantitative studies included in the review.

In two primary studies included in the review, the authors used their respective country’s validated version of the Supportive and Palliative Care Indicators Tool (SPICT). This is a tool structured in three dimensions, as follows: overall clinical indicators; specific clinical indicators of the condition; and recommendations for PC actions (for example, the review of prescribed medications, conversation about the deterioration of health and death with the patients and the parents, the planning of early care or the referral to a PC specialist).

In a study carried out at the Segovia PHC, the authors used the Identificación y Atención Integral-Integrada de Personas con Enfermedades Crónicas Avanzadas en Servicios de Salud y Sociales (NECPAL CCOMS-ICO© 1.09) PC identification tool, which is divided into “question 1” (surprise question); “question 2” (choice/demand or need); and “question 3” (overall clinical indicators of severity and progression). This last question refers to the following indicators: nutritional decline, functional decline (Karnofsky or Barthel test), cognitive decline (Mini Mental/Pfeiffer), geriatric syndromes (falls, dysphagia, recurrent infections, pressure lesions, delirium), persistent symptoms (Edmonton Symptom Assessment System – ESAS), psychosocial aspects (suffering and/or severe adjustment disorder, severe social violation), multimorbidity (Charlson test), and the use of resources (evaluation of the demand or intensity of interventions).

The aim of another study included in this review was to evaluate, in terms of the improvement of processes and economic impact, the implementation of a PC integrated program, focused on identifying the patient. The implementation of the integrated intervention began in 2013 and was based on the identification of patients, using code 9 of the International Classification of Diseases (ICD-9), referent to PC patients. McNamara’s minimum estimate was used as an identification criterion, which refers to an approach that seeks to provide minimum, average, and maximum estimates of a population in relation to the need for PC.

Another form used to identify people who could benefit from PC in the context of PHC was called the ARIANNA project. This project is an organizational model where basic care and PC are integrated, following up on patients throughout the entire care process, from the early identification to future death, registering the trajectory and clinical conditions throughout the study, using tools shared by different environments. To
enroll the patients in this study, the doctors used the version of the Standard Framework (GSF) called the Prognostic Indicator Guidance, adapted to the Italian context, which uses a guide for the professionals to identify the people who appear to be in the final stages of life. In addition, it has the purpose of anticipating the needs of the patients in order to guarantee the proper PC planning. The criteria to include the GSF are based on the negative answer to the “surprise question” (“Would you be surprised if a patient died in the next 12 months?”). The overall criteria included factors related to psychophysical decline and growing needs, such as dependence in most daily routine activities, the presence of comorbidities, the reduced response to treatment, the progressive loss of weight (> 10%) during the prior six months, and non-planned and repeated hospital admissions in moments of crisis. Specific clinical indicators represented specific subcriteria in this study24.

To evaluate the state of the patient, both at the moment of identification, as well as in the subsequent evaluations, the authors used specific internationally validated scales, in addition to information logged in the electronic medical re-
Chart 1. Synthesis of studies included in the integrative review (n = 8). Ribeirão Preto, SP, Brazil, 2021.

