

IMPLICATIONS OF PALLIATIVE CARE FOR THE PRACTICE OF PRIMARY CARE NURSING

A enfermagem e os cuidados paliativos na atenção primária à saúde

La enfermería y los cuidados paliativos en la atención primaria a la salud

Larissa Milani¹, Marcelle Miranda da Silva²

How to quote this article:

Milani L, Silva MM. Nursing and palliative care in primary health care. Rev Fund Care Online. 2021 jan/dez; 13:434-442. DOI: <http://dx.doi.org/10.9789/2175-5361.rpcfo.v13.7485>

ABSTRACT

Objective: the purpose of this review of the literature is to address the implications of Palliative Care (PC) for the practice of Primary Care Nursing. **Methods:** this integrative literature review was performed by searching the databases of CINAHL, LILACS, MEDLINE and SCIELO for publications from July to August 2017. **Results:** four categories emerged: “primary care nurses’ role in Palliative Care”; “impact of the multidisciplinary team on nursing practice”; “ethical conflicts experienced by primary care nursing professionals when delivering Palliative Care”; and “Useful tools for nursing evaluation”. **Conclusion:** the obstacles and challenges faced by primary care professionals when delivering PC occur not only during the implementation of governmental measures but also during the nursing professionals’ training. Difficulties in relation to interdisciplinary teams, ethical conflicts and lack of knowledge about the patient were pointed out. The instruments can help in implementing and assessing PC.

Descriptors: Palliative care; Nursing; Primary health care; Review.

¹ Obstetrical Nursing undergraduate student at UFRJ.

² Nursing graduate by the UFRJ, Specialist’s Degree in Oncology Nursing by the *Instituto Nacional de Câncer (INCA)*, MSc in Nursing by the UFRJ, PhD in Nursing by the UFRJ, former Postdoctoral Researcher at Osnabrück University of Applied Sciences, Adjunct Professor at UFRJ.

RESUMO

Objetivo: identificar as produções que abordem implicações à prática da enfermagem nos Cuidados Paliativos (CP) no âmbito da Atenção Primária à Saúde (APS). **Métodos:** trata-se de uma revisão integrativa realizada nas bases de dados CINAHL, LILACS, MEDLINE e SCIELO, no período de julho a agosto de 2017. **Resultados:** emergiram quatro categorias: O papel do enfermeiro nos Cuidados Paliativos na Atenção Primária à Saúde; A equipe multidisciplinar e suas inferências à enfermagem; Conflitos éticos da enfermagem na prestação de cuidados paliativos na atenção primária; Instrumentos úteis à avaliação da enfermagem. **Conclusão:** as barreiras e os desafios à implementação dos CP na APS perpassam as esferas governamentais e atingem a prática da enfermagem, seja pelas dificuldades nas relações com a equipe interdisciplinar, pelos conflitos éticos ou pelo déficit de conhecimento sobre a temática. Os instrumentos podem auxiliar na execução e avaliação dos CP.

Descritores: Cuidados paliativos; Enfermagem; Atenção primária à saúde; Revisão.

RESUMEN

Objetivo: identificar las producciones que aborden implicaciones a la práctica de la enfermería en los Cuidados Paliativos (CP) en el ámbito de la Atención Primaria a la Salud (APS). **Métodos:** se trata de una revisión integrativa realizada en las bases de datos CINAHL, LILACS, MEDLINE y SCIELO, en el período de julio hasta agosto de 2017. **Resultados:** emergieron cuatro categorías: el papel del enfermero en los cuidados paliativos en la atención primaria a la salud; El equipo multidisciplinario y sus inferencias a la enfermería; Conflictos éticos de la enfermería en la prestación de cuidados paliativos en la atención primaria; Instrumentos útiles para la evaluación de la enfermería. **Conclusión:** las barreras y los desafíos a la implementación de los CP en la APS atraviesan las esferas gubernamentales y alcanzan la práctica de la enfermería, sea por las dificultades en las relaciones con el equipo interdisciplinario, por los conflictos éticos o por el déficit de conocimiento sobre la temática. Los instrumentos pueden auxiliar la ejecución y evaluación de los CP.

Descriptorios: Cuidados paliativos; Enfermería; Atención primaria a la salud; Revisión.

INTRODUCTION

Demographic transition is a global reality and is happening at an accelerated pace in Brazil. It is estimated that by 2020, for the first time, the world's elderly population will be greater than that of children up to five years old. It will reach 2 billion individuals by 2050,¹ 66.5 million of them in Brazil.²

This population aging, together with technological and scientific advances, causes a higher prevalence of non-communicable diseases (NCDs) and, consequently, the increased demand for Palliative Care (PC). It is estimated that 40 million people on the planet need this care but only 10% of them receive it.³

PC promotes the quality of life of people and their relatives facing together the problems associated with diseases that threaten the continuity of life. To accomplish this, PC uses early identification, correct assessment, and treatment of pain and other problems of physical, psychosocial, emotional and spiritual nature.⁴

In order to effectively cover the population demanding this type of care, PC must be integrated into the entire

Brazilian health care system as advocated by the Oncological Care Policy. Nevertheless, there are many difficulties in implementing PC in health care services,⁵ and many people sometimes receive inadequate, mistaken, biotechnocratic palliative treatment. This happens regardless of the possibility of receiving harmonious care, adapted to their socio-cultural, environmental, and economic reality within the context of Primary Health Care (PHC).

