

Performance of the nursing team in a home care program in palliative care

Atuação da equipe de enfermagem em um programa de atenção domiciliar em cuidados paliativos

Stephany Rayane da Costa Gama¹ 

Brenda Aline Costa de Mendonça² 

Gigliane Santos da Silva³ 

Ruth Silva Lima da Costa⁴ 

^{1,3}Centro Universitário Uninorte (Rio Branco). Acre, Brazil. stephanygama2@gmail.com, brendaalinescosta14@gmail.com, gi.daricley1234@gmail.com

⁴Corresponding author. Centro Universitário Uninorte (Rio Branco). Acre, Brazil. rutylyma@gmail.com

ABSTRACT | OBJECTIVE: To know the performance of the nursing team in front of a home care program in palliative care aimed at terminally ill individuals. **METHOD:** A qualitative study developed with nurses working in a home care program of the State Department of Health of Acre. Data were collected in October 2021 through a semi-structured interview and analyzed following Bardin's content analysis proposal. **RESULTS:** Nurses demonstrated knowledge about palliative care applied to the individuals they serve, evidencing that the care provided is dynamic and requires specific skills to develop them, from the simplest to the most complex, being of fundamental importance for the quality of life of the assisted individuals. Some factors favor the assistance provided, such as the knowledge and dedication of the team, the partnership with the family, and the resources made available by the program. However, the location of the patient's home makes access difficult and interferes with the quality of care to be provided. **CONCLUSION:** The role of nursing professionals in the home care program in question was considered essential to ensure dignity and relief from suffering for those whose clinical condition is unfavorable.

KEYWORDS: Palliative Care. Nursing care. Termination.

RESUMO | OBJETIVO: Conhecer a atuação da equipe de enfermagem frente a um programa de atenção domiciliar em cuidados paliativos, voltado a indivíduos em estado terminal. **MÉTODO:** Estudo qualitativo, desenvolvido com enfermeiros atuantes em um programa de atenção domiciliar da Secretaria de Estado de Saúde do Acre. Os dados foram coletados no mês de outubro de 2021, por meio de entrevista semiestruturada, e analisados seguindo a proposta de análise de conteúdo de Bardin. **RESULTADOS:** Os enfermeiros demonstraram possuir conhecimento sobre os cuidados paliativos aplicados aos indivíduos por eles atendidos, evidenciando que o atendimento prestado é dinâmico e requer habilidades específicas para desenvolvê-los, desde os mais simples aos mais complexos, sendo de fundamental importância para a qualidade de vida dos indivíduos assistidos. Alguns fatores favorecem a assistência prestada, como o conhecimento e a dedicação da equipe, a parceria com a família e os recursos disponibilizados pelo programa. No entanto, a localização do domicílio do paciente dificulta o acesso e acaba interferindo na qualidade da assistência a ser prestada. **CONCLUSÃO:** A atuação do profissional de enfermagem no programa de atenção domiciliar em questão foi considerada fundamental para garantir dignidade e alívio do sofrimento para aqueles cuja condição clínica é desfavorável.

PALAVRAS-CHAVES: Cuidados Paliativos. Assistência de enfermagem. Terminalidade.

Introduction

The verb to palliate derives from the Latin *palliare* or *pallium*, and generally means to protect, to cover with a cover. However, palliating is more used in our environment, such as temporarily relieving, remedying, postponing, and delaying. Palliative care (PC) is more than a method, it is a philosophy of care. The PC aims to prevent and alleviate human suffering in many dimensions. It aims to give patients and their loved ones the best possible quality of life regarding the stage of an illness or the need for other treatments.¹

In 2002, the World Health Organization revised the definition of palliative care (PCs) described in 1990, which came to be cited as an approach that aims to improve the patients' quality of life and their families' facing problems associated with diseases that put lives at risk. This approach is done through the prevention and relief of suffering, through early identification, correct assessment, and treatment of pain and other physical, psychosocial, and spiritual problems. This care focuses on the needs and not on the diagnoses of these individuals.²