<table>
<thead>
<tr>
<th>Primary Study</th>
<th>Aim</th>
<th>Method</th>
<th>Investigated population</th>
<th>Level of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afshar et al.\textsuperscript{10} (2020)</td>
<td>To investigate the feasibility and practicality of the German version of the Supportive and Palliative Care Indicators Tool (SPICT-DE) for the systematic identification of these patients in a general clinic.</td>
<td>Descriptive study</td>
<td>10 general practitioners participated, from both urban and rural regions, with different professional experience in Family and Community Medicine, with and without additional qualification in palliative care.</td>
<td>VI (clinical question/diagnosis)</td>
</tr>
<tr>
<td>Trapero et al.\textsuperscript{22} (2019)</td>
<td>To identify, through the application of the NECPAL tool in the field of Primary Health Care in Segovia, people with advanced chronic diseases with a potential need for palliative care.</td>
<td>Observational, descriptive, longitudinal, and prospective study</td>
<td>Population sample from the health area that attended to basic health units from December 1, 2014, to May 16, 2015.</td>
<td>VI (clinical question/diagnosis)</td>
</tr>
<tr>
<td>Larrañaga et al.\textsuperscript{23} (2019)</td>
<td>To evaluate, in terms of improvements in processes and economic impacts, the implementation in two integrated healthcare organizations from the palliative care program, focused on the identification of the patient.</td>
<td>Cross-sectional study. The necessary information was extracted from a databank</td>
<td>Patients who died (oncological or not) in 2012 (control group) and in 2015 (intervention group).</td>
<td>VI (clinical question/diagnosis)</td>
</tr>
<tr>
<td>Scaccabarozzi et al.\textsuperscript{24} (2017)</td>
<td>To illustrate the characteristics of the patients, focused on their early identification by general practitioners and to analyze the care process in home palliative care services.</td>
<td>Multicenter prospective observational study</td>
<td>94 general practitioners from 10 different units of home palliative care.</td>
<td>IV (clinical question/prognosis)</td>
</tr>
<tr>
<td>Urquhart et al.\textsuperscript{25} (2018)</td>
<td>To explore the acceptability and the implications of use of an electronic medical record algorithm based on the PHC to help service providers to identify patients at risk of a decline in health and death.</td>
<td>Qualitative study</td>
<td>The participants were 29 health professionals (doctors, nurses, and social assistants), managers, and policymakers who worked in PHC, palliative care, geriatrics, long-term care, and home care in Nova Scotia and Ontario (Canada).</td>
<td>II (clinical question/meaning)</td>
</tr>
<tr>
<td>Van der Plas et al.\textsuperscript{9} (2018)</td>
<td>To study the effects of the implementation of the PaTz groups and provide additional analyses about two important elements: PaTz records and patient discussions.</td>
<td>Quantitative study (with pre and post-assessment)</td>
<td>37 PaTz groups</td>
<td>VI (clinical question/intervention)</td>
</tr>
<tr>
<td>Mason et al.\textsuperscript{8} (2018)</td>
<td>To refine and test the usefulness of the general practitioners’ practices who regularly execute their own computer research based on barcodes to aid in identifying patients for the palliative care approach.</td>
<td>Mixed study</td>
<td>8 female practitioners 8 male practitioners and 10 patients were interviewed</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Hamano et al.\textsuperscript{26} (2018)</td>
<td>To explore the prevalence and characteristics of the patients from family health care who need the palliative care approach, according to that defined by the Supportive and Palliative Care Indicators Tool (SPICT, April 2015) in Japan.</td>
<td>Single center cross-sectional study</td>
<td>87 patients</td>
<td>IV (clinical question/prognosis)</td>
</tr>
</tbody>
</table>

\textsuperscript{*VI = unique qualitative or descriptive studies; **IV = unique qualitative or descriptive studies; ***II = unique qualitative studies; **** VI = unique qualitative or descriptive studies; *****IV = unique descriptive studies.}

Source: Authors.
cords. Among these, the Karnofsky Performance Status (KPS) was applied to evaluate the physical function of the patient. This index is comprised of 11 categories, ranging from 100 (patient without signs or symptoms of disease) to 0 (death) points. To evaluate the pain, the Numeric Pain Rating Score was used, with values ranging from 0 (no pain) to 10 (maximum level of pain) points. The performance of patients in their daily routines was evaluated by means of the activities of daily living (ADL)²⁴.

The adaptation of the GSF scale was also used in another study that applied the method for identification, called the Palliatieve Thuiszorg (PaTz) group, which means home care. In this casuistry, interpersonal meetings were conducted, generally six times per year, between general practitioners and community nurses who worked in the same area, with the support of PC consultants (doctor or nurse with a formal education and experience in PC). Using the surprise question, it was defined if the patient should be included in the PaTz palliative care records. In addition to the identification of people who can benefit from PC, this group also discussed the actions that can be developed for each identified patient⁹.

In another study, the authors investigated the acceptability and the implications of using the electronic system based on PHC to identify people who run the risk of dying within the period of 12 months. This algorithm can be incorporated in the electronic medical records to generate, systematically and routinely, lists based on patient practices that benefited from the PC approach and conversations about the end of life, such as early planning for PC and discussion about the goals of PC to be achieved²⁵.

Similar to the previous study, some researchers also used a barcode to help them identify patients for the PC approach. Called the AnticiPal, this method uses a list of barcodes that, individu-
usually or in combination, can indicate people with health needs that are ever-increasingly worse and require PC.

**Discussion**

In most of the studies, the identification of the target population increased significantly with the implementation of the methods or instruments explained above. Only the use of the PaTz method indicated a certain weakness concerning the identification of non-oncological patients.

PC is fitting for people in conditions that can limit one’s life and should be made available as early as possible, shortly after the diagnosis, and incorporated into the disease modifying treatments. Most people’s needs at the end of life can be remedied by offering this type of early care in PHC.

The attribution of PC, in an interpersonal manner, opens the door to a broader view in order to provide complete care in the final stages of life, thereby improving the quality of life of the patient and the family. Conversation about the finiteness of life should not be limited to only one professional or to a specific environment, as it demands an approach on the part of the team, both inside and outside of PHC, in an attempt to mitigate problems and benefit from the set of skills and knowledge of each component of the team.

It is also important to note that conversations about the end of life with the identified patient require a sensitive and ethical approach, which is not an easy task for the health professionals involved in this process. Special skills, such as communication, empathy, and professional experience, are essential for the success of the approach taken by these health providers.

Individuals who present multimorbidities, weaknesses, or organ failure are still at a disadvantage in the offer of PC. In general, the recognition of people who are approaching the end of life is morose, making it difficult for care planning to be put into practice. The early identification of this patient profile can expedite their referral to other care levels, when necessary.