Home Care, a modality of PC established in Article 9 of the Ordinance No. 825,⁶ is essential for the fair and broad implementation of this care, particularly in countries such as Brazil in which there are limited resources in the health care area and restricted possibilities of institutional care. It is intended for people with a disease in an advanced stage that is progressing. Furthermore, these people need continuous monitoring of symptoms supported by an established preliminary care plan. It allows peoples' permanence in a known environment, preserves intimacy, enables the performance of some work tasks, promotes habits and leisure activities, makes schedules more flexible, and strengthens their autonomy, integrity, and dignity. Generally, family members are more satisfied with actively participating in the care process and respecting the will of the entity, being able to prevent pathological mourning.⁷

The *Política Nacional de Atenção Básica (PNAB)* [National Policy on Primary Care], through the *Estratégia de Saúde da Família (ESF)* [Family Health Strategy], which reorganized primary care in Brazil aiming at breaking the hegemony of the biological positivist model,⁸ has principles and guidelines in line with PC that can be followed: capillarity, universality, accessibility, linkage, longitudinality, completeness, accountability, humanization, equity, and social participation.⁹

Bearing in mind this framework, nursing appears as a leading occupation and its performance in PC is paramount, because it is in the front line of health care and has greater continuity of the home environment.

Given the aforesaid, the objective of this study was to identify the studies that looked at the implications of PC for the practice of Primary Care Nursing.

METHODS

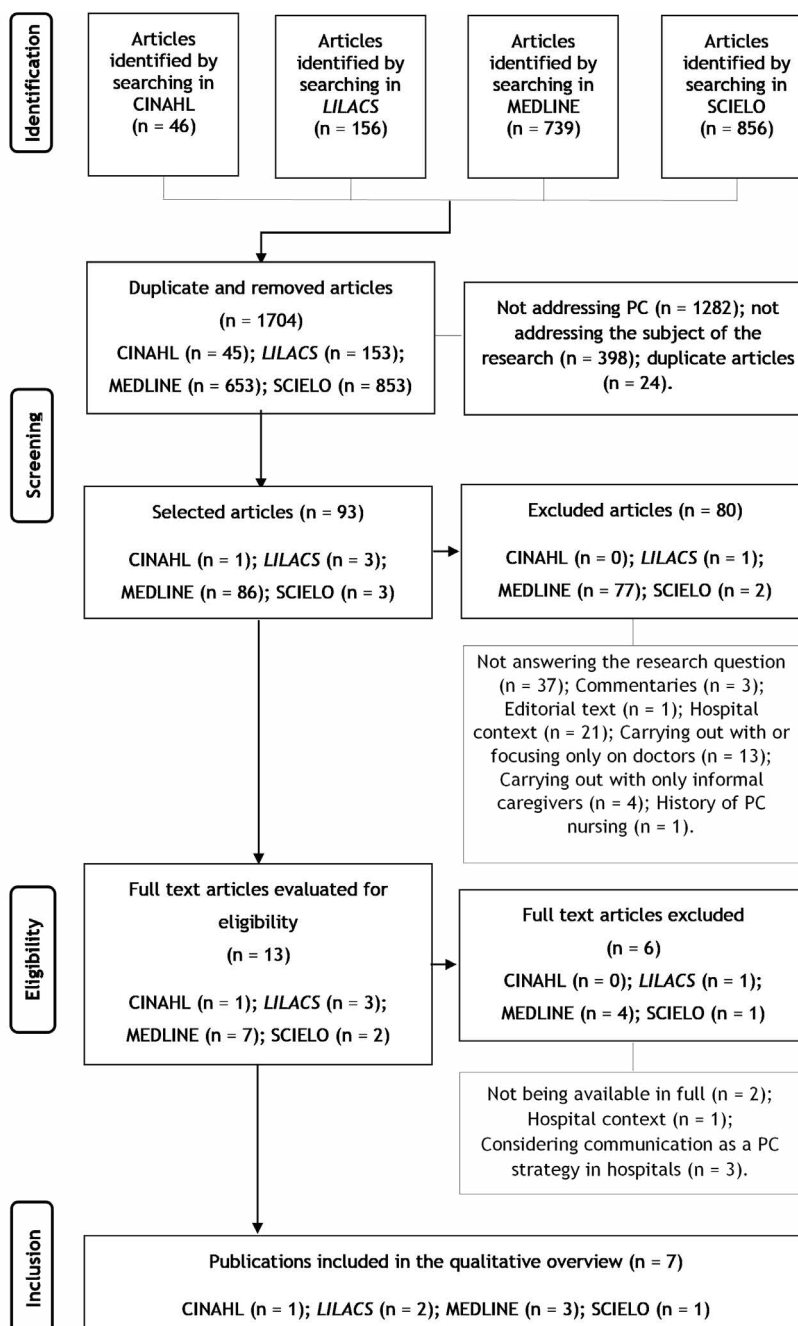
This integrative literature review was conducted from July to August 2017 by summarizing the results of previous research and exposing mainly the conclusions about a given phenomenon according to the *corpus* of literature. The integrative review was comprised of six stages as follows: 1) identifying the theme and selecting the hypothesis or research question for conducting the integrative review; 2) establishing inclusion and exclusion criteria for the search of the literature; 3) defining the information to be extracted from the selected studies; 4) evaluating the studies included in the integrative review; 5) interpreting the results; and 6) presenting the review/knowledge synthesis.¹⁰

The subject defined according to the method was “PC provided by primary care nursing professionals”. The research question was as follows: “what is the current state of the scientific literature on the PC provided by primary care nursing professionals?”. In addition to obtaining the Decs/Mesh descriptors, the PICo strategy (Population, Interest, Context) was used.