Palliative care aims to control symptoms without a curative function and preserve quality until the end of life. Palliative action is not intended to cure, it is a therapeutic measure intended to reduce the negative repercussions of the disease on the individual's well-being, whether in a hospital or home environment. It should be an integral part of professional health practice, regardless of the stage of disease evolution, and can be provided at the basic level of care, both in irreversible cases and progressive chronic disease.³

Within the multidisciplinary team, the professional nurse stands out as the one who has the most contact and deals daily with the patient and their families, and the interventions developed by them can help determine the success of this therapeutic measure.⁴

Providing competent, qualified, and differentiated care in the terminal phase of an individual is the responsibility of all health professionals, each within their area of competence. However, nurses have the scientific-technical training to perform the care in question since the curriculum structure of undergraduate nursing courses contains subjects in human sciences, preparing them to assist with the

signs and symptoms presented by the individual in its multiple dimensions. It also associates it with science, the art of caring in their professional daily life.⁵ The professional nurse can offer favorable conditions for the well-being of the individual in his terminality, providing the necessary assistance and promoting conditions for the fulfillment of his desires.⁶

From this perspective, studies with this approach are relevant in view of the need to expand knowledge in the area and support the conduct of nurses in this care modality. Based on these questions, the present study aims to understand the performance of the nursing team in a home care program in palliative care, aimed at terminally ill individuals.

Method

This is a study with a qualitative approach, carried out with nurses who work in a home care program in palliative care of the Acre State Health Department.

The home care service, through the "Best at Home" program, was implemented in 2011 and is composed of a multidisciplinary team, which includes doctors, nurses, nursing technicians, nutritionists, physiotherapists, and social workers, who provide home care for individuals who need more intensive health care, including those in a terminal state, with no possibility of cure.

The study population consisted of all nurses working in the program, a total of three professionals. Male and female Nurses who worked in that program developing activities aimed at palliative care for a period equal to or greater than six months were included. Those who worked in the program for fewer than six months would be excluded. No participant was excluded. The invitation to participate in the study was made after the research was approved by the local ethics committee.

Data collection took place in October 2021, on the premises of the State Health Department, in a place reserved for this purpose, and lasted 20 minutes. A semi-structured instrument, developed by the researchers themselves, was applied, containing open questions about the work developed by professionals, in the face of palliative care aimed at terminally ill patients.

Data analysis was performed by categorizing information based on content analysis by Bardin.² First, the ordering of the data obtained was performed; followed by its classification with the exhaustive and repeated reading of the texts, establishing questions to identify what emerged of relevance.

As this is qualitative research, the data were carefully analyzed regarding the interconnections of all the instrument's questions individually and presented with the full description of the participants' speeches.

To preserve the identity of the study participants, according to Resolution 466/12, which deals with research with human beings, the letter E will be used followed by a numerical identification, in the citations of their speeches.

This research was based on the recommendations of Resolution No. 466, of December 12, 2012, of the National Health Council, which governs the conduct of research with information on human beings and was approved by the local research ethics committee through opinion No. 5,096,875. Data collection only started after explanatory reading and signing of the Free and Informed Consent Term (FICT).

Results

The analysis of the statements made it possible to define five thematic categories (i) knowledge of professionals about palliative care; (ii) Main activities developed in relation to palliative care; (iii) factors that favor the practice of patient care in palliative care; (iv) factors that hinder the practice of patient care in palliative care; (v) importance of palliative care for terminally ill patients and their families.

(i) Knowledge of professionals about palliative care

This theme reveals, through the nurses' discourse, their knowledge of the PCs applied to patients treated in the program, evidencing that they demonstrate knowledge to work in the home care program for terminally ill individuals:

For me, palliative care or end-of-life care is trying to provide the patient with the comfort and well-being necessary for him and his family at this time, because

we cannot define the time that this process will last, but we can provide the necessary care to them together with the team and with family members. (E1).

Palliative care is the care provided to the patient at the end of life or when there is no longer any possibility of rehabilitation. The intent of this type of care is to avoid or reduce pain and other symptoms of discomfort and also to provide dignity to the patient and family. (E2).