Therefore, it is of utmost importance that PHC teams adopt this care approach, fostering a broad comprehension, in addition to the formulation of therapeutic plans that can enable the optimization of the quality of life. In addition, these actions can enable better results in the establishment of targets, the coordination of care, and access to services, leading to a reduction in hospitalizations and a diminishing of unfavorable conducts during treatment, in addition to allowing more people to choose the location of their dying days and providing a greater support for the mourning of the family.

Among the barriers to the offering of PC in PHC, what stands out is the difficulty in the systematic identification of the people who are in need of this type of care. Another difficulty is the limited understanding of the people who have advanced and progressive diseases, as well as of the caretakers, about the concept and benefits of PC, associating this treatment with death, without seeing the possibility of the contribution of this care in their daily routines.

The early introduction of the PC approach in PHC is a challenge in a population with diverse advanced conditions involved in the health-disease process.

Early identification can have a positive impact upon the health system, considering that it has the potential to reduce the workload and stress levels of the health professionals involved, since with prior care planning provided to the patient who is in the final stages of life, the access to services and available aid tends to be more dynamic.

The provision of the PC approach in PHC is urgent in many health systems, since in many situations the patients are identified late in the trajectory of the disease, thus hindering them from benefitting from the coordinated and planned health care for their individual needs, resulting, over the long term, in significant impacts upon the health system.

In this light, it is extremely important to highlight that patient with a potential need for PC, along with their families, need social support as well as an interaction between the health system and engaged communities. Such actions are the key to increasing the reach and the effectiveness of the services offered by the health professionals. Thus, the integration between the health systems and social assistance has become crucial.

In most countries, PC is still a neglected issue, and for this reason, social and political actions are necessary to promote the well-being and quality of life of the people who have an urgent need for this type of care. More specifically, in the realm of PHC, PC stands out, as it deals with a reference scenario relevant to the majority of people with noncommunicable diseases (NCDs), given that these represent conditions that are outside of the therapeutic possibility of care.
It is important to remember the key role played by PHC in the humanization of care, which favors not only improvements in the quality of life, but also in the quality and continuity of medical care provided to individuals in PC, inside and outside of the home28.

In recent decades, some countries have sought to increase the empowerment of PHC in the coordination of other care levels and have included, among other services, embracement in PC with the support of interdisciplinary teams. When we refer to the Brazilian context, this interdisciplinary support from the PHC is offered by the Expanded Family Health and Primary Care Center (NASF, in Portuguese), but without distinctly clarifying PC actions in its guidelines6. The inclusion of PC in PHC has been seen as one of the main hindrances to the development of PC in Brazil28.

It is important to remember that the care provided by PC encompasses a wide range of conditions that can possibly be recommended, and should not be limited to the patient's age or specific diseases. PC seeks to develop actions that will increase and maintain the quality of life of individuals with diseases that threaten life, or with no known cure, by controlling symptoms, encouraging autonomy, preventing complications, and providing psychosocial support to the patients and family members6.

Considering the analysis of the PC interventions in the realm of PHC raised in this recent scoping review, the authors perceived the need for professional improvements on this theme29. Consequently, it is important to emphasize that for the overall implementation of PCs, or any humanized and comprehensive medical care, academic and practical reflection is necessary in all health fields that value knowledge in interpersonal relations and not only technical-scientific knowledge60.

Conclusion

The present study analyzed the evidence available in the literature on the process of the identification of adult and elderly individuals with a potential need for PC in PHC, where a wide range of tools have been used as a means through which to aid in recognizing people who need PC, considering probable means through which PC can be implemented in the context of PHC.

This study highlights the pressing need for greater exploration of the theme through further research, since the demographic and epidemiological profiles point to an increase in people who with a potential need for PC.

In Brazil, continuing reflection and discussion on the early identification of the need for PC in PHC are warranted so that the guiding strategies concerning this approach become present at this care level, considering that the PNAB specifies the competencies of PHC in providing support to people with a potential need for PC.

As regards the limitations of the present review, what stands out are the restrictions relevant to the number of databases selected to search for studies, when the study was published (last four years), and the language (English, Portuguese, and Spanish), as well as the non-inclusion of gray literature.

Among the gaps in knowledge produced on this theme, there is a lack of studies that investigate the approach used to identify people with a potential need for PC in PHC, indicating the need for future studies, since the process of global aging is contributing to the increase in this profile of users on the doorsteps of health systems.
Collaborations

CMS Paraizo-Horvath: conception, planning, analysis, interpretation and writing of the work; critical review of the work. DS Fernandes, TMS Russo and AC Souza: conception, planning, analysis, interpretation and writing of the work. RCCP Silveira: analysis, interpretation, final review of the work. CM Galvão: analysis, interpretation, final review of the work. KDS Mendes: conception, planning, analysis, interpretation, writing of the work; final review of the work.

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