Chart I – PICo strategy used in the study.

Strategy	Description	Decs/Mesh
P	Palliative Care Patient	<i>Cuidados paliativos</i> /palliative care
I	Nursing	<i>Enfermagem</i> /nursing
Co	Primary Health Care	<i>Atenção primária à saúde</i> /primary health care

Figure 1 – PRISMA flowchart for selecting publications from the databases.



Considering the scientific knowledge available on the subject, the following databases were consulted through remote access to the portal of the *Coordenação de Aperfeiçoamento de Pessoal do Nível Superior (CAPES)*

[Coordination for the Improvement of Higher Education Personnel]: Cumulative Index to Nursing & Allied Health Literature (CINAHL), *Literatura Latino-americana e do Caribe em Ciências da Saúde (LILACS)* [Latin American and

Caribbean Literature in Health Sciences], Medical Literature Analysis and Retrieval System Online (MEDLINE) and Scientific Electronic Library Online (SCIELO).

The Decs/Mesh terms were associated with the trio and pairs with the Boolean operator AND in order to obtain all possible combinations and broad coverage. The inclusion criteria were articles answering the research question; available in Portuguese, English or Spanish; and in full. The exclusion criteria were commentaries, editorial texts, dissertations, and theses. No restrictions on the year of publication were applied.

Hence, the search process resulted in 1797 publications, to which the PRISMA recommendations were applied. Seven articles were selected at the end of the process. PRISMA consists of a checklist with 27 items and a four-step flowchart.¹¹ A descriptive table was used to organize, analyze and summarize the articles included in the review. The Bardin content analysis was applied to the articles

included in the meta-synthesis. It is composed of three major steps: 1) pre-analysis; 2) exploration of the material; and 3) treatment of the results and interpretation.¹²

RESULTS

The articles included in the meta-synthesis were characterized according to reference, objectives, and conclusion. After this, they were organized in charts according to the database of origin.

The articles were published in *Acta Paulista de Enfermagem*, *Annual of Palliative Medicine*, *BMC Palliative Care*, *British Journal of General Practice*, *Ciência & Saúde Coletiva*, *International Journal of Older People Nursing*, *Journal of Palliative Care*, *Revista da Escola de Enfermagem da USP*, *Revista de Bioética*, *Revista Mineira de Enfermagem*, and *Texto & Contexto Enfermagem* from 2006 to 2017. Moreover, they used qualitative and descriptive approaches.

Chart 2 – Characterization of the article selected from CINAHL.

Reference	Objectives	Conclusions
Hey A, Hermann AP, Mercês NNA, Lacerda MR. Participação da enfermeira nos cuidados paliativos domiciliares. <i>Rev Min Enferm.</i> 2017; 21:1-7. ¹³	Describing home PC performed by the nurse; identifying the interrelationships between the nurse, family, and patient; and characterizing the significant moments in which the nurse participated within this context.	The nurse's presence in this modality of care is fundamental and can contribute to structuring this care in the Brazilian health care system.

Chart 3 – Characterization of the articles selected from LILACS.

Reference	Objectives	Conclusions
Saito DYT, Zoboli ELCP. Cuidados paliativos e a atenção primária à saúde: <i>scoping review</i> . <i>Rev bioét.</i> 2015; 23 (3): 593-607. ¹⁴	Identifying, considering the view of health care professionals, the ethical problems arising from the practice of PC by primary care nursing professionals.	In this context, the problems encountered differed from those experienced while delivering PHC in specific situations. In order to incorporate PC into PHC, specific norms and training are required in addition to the culture of shared and co-responsible care.
Souza HL, Zoboli ELCP, Paz CRP, Schweitzer MC, Hohl KG, Pessalacia JDR. Cuidados paliativos na atenção primária à saúde: considerações éticas. <i>Rev bioét.</i> 2015; 23 (2): 349-59. ¹⁵	Identifying user cases in order to describe the ethical problems experienced by the team members.	The results indicate that the formation of human resources with technical competence and the continuity of assistance during the transition to PC are favorable factors for integrality and obtaining more adequate responses to the ethical challenges experienced by the team.

Chart 4 – Characterization of the articles selected from MEDLINE.

Reference	Objectives	Conclusions
Ewing G <i>et al.</i> Palliative care in primary care: a study to determine whether patients and professionals agree on symptoms. <i>British Journal of General Practice.</i> January 2006:27-34. ¹⁶	Investigating the agreement on symptom evaluations among patients at home, primary care physicians and district nurses.	The evaluation tool used (CAMPAS-R) is quick and easy to be completed. It may monitor the quality of control of PC symptoms at home.
Marcucci FCI <i>et al.</i> Identification and characteristics of patients with palliative care need in Brazilian primary care. <i>BMC Palliative Care.</i> 2016; 15:51. ¹⁷	Identifying how many patients covered by the <i>Estratégia de Saúde da Família (ESF)</i> [Family Health Strategy] need PC; describing their health conditions and sociodemographic status; and describing the professional and social support given to them.	There are <i>ESF</i> patients needing PC. PHC is provided for them, except in some specific situations. PC policies should be implemented and professional training performed to improve this area.