Palliative care is nothing less than a set of actions that aim to improve the quality of life, promote comfort, relief from pain and suffering of an individual who is in a terminal phase. (E3).

(ii) Main activities developed in relation to palliative care

Regarding the main activities developed by nurses in front of PCs, the speeches showed that the service is dynamic and complex and requires specific skills of the professional nurse to develop them, here are the lines:

I provide care in its wide range of care with all devices, from dressings for chronic injuries, to clearing up doubts, and attending to the routine complications of patients admitted to the program. (E1).

The nursing of the better at home program performs treatment of pressure injuries and all types of injuries, using special covers, removal of stitches, exchange of gastrostomy tubes, indwelling and relieved bladder catheterization and post-pyloric gastric tube - nasoenteral, positioning in bed, aspiration of tracheal secretion, diaper change, assistance in bed bath, and guidance to family members about the care offered. (E2).

My main duties are to carry out home monitoring and evaluation of patients undergoing non-invasive mechanical ventilation, administration of immunoderivatives and medications, performing bladder catheterization, collection of material for exams, tracheostomy care, among others necessary for a better quality of life for patients same. (E3).

(iii) Factors that favor the practice of patient care in palliative care

As for the factors that favor the practice of patient care in PCs, the participants report some facilities that make their work more effective, especially knowledge, dedication and competence of the team,

awareness of the patient's clinical condition by family members, and resources offered by program:

The team's knowledge and dedication to the palliative care provided. (E1).

When family members are aware of the patient's clinical situation and are willing to actively contribute to the process, in addition to professionals with technical competence and proactivity willing to resolve everyday situations. (E2).

The resources that the program makes available are essential to guarantee the care that is performed, in addition to the training that is always offered to the team, thus guaranteeing high quality and precision. (E3).

(iv) Factors that hinder the practice of patient care in palliative care

For nurses, the factors that have hindered patient care are the lack of knowledge of family members and professionals, resistance from family members regarding the patient's clinical condition and the location of the patient's residence, as seen in the statements:

The lack of knowledge about palliative care of some family members and professionals who perform the process ends up making this care unknown to many in the area. (E1).

Some family members are resistant to accepting the clinical condition of the patient, who are not active in the care guided by the team and professionals without the ability to handle this type of patient. (E2).

The location where the patient lives makes it difficult for the team to access, the social issue that makes the quality of care very difficult and often the lack of knowledge about the situation of the family members ends up interfering with the quality of care. (E3).

(v) Importance of palliative care for terminally ill patients and their families

Faced with this category, professionals verbalized that the care provided is of fundamental importance for the quality of life of the individuals assisted by them, as evidenced by the statements:

Of great value to the patient who will know about his pathology and diagnosis and will have the chance to

spend his final time with his family and will have the necessary support to remain as comfortable as possible in his family environment for as long as possible, for a calm and peaceful departure. (E1).

The organism of a patient with an unfavorable clinical condition for rehabilitation has already suffered enough. Therefore, offering care worthy of the end of life and with minimal suffering to the patient and family members who also suffer physically and psychologically is essential. Our work as nursing is transversal and must go through both rehabilitation and palliation. One should not be more important than the other, and in home care this is clearer to observe. Empathy must exist and the bond with patients and family members becomes a reality. (E2).

Undoubtedly, palliative care is of fundamental importance for the quality of life of this patient, even if he has little time left. (E3).

Discussion

Nursing professionals may come across terminally ill patients in the various contexts of their work, and although PCs require a multidisciplinary approach⁸, the importance of nurses in the team is undeniable, as they are the first link between the team, the patient, and the family.⁹ Thus, it is fundamental that they have the necessary knowledge to develop their actions against the PCs.