(Continue)

(Continuation)

Reference	Objectives	Conclusions
Pelayo-Alvarez M, Perez-Hoyos S, Agra-Varela Y. Reliability and concurrent validity of the palliative outcome scale, the rotterdam symptom checklist, and the brief pain inventory. <i>Journal of Palliative Care</i> . 2013; 16(8):867-74. ¹⁸	Investigating the reliability and concurrent validity of the Palliative Results Scale (PRS), Rotterdam Symptom Checklist (RSC) and the Raw Brief Pain Inventory (RBPI).	The RBPI, PRS, and RSC showed adequate reliability and concomitant moderate validity.

Chart 5 – Characterization of the articles selected from SCIELO.

Reference	Objectives	Conclusion
Sousa JM, Alves ED. Competences of the nurse for palliative care in home care. <i>Minutes Paul Enferm</i> . 2015; 28(3):264-9. ¹⁹	Identifying the home care nurses' competences in delivering PC.	The competencies found presented internal reliability and provided assertive statements about the home care nurse's performance while delivering PC.

DISCUSSION

Based on the results of the selected articles, four categories were highlighted as shown below.

Primary care nurses' role in Palliative Care

Nurses play a key role in primary care in Brazil because of their autonomy and activities according to the PNAB. They also play a key role in delivering PC as primary care nursing professionals. Thus, they have the competence to perform a variety of activities, some of them being highlighted by the articles studied.

Recognizing the life context in which people and their relatives are inserted as well as their needs for planning assistance¹³ are one of the nurses' main activities. Two nurses' duties can be employed as strategies for implementation according to the analyzed articles: the systematization of nursing care¹⁹ and home visits.¹³

Systematization of nursing care is a necessary legal tool for quality care and enables nurses to deliver care in an integral and individualized way. Considering its operational planning, it helps nurses to perform actions that include the analysis of the client's history with an integral view, physical examination, diagnosis and behavior planning.²⁰ The first stage of the nursing process provides the opportunity to obtain purposeful, systematic and continuous information about the person and the family²¹, as well as reports on their reality.

The application of the nursing process also contributes to symptom management, since its control is essential for primary care nurses to deliver PC, and represents an important factor that may influence the decision to admit patients in hospitals.²² More effective symptom management includes an integrated assessment and the use of integrative and complementary health care practices. For this to occur, it is clear that contact between professionals and clients must be made. However, regular home visits have been identified as an obstacle to maintaining the person at home and effective symptom control. A study identified that primary

care professionals did not contact people needing PC during the last four months of life.¹⁶

Home visits are perhaps the most important aspect of the process of delivering PC by primary care nurses. It allows them not only to provide contact but also to recognize and witness the context lived by the person and his/her family. It is one of the main actions that allow a closer approach to the determinants of the health-disease process, knowledge of the characteristics of the place (hygiene, sanitation, among others) and establishment of links.²³

Currently, a responsible and positive link is employed to organize the relationship between health care teams and population. It enables the formation of strong interpersonal bonds, co-responsibility, sharing and humanization of care, feelings of renewal and re-energization in the professional's practice. In addition, it is a therapeutic resource that enables the closeness between those involved through conversation, listening, and exchange of knowledge, also ensuring the continuity of care and the achievement of objectives.²⁴

Another nurse's activity highlighted is the support and education of relatives and caregivers. This support is composed of the following actions: responding holistically to the human suffering generated by experiencing fragility in the face of the death process occurring at home; establishing emotional support for the family and caregivers to deal with suffering during the PC period and mourning, providing them with access to the multiprofessional team after the client's death.^{13,16,17,19} In addition to agreeing with the very definition of PC, these actions comply with the principles that govern the performance of professionals: offering "a support system to assist family members during the patient's illness and facing mourning" and "focusing on the needs of patients and their relatives, including follow-up during mourning"²⁵ and minimizing the (over)burden faced by those involved in home PC.¹⁵

The education interventions toward family members and caregivers mentioned in the studies were: teaching how provide care, covering safety measures, fall prevention, body

care, use of medication, use of dressings, proper care when using catheters, active-passive exercises and posture; and evaluating and managing common signs and symptoms, paying attention to the patient's capacity for understanding them.^{13,16,17,19} The education and behavioral actions toward caregivers are associated with positive results regarding anxiety control, competence in delivering care, preparation to act and feelings of reward.¹⁷ It is important to emphasize that frequently the family members are also caregivers and that guardianship is primordial for people receiving PC at home. Therefore, in order to deliver this care and evaluate health within the context of PHC, family members and caregivers should be supported and educated - often including nurse technicians and community health agents.