In a survey carried out with nursing professionals from a health unit in Portugal, it was observed that the majority knew about PCs. However, it is key to reflect on the percentage of professionals who revealed insufficient knowledge, demonstrating that there is still a way to go at the level of training on this subject during graduation.¹⁰

The results of another study developed with health professionals working in the PC team of a hospital in the interior of São Paulo - SP showed that it is necessary to promote this type of care and make the population aware of its importance for a better quality of life. In addition to intensifying the training with the different teams and health specialties, from diagnosis and not only when there is a risk of imminent death.¹¹

Therefore, it is of fundamental importance that training schools favor practical activities in learning in

PCs, as well as the appreciation of multidisciplinary work in the face of this care and prepare individuals to acquire the emotional maturity necessary for palliative care.¹²

It is necessary to expand the number of professionals who can work in the management of patients on PCs, providing a better knowledge of the subject in question and widening their skills to meet individuals' needs through the development of essential skills in PCs such as communication tools, pain, and symptom control and psychosocial assessment to provide more qualified and humanized care.¹³

The basic requirements for nursing in PCs consist of knowledge of the pathophysiology of degenerative malignancies, human anatomy, and physiology, pharmacology of drugs used to control symptoms, comfort techniques, and the ability to establish good communication.¹⁴

Thus, the nursing professionals' work can be performed in specific tasks in palliative care, such as pain management and care or broad functions, such as case management and both positions, the role of nursing is fundamental in the critical relief of patients' symptoms and emotional support to individuals and family members during the process of coping with the disease.¹⁵

A study that aimed to recognize the attributions of nursing professionals in the provision of PCs showed that the care attributions that emerged were bathing, dressing, administering medication, passing probes, controlling, and relieving low-complexity symptoms with a view to reduction of suffering, clarification of the pathology or complications related to illness, promotion of self-care, prevention of complications and health education.¹⁶

Assistance in a home environment with the support of the family favors the application of the principles of PCs, integrates psychosocial and spiritual aspects, and provides support so that the family can assist in the care of the disease and work with grief and loss.¹⁷

In addition, the care in a home environment allows an increase in the quality of care and helps reduce the demand for hospital care, the average length of stay in the hospital, the risks of hospital infection, especially cross-infection, and costs associated with these situations.¹⁸

Therefore, this care can optimize the quality of life of people with serious illnesses by anticipating, preventing, and alleviating suffering throughout the care process provided to them.¹⁹

Even though PCs are a widely used method of action, there are still some challenges concerning their applicability, such as the need to provide effective assistance to promoting comfort and relief instead of painful and traumatic care, avoiding that this worsens the patient and the caregiver suffering.²⁰

Thus, taking care of a patient outside the therapeutic possibility encompasses several challenges for the health team, more specifically, nursing since these are the professionals who most experience the patient's reality, being their responsibility to promote well-being, comfort in the face of the particularities of each patient and family, thus, difficulties arising in the personal and professional scope are also elements that influence the care offered, giving rise to feelings that interfere negatively in the performance of effective care.²¹

As a result, controlling feelings is one of the biggest challenges for the nursing team, because dealing with the loss of a patient brings with it a high emotional charge, such as anger, frustration, impotence, among others. It is increasingly important that educational institutions incorporate into their curricula disciplines that can prepare the future professional for coping with the feelings that may arise during the care provided.²²

In this way, palliative care professionals must assist so that the patient can die as peaceful and serene as possible since the clinical condition becomes increasingly critical, this does not mean that nothing else can be done for them, and through this, new possibilities of care are opened, where emotional support and pain relief allow the patient to reach the moment of death being alive inside.²³

It is noteworthy that the family is one of the fundamental axes for the care of patients with no therapeutic possibilities of cure, occupying a protagonist place, integrating the care team, as its role is vital in the conduct of care and in the relationships that established between the team and the patients.²⁴

Finally, it is noteworthy that nurses who work in PCs must have adequate skills to provide high-quality care, maintaining hope and ensuring effective and increasingly humanized care.²⁵

Conclusion

The results found in the present study showed that, in palliative care, nurses demonstrated to know their work and that they recognize the importance of providing humanized care, promoting measures that can bring comfort, decrease pain, and seeking family interaction to effective care for those who no longer respond to curative therapy.

The study also showed that family support is essential for the success of the actions developed and that the professional nurse finds challenges facing their performance but recognizes the advantages that this type of treatment can bring to individuals and their families, guaranteeing the development of their practices, that they receive the most suitable treatment that meets their main needs at that moment, whether in the clinical or psycho-emotional context.

The main limitation of this study was the fact that it was carried out in a local home care program with a small number of participants, thus not allowing the generalization of the results obtained.

In this sense, the authors suggest the performance of other studies that cover a greater number of participants, for greater coverage of the results, as well as studies with other approaches for better dissemination of the theme in question, in addition to the incorporation of new investments that can guarantee the expansion of the program and thus be able to assist a greater number of individuals and count on the participation of a greater number of professionals.

Authors' contributions

Costa BA participated in the conception, design, research data collection, interpretation, data search and analysis, and writing of the scientific article. Silva GS and Gama SRC participated in the collection and interpretation of research data. Costa RSL

participated in the conception, design, submission of the project to the Ethics and Research Committee, interpretation of data, search and statistical analysis of research data, interpretation of results, and writing of the scientific article.

Conflicts of interest

No financial, legal, or political conflicts involving third parties (government, companies, and private foundations, etc.) were declared for any aspect of the submitted work (including, but not limited to grants and funding, participation in an advisory board, study design, preparation manuscript, statistical analysis, etc.).

References

1. Stoneberg JN, von Gunten CF. Assessment of palliative care needs. *Anesthesiol Clin*. 2006;24(1):1-17. <https://doi.org/10.1016/j.atc.2005.12.002>
2. World Health Organization (WHO). National cancer control programmes: policies and managerial guidelines [Internet]. 2nd ed. Geneva: WHO; 2002. Available from: <https://apps.who.int/iris/handle/10665/42494>
3. Bifulco V, Iochida L. Undergraduate training in the health professions and education for care of patients beyond possibility of cure with available therapeutic resources. *Rev. bras. educ. med.* 2009;33(1):92-100. <https://doi.org/10.1590/S0100-55022009000100013>
4. Monteiro FF, Oliveira MD, Vall J. The importance of palliative care in nursing. *Rev dor* [Internet]. 2010;11(3):242-8. Available from: <http://files.bvs.br/upload/S/1806-0013/2010/v11n3/a1470.pdf>
5. Silva C, Souza D, Pedreira L, Santos M, Faustino T. Perceptions of the multi-professional team on the implementation of palliative care in intensive care units. *Ciêns saúde coletiva*. 2013;18(9):2597-2604. <https://doi.org/10.1590/S1413-81232013000900014>
6. Fernandes M, Evangelista C, Platel I, Agra G, Lopes M, Rodrigues F. The perception by nurses of the significance of palliative care in patients with terminal cancer. *Ciêns saúde coletiva*. 2013;18(9):2589-96. <https://doi.org/10.1590/S1413-81232013000900013>
7. Bardin L. *Análise de conteúdo*. São Paulo: Edições 70; 2011.
8. Reed SM. A unitary-caring conceptual model for advanced practice nursing in palliative care. *Holist Nurs Pract*. 2010;24(1):23-34. <https://doi.org/10.1097/hnp.0b013e3181c8e4c7>
9. Ferreira M, Pereira A, Martins J, Barbieri-Figueiredo M. Palliative care and nursing in dissertations and theses in Portugal: a bibliometric study. *Rev Esc Enferm USP*. 2016;50(2):317-23. <https://doi.org/10.1590/S0080-623420160000200019>