Impact of the multidisciplinary team on nursing practice

The PC delivered by primary care nursing professionals is complex, not only requiring the execution of techniques but also a global, humanized and shared care with the multidisciplinary team that helps in the actions and sharing of findings, knowledge, and procedures.^{13,19}

The multiprofessional approach is advocated by the PC principles and seeks to integrally develop the role of health education and care, improving the subject's quality of life and family members.^{13,25}

Nursing professionals are part of the PHC's basic team.^{8,19} They are among the professionals who suffer most from emotional distress since they constantly interact with people and their relatives, closely following suffering, pain, illness, and death.²⁶

The nursing actions can also receive the support of the *Núcleos de Apoio à Saúde da Família* (NASFs) [Family Health Support Centers], which have psychologists, social assistants, physical therapists, occupational therapists, etc. Nonetheless, the lack of multidisciplinary support for people in need of PC is still observed.¹⁷

The lack of collaboration between professionals is presented as a problem. Conflicts, ambiguous and overlapping professional roles, inadequate communication and leadership problems are constant challenges.¹⁴

For nurses, the quality of relationships and each professional's perception about the others' performance are factors that influence teamwork and the process of referring patients to another service. Communication between doctors and nurses and between the team and health care network is a failure.¹⁴

Communication is a skill that is present in health care and relationships between professionals and caregivers and among the multidisciplinary team members. The health care team members view communication as a link in the work process; nevertheless, it is ineffective according to the daily practice and scientific literature. Diversity in training, hierarchical differences, power, and conflicts contribute to the situation and, consequently, have repercussions for the

safety of the care provided.²⁷ Continued health education is a resolute and participatory strategy that can be developed with the PHC team and can be executed through active methodologies, such as realistic simulations. As a result, more effective and efficient communication may be obtained.

The leadership exercised by doctors is evidenced in focal groups, in which nurses did not have opinions and groups were represented, formally or informally, by a doctor.¹⁴ Technical and scientific knowledge is highlighted in the literature as the most important competence in relation to those associated with relational practices. The nurses' unpreparedness while playing a coordinating role was also highlighted. Heavy workload, overlapping tasks and lack of training were considered as factors hindering this practice.²⁸ Therefore, there is a need for discussing the nurses' training, which may be focused on leadership as well as technical and scientific content.

Ethical conflicts experienced by primary care nursing professionals when delivering Palliative Care

The studies showed that ethical conflicts are constantly experienced by primary care nurses when providing PC for people and families.

Shortcomings in professional training, in resources for making home visits, and in the organization and access to PC provided by primary care professionals are cited as problems that lead to a lack of formal support and workload for caregivers and relatives. Consequently, the professionals think that "they need to consider the family as a single unit while caring for its members"^{15:354}

The nursing team, in addition to providing the PC, has to meet the spontaneous demand and monitor the entire population's state of health. The proximity characteristic of the primary level intensifies the link and hinders the maintenance of objectivity in relationships with caregivers, family members, and clients receiving PC, causing suffering¹⁴ and favoring workload. In order to develop a support network aiming at improving and promoting the health of all its members, it is necessary to identify who they are, maintain active listening and therapeutic communication. In addition to knowing the nature of the interventions, it is also necessary to understand the possible work mechanisms.^{14,15}

The lack of knowledge about PC among professionals contributes to the emergence of ethical problems associated with this care, such as spirituality¹⁵ and the communication of bad news. The latter generates paternalistic and protective attitudes that interfere with the subject's autonomy.¹⁴ Lack of communication skills is perceived by professionals as a factor that causes intense suffering because it creates conflicting situations involving their feelings and those of the patients and their relatives. Commonly, the family's desire to spare the sick member leads to the use of technical and complex language by professionals. Consequently, more direct communication with them is not achieved.

The professionals constantly seek to act based on the compromise between nullifying hope or strengthening false expectations.²⁹ Clients and their relatives prefer communication that includes empathy, honesty, and balance with sensitivity and hope. To this end, the development of communication programs and training is effective and improve the professionals' performance.³⁰

Training the team members, including inherent ethical aspects, and implementing programs that integrate and articulate the PC with the health care system will contribute to humanization, assistance integrity, and more adequate answers to the ethical problems experienced and less workload.¹⁴ The need for reviewing the number of families receiving PHC services and reorganizing the work process were also mentioned.¹⁵

Useful tools for nursing evaluation

The instruments incorporate scientific knowledge, reliability, and standardization to data collection and/or evaluation of results. Thus, they contribute to the scientific construction of nursing and the quality of care.

A study conducted with clients with cancer receiving PC by primary care nurses revealed that these professionals usually overestimate the PC patients' symptoms.¹⁶ Therefore, it is of paramount importance that they use standardized tools to evaluate the signs and symptoms of PC patients.¹⁹

In a study conducted in Brazil,¹⁷ the Palliative Care Screening Tool (PCST) proved to be useful for identifying people eligible to receive PC by PHC professionals. The tool allows an objective approach to screening, ease, and speed of use, the inclusion of non-malignant conditions and is not limited to the assessment of functional status. In other words, it can be useful and sensitive to detect individuals with good functionality but who present life-limiting conditions.³⁴ However, using it without professional evaluation is not recommended.^{33,35}

The Karnofsky Performance Scale (KPS), which allows the functional classification of people,³⁷ and Edmonton Symptom Assessment System (ESAS), a numerical visual scale ranging from zero to ten used to assess nine symptoms (pain, tiredness, nausea, depression, anxiety, drowsiness, lack of appetite, shortness of breath, and well-being),³⁸ were also employed by primary care professionals in Brazil.¹⁷

In order to evaluate symptoms, the articles also cited the Brief Pain Inventory (BPI) short form,¹⁸ which quickly assesses the severity of pain and its impact on the individual's functioning³¹, and The Rotterdam Symptom Checklist (RSCL),¹⁸ which is a means of self-reporting to assess the quality of life of subjects with cancer. The RSCL has four domains: physical symptom distress, psychological distress, activity level, and overall global life quality.³² It needs to be adapted for chemotherapy since it is useless for subjects not receiving active treatment.¹⁸ The Cambridge Palliative Assessment Schedule (CAMPAS-R) has been validated

for home use³³ and allows the evaluation of the eight most frequently reported symptoms (pain, nausea, constipation, fatigue, shortness of breath, anxiety, and depression) according to their classification on the Visual Analogue Scale (VAS).¹⁶

The Palliative Care Outcome Scale (POS) is cited as a tool for care evaluation.^{17,18} It is a scale for multidimensional analysis of the quality of life of PC patients with non-communicable chronic diseases. Furthermore, it can be applied easily, featuring bio-psycho-social, spiritual and practical aspects. The POS presents the answers using the Likert scale of five points (except an open question),³⁹ but it needs to be slightly adapted since item 9 (time wasted while waiting for test results in the hospital) does not apply to the PHC scenario.¹⁸

The instruments may be used together in order to obtain complete information. There is evidence that the RSCL may be used interchangeably with the POS in relation to symptoms. Considering the BPI, its pain intensity might be used interchangeably with the RSCL concerning physical pain items.¹⁸

CONCLUSIONS

In order to be more effective and efficient, it is necessary to deliver PC to patients covered by the Health Care Network, especially in the context of PHC. This level of attention has unique characteristics that contribute and facilitate the implementation of the palliative philosophy.

The study results pointed out the primary care nurse as a key agent for and protagonist of the implementation of home PC. It is also highlighted that the multiprofessional team provides comprehensive care, but conflicts between members can hinder the practice. The nursing team faces ethical problems while performing PHC; however, the lack of knowledge about this care aggravates the scenario. Conclusively, the use of tools for assessing the health status of people in need of PC is essential for the data reliability and quality of care.

Several challenges were perceived by the primary care professionals when delivering PC. These challenges occur not only during the implementation of governmental actions but also during the nursing professionals' training. Nonetheless, it is fundamental to train nursing teams to deliver PC and reorganize the work process and PHC services so that the realistic implementation of PC could be facilitated and made possible.

It was also verified that more research on primary care delivered by nursing professionals, especially certified technicians and community health agents, needs to be conducted to fill these knowledge gaps. Such new research should include the application of instruments after training and under the nurse's supervision. The application of methods beyond describing empirical realities should be considered as well.