10. Lopes SAP. Cuidados Paliativos: Conhecimentos dos Estudantes de Licenciatura em Enfermagem. [dissertação] [Internet]. Viseu, Portugal: Escola Superior de Saúde de Viseu; 2013. Available from: <https://repositorio.ipv.pt/handle/10400.19/1999>
11. Rodrigues LA, Ligeiro C, Silva M. Hospice care, diagnostic and terminally: indication and process start palliation. *CuidArte, Enferm* [Internet]. 2015;9(1):26-35. Available from: <http://fundacaopadrealbino.org.br/facfipa/ner/pdf/Revistacuidartenfermagem%20v.%209%20n.1%20%20jan.%20jun%202015.pdf>
12. Costa Á, Poles K, Silva AE. Palliative care education: experience of medical and nursing students. *Interface*. 2016;20(59):1041-52. <https://doi.org/10.1590/1807-57622015.0774>
13. Kelley AS, Morrison RS. Palliative Care for the Seriously Ill. *N Engl J Med*. 2015;373(8):747-55. <https://doi.org/10.1056/nejmra1404684>
14. Matos FA, Moraes TM. A enfermagem nos cuidados paliativos. In: Figueiredo MTA. Coletânea de textos sobre cuidados paliativos e tanatologia. São Paulo: UNIFESP; 2006. p. 49-61.
15. Schroeder K, Lorenz K. Nursing and the Future of Palliative Care. *Asia Pac J Oncol Nurs*. 2018;5(1):4-8. https://dx.doi.org/10.4103%2Fapjon.apjon_43_17
16. Oliveira JS, Constâncio TOS, Silva RS, Boery RNSO, Vilela ABA. Palliative care in Primary Health Care: assignments of the nursing team. *Rev APS* [Internet]. 2021;24(2):410-28. Available from: <https://periodicos.ufjf.br/index.php/aps/article/view/16848/23557>
17. Fripp J. Ação prática do profissional de cuidados paliativos no domicílio [Internet]. In: Carvalho RT, Parsons HA, organizadores. Manual de cuidados paliativos. Ribeirão Preto: ANCP; 2009. Available from: <http://biblioteca.cofen.gov.br/wp-content/uploads/2017/05/Manual-de-cuidados-paliativos-ANCP.pdf>
18. Vasconcelos GB, Pereira PM. Palliative care in home care: a bibliographic review. *Rev. Adm. Saúde*. 2018;18(70). <http://dx.doi.org/10.23973/ras.70.85>
19. Miller SC, Lima JC, Intrator O, Martin E, Bull J, Hanson LC. Palliative Care Consultations in Nursing Homes and Reductions in Acute Care Use and Potentially Burdensome End-of-Life Transitions. *J Am Geriatr Soc*. 2016;64(11):2280-7. <https://doi.org/10.1111/jgs.14469>
20. Alves R, Andrade S, Melo M, Cavalcante K, Angelim R. Palliative care: challenges for caregivers and health care providers. *Fractal, rev psicol*. 2015;27(2):165-76. <https://doi.org/10.1590/1984-0292/943>
21. Morais EN, Conrad D, Mattos EM, Cruz SAC, Machado GC, Abreu MO. Palliative care: coping nurses in a private hospital in the city of Rio de Janeiro - RJ. *R. pesq. cuid. fundam. online*. 2018;10(2):318-25. <https://doi.org/10.9789/2175-5361.2018.v10i2.318-325>
22. Markus LA, Betiolli SE, Souza SJP, Marques FR, Migoto MT. The nurse's activities in patient assistance in palliative care. *Rev Gestão Saúde* [Internet]. 2017;17(1):71-81. Available from: <https://www.herrero.com.br/files/revista/file808a997f5fc0c522425922dc99ca39b7.pdf>
23. Menezes RA, Barbosa PC. The construction of a "good death" at different stages of life: reflections on the palliative care approach for adults and children. *Ciênc. saúde coletiva*. 2013;18(9):2653-62. <https://doi.org/10.1590/S1413-81232013000900020>
24. Matos JC, Borges MS. The family as a member of palliative care assistance. *Rev. enferm. UFPE on line*. 2018;12(9):2399:2406. <https://doi.org/10.5205/1981-8963-v12i9a234575p2399-2406-2018>
25. Hökkä M, Melender HL, Lehto JT, Kaakinen P. Palliative Nursing Competencies Required for Different Levels of Palliative Care Provision: A Qualitative Analysis of Health Care Professionals' Perspectives. *J Palliat Med*. 2021;24(10):1516-24. <https://doi.org/10.1089/jpm.2020.0632>