REFERENCES

1. Nações Unidas no Brasil. Mundo terá 2 bilhões de idosos em 2050: OMS diz que envelhecer bem deve ser prioridade global [Internet] [atualizado em 2014 Nov 11; cited 2017 Aug 19]. Disponível em: <https://nacoesunidas.org/mundo-tera-2-bilhoes-de-idosos-em-2050-oms-diz-que-envelhecer-bem-deve-ser-prioridade-global/>.
2. Instituto Brasileiro de Geografia e Estatística. Síntese de indicadores sociais: uma análise das condições de vida da população brasileira. 2016 [cited 19 Aug 2017]. Disponível em: <https://biblioteca.ibge.gov.br/visualizacao/livros/liv98965.pdf>.
3. Nações Unidas no Brasil. Só 10% das pessoas que precisam de cuidados paliativos recebem assistência, mostra OMS [Internet] [atualizado 2014 Jan 29; cited 2017 Aug 19]. Disponível em: <https://nacoesunidas.org/so-10-das-pessoas-que-precisam-de-cuidados-paliativos-recebem-assistencia-mostra-oms/>.
4. World Health Organization. Global Atlas of Palliative Care at the End of Life [Internet]. 2014 Jan. [cited 2017 Aug 19]. Disponível em: http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf.
5. Silva MM, Büscher A, Moreira MC. Palliative cancer care in Brazil: perspective of nursing and physicians. *Cancer Nursing*. 2016 [cited 2017 Aug 19]; 40(4):289-96.
6. BRASIL. Portaria nº 825, de 25 de abril de 2016. Redefine a Atenção Domiciliar no âmbito do Sistema Único de Saúde (SUS) e atualiza as equipes habilitadas [cited 2017 Aug 19]. Disponível em: http://bvsm.s.saude.gov.br/bvs/saudelegis/gm/2016/prt0825_25_04_2016.html.
7. Agência Nacional de Cuidados Paliativos. Manual de Cuidados Paliativos ANCP [Internet]. 2012 [cited 2017 Aug 19]; ampliado e atualizado; 2ª edição; p21-30. Disponível em: www.paliativo.org.br/dl.php?bid=146.
8. Ministério da Saúde (BR), Secretaria de Políticas de Saúde, Departamento de Atenção Básica. A Implantação da Unidade de Saúde da Família. Brasília. 2000 [cited 2017 Aug 19]; 44 p.
9. Ministério da Saúde (BR), Secretaria de Atenção à Saúde, Departamento de Atenção Básica. Política Nacional de Atenção Básica. Brasília. 2012 [cited 2017 Aug 19]; 110p.
10. Mendes KDS, Silveira RCCP, Galvão CM. Revisão integrativa: método de pesquisa para a incorporação de evidências na saúde e na enfermagem [Internet]. *Texto Contexto Enferm*; Florianópolis. 2008 Out-Dez [cited 2017 Aug 19]; 17(4): 758-64. Disponível em: <http://www.scielo.br/pdf/tce/v17n4/18.pdf>.
11. Moher D, Liberati A, Tetzlaff J, Altman DG. Tradução de Galvão TF, Pansani TSA, Harrad D. Principais itens para relatar Revisões sistemáticas e Meta-análises: A recomendação PRISMA [Internet]. *Epidemiol Serv Saúde*; Brasília. Abr-Jun 2015 [cited 2017 Aug 19]; 24(2): 355-42. Disponível em: <http://www.scielo.br/pdf/ress/v24n2/2237-9622-ress-24-02-00335.pdf>
12. Caregnato RCA, Mutti R. Pesquisa qualitativa: análise de discurso versus análise de conteúdo [Internet]. *Texto Contexto Enferm*; Florianópolis. 2006 Out-Dez [cited 2017 Aug 19]; 15(4): 679-84. Disponível em: <http://www.scielo.br/pdf/tce/v15n4/v15n4a17.pdf>.
13. Hey A, Hermann AP, Mercês NNA, Lacerda MR. Participação da enfermeira nos cuidados paliativos domiciliares [Internet]. *Rev Min Enferm*. 2017 [cited 2017 Oct 3]; 21:1-7. Disponível em: <http://www.reme.org.br/artigo/detalhes/1136>.
14. Saito DYT, Zoboli ELCP. Cuidados paliativos e a atenção primária à saúde: *scoping review* [Internet]. *Rev bioét*. 2015 [cited 2017 Oct 3]; 23 (3): 593-607. Disponível em: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/1105/1337.
15. Souza HL, Zoboli ELCP, Paz CRP, Schweitzer MC, Hohl KG, Pessalacia JDR. Cuidados paliativos na atenção primária à saúde: considerações éticas [Internet]. *Rev bioét*. 2015 [cited 2017 Oct 3]; 23 (2): 349-59. Disponível em: <http://www.scielo.br/pdf/bioet/v23n2/1983-8034-bioet-23-2-0349.pdf>.
16. Ewing G *et al*. Palliative care in primary care: a study to determine whether patients and professionals agree on symptoms [Internet]. *British Journal of General Practice*. Jan 2006 [cited 2017 Oct 3]; 27-34. Disponível em: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1821417/pdf/bjjpg56-27.pdf>.
17. Marcucci FCI *et al*. Identification and characteristics of patients with palliative care needs in Brazilian primary care [Internet]. *BMC Palliative Care*. 2016 [cited 2017 Oct 3]; 15:1-10. Disponível em: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4888621/pdf/12904_2016_Article_125.pdf.
18. Pelayo-Alvarez M, Perez-Hoyos S, Agra-Varela Y. Reliability and concurrent validity of the palliative outcome scale, the rotterdam symptom checklist, and the brief pain inventory [Internet]. *Journal of Palliative Care*. 2013 [cited 2017 Oct 3]; 16(8):867-74. Disponível em: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3717199/>.
19. Sousa JM, Alves ED. Competências do enfermeiro para o cuidado paliativo na atenção domiciliar [Internet]. *Acta Paul Enferm*. 2015 [cited 2017 Oct 3]; 28(3):264-9. Disponível em: <http://www.scielo.br/pdf/ape/v28n3/1982-0194-ape-28-03-0264.pdf>.
20. Zanardo GM, Zarnado GM, Kaefer CT. Sistematização da Assistência de Enfermagem [Internet]. *Rev Contexto & Saúde*. Jan/Jun 2011 [cited 2017 Oct 13]; v.10, n.20, p. 1371-4. Disponível em: <https://revistas.unijui.edu.br/index.php/contextoesaude/article/view/1811/1517>.
21. Resolução COFEN nº 242, de 31 de agosto de 2000. Dispõe sobre a Sistematização da Assistência de Enfermagem e a implementação do Processo de Enfermagem em ambientes, públicos ou privados, em que ocorre o cuidado profissional de Enfermagem, e dá outras providências [Internet] [cited 2017 Oct 3]. Disponível em: http://www.cofen.gov.br/resoluco-cofen-3582009_4384.html.
22. Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? [Internet]. *Soc Sci Med*. 1998 [cited 2017 Oct 3]; 47: 565-79. Disponível em: <http://www.sciencedirect.com/science/article/pii/S0277953698001154?via%3Dihub>
23. Kebian LVA, Acioli S. A visita domiciliar de enfermeiros e agentes comunitários de saúde da Estratégia Saúde da Família [Internet]. *Rev Eletr Enf*. 2014 Jan/Mar [cited 2017 Oct 13]; 16(1):161-9. Disponível em: <https://www.revistas.ufg.br/fen/article/view/20260/16455>.
24. Santos RCA, Miranda FAN. Importância do vínculo entre profissional-usuário na Estratégia de Saúde da Família [Internet]. *Rev Enferm UFSM*. 2016 Jul/Set [cited 2017 Oct 13];6(3): 350-9. Disponível em: <https://periodicos.ufsm.br/reufsm/article/view/17313/pdf>.
25. World Health Organization. Definition of Palliative Care [Internet], 2002 [cited 2017 Oct 13]. Disponível em: <http://www.who.int/cancer/palliative/definition/en/>.
26. Hermes HR, Lamarca ICA. Cuidados paliativos: uma abordagem a partir das categorias profissionais de saúde [Internet]. *Ciência & Saúde Coletiva*. 2013 [cited 2017 Oct 2]; 18(9):2577-88. Disponível em: <http://www.redalyc.org/articulo.oa?id=63028227012>.
27. Nogueira JWS, Rodrigues MCS. Comunicação efetiva em equipe em saúde: desafio para a segurança do paciente [Internet]. *Cogitare Enferm*. 2015 Jul/Set [cited 2017 Nov 09]; 20(3): 636-40. Disponível em: <http://docs.bvsalud.org/biblioref/2016/08/1241/40016-162735-1-pb.pdf>.
28. Spagnuolo RS, Juliani CMCM, Spiri WC, Bocchi SCM, Martins STF. O enfermeiro e a Estratégia Saúde da Família: desafios em coordenar a equipe multiprofissional [Internet]. *Cienc Cuid Saude*. 2012 Abr/Jun [cited 2017 Nov 09]; 11(2):226-34. Disponível em: https://www.researchgate.net/profile/Regina_Spagnuolo/publication/273974759_O_enfermeiro_e_a_estrategia_saude_da_familia_desafios_em_coordenar_a_equipe_multiprofissional/links/553e2e4b0cf20184050ddb3.pdf.
29. Silva LPS, Santos I, Castro SZM. Comunicação de notícias difíceis no contexto do cuidado em oncologia: revisão integrativa de literatura [Internet]. *Rev enferm UERJ*, Rio de Janeiro. 2016 [cited 2017 Nov 09]; 24(3):1-8. Disponível em: <http://dx.doi.org/10.12957/reuerj.2016.19940>.
30. Baer L, Weinstein E. Improving oncology nurses' communication skills for difficult conversations [Internet]. *Clinical Journal of Oncology Nursing*. Jun 2013 [cited 2017 Nov 09]; 17(3):45-51. Disponível em: <http://cjon.ons.org/cjon/17/3/improving-oncology-nurses-communication-skills-for-difficult-conversations>.
31. MD Anderson Cancer Center (University of Texas). The Brief Pain Inventory [Internet] [cited 2017 Nov 11]. Disponível em: <http://mdanderson.org/research/departments-lab-institutes/departments-divisions/symptom-research/symptom-assessment-tools/brief-pain-inventory.html>.
32. Haes CJJM *et al*. Measuring the quality of life of cancer patients with the Rotterdam Symptom Checklist (RSCl): a manual [Internet]. University of Groningen, 2012 [cited 2017 Nov 11];2. Disponível em: https://www.umcg.nl/SiteCollectionDocuments/research/institutes/SHARE/assessment%20tools/handleiding_rscledruk.pdf.

33. Ewing G, Todd C, Rogers M, Barclay S, McCabe J, Martin A. Validation of a Symptom Measure Suitable for use among palliative care patients in the community: CAMPAS-R [Internet]. *Journal of Pain and Symptom Management*. April 2004 [cited 2017 Nov 11]; Vol. 27 No. 4, p.287-99. Disponível em: [http://www.jpmsjournal.com/article/S0885-3924\(03\)00535-9/fulltext](http://www.jpmsjournal.com/article/S0885-3924(03)00535-9/fulltext).
34. Center to Advance Palliative Care. CAPC: Crosswalk of JCAHO Standards and Palliative Care — Policies, Procedures and Assessment Tools. 2007 [cited 2017 nov 11]. Disponível em: <http://www.palliativedrugs.com/download/JCAHO-crosswalk.pdf>.
35. Van Mechelen W, Aertgeerts B, De Ceulaer K, Thoosen B, Vermandere M, Warmenhoven F, et al. Defining the palliative care patient: A systematic review. *Palliat Med*. 2013 [cited 2017 Nov 11];27(3):197-208. Disponível em: <http://pmj.sagepub.com/content/27/3/197.abstract>.
36. Lucchetti G, Badan Neto AM, Ramos SAC. Uso de uma escala de triagem para cuidados paliativos nos idosos de uma instituição de longa permanência [Internet]. *Geriatr Gerontol*. 2009 [cited 2017 Nov 11];3(3):104-8. Disponível em: www.ggaging.com/export-pdf/299/v3n3a02.pdf.
37. Schag CC, Heinrich RL, Ganz PA. Karnofsky performance status revisited: reability, validity, and guidelines [Internet]. *Journal of Clinical Oncology*, 1984 [cited 2017 Nov 11]; vol. 2, no. 3, p. 187-93. Disponível em: <http://ascopubs.org/doi/pdfdirect/10.1200/JCO.1984.2.3.187>.
38. Monteiro DR, Almeida MA, Kruse MHL. Tradução e adaptação transcultural do instrumento Edmonton Symptom Assessment System para uso em cuidados paliativos [Internet]. *Rev Gaúcha Enferm*; Porto Alegre. Jun 2013 [cited 2017 Nov 11]; 34(2):163-71. Disponível em: http://www.scielo.br/scielo.php?pid=S1983-14472013000200021&script=sci_abstract&tlng=pt.
39. Rugno FC, De Carlo MMRP. A Palliative Outcome Scale (POS) aplicada à prática clínica e pesquisa: uma revisão integrativa [Internet]. *Rev Latino-Am Enfermagem*. 2016 [cited 2017 Nov 11]; 24:1-11; Disponível em: <http://dx.doi.org/10.1590/1518-8345.0993.2764>.

Received on: 01/04/2018
Reviews required: 04/07/2018
Approved on: 20/08/2018
Published on: 05/01/2021

Corresponding author:

Larissa Milani
Address: Rua Rodrigues Barbosa, 158,
Vila Regente Feijó, São Paulo, Brazil.
Zip code: 03.334-040
E-mail: larissamilan94@gmail.com
Telephone number: +55 (11) 94295-2502