

Evidences of Nursing Performance in Palliative Care for Children and Adolescents



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Abstract

Palliative care aims to improve the quality of life of patients who have serious diseases that put their lives at risk. In the pediatric setting, this modality is considered recent and, due to this, the roles of health professionals of the multiprofessional team are still not well established, especially the Nursing one. The objective of the study is to identify in the international literature the evidences of the Nursing performance to children and adolescents who are in palliative care. It is an integrative literature review where a search of publications in the electronic databases Scopus and PubMed was carried out. After analyzing the studies selected, deficiencies in communication skills, palliative care education, and in the emotional and ethical aspects inherent to healthcare professionals were perceived. This makes it difficult to perform specific care and precarizes the holistic care that is provided to the client. The shortage of publications on the subject has been perceived and the need for more studies that explicitly address the research question is reinforced.

Keywords: Palliative care; Nurse; Pediatric; Barriers

Introduction

In the scenario of pediatric hospitalization, death, whether is of children or adolescents, is not a usual event, but a subversion of the natural order of life, causing commotion in the people involved in their healthcare. These patients need to receive specialized pediatric care due to the specific stages of their physical and cognitive development, since they have to deal with the alteration of their well-being and the installation of a serious pathology. The curative care associated with palliative care is intended to provide the patient with the best possible health allied to a better quality of life and comfort [1,2]. The care within the palliative Nursing covers beyond evaluating, performing, coordinating and educating. Nurses need to be able to detect verbal and non-verbal complaints inherent to pain, sleep, corporal eliminations and nutritional aspects of the patient, as well as particularities of the anatomy and physiology of the human body. The evaluation of the patient transcends the physical plane and involves the psychosocial, biological, spiritual, economic and cultural spheres, characterizing a qualified holistic care. Promoting personal growth, empowering patients' autonomy, preserving their mental health, and helping them find meaning at difficult times is part of the arduous task that is being a nurse [3-5]. The motivation to carry out this study was due to the lack of relevance given to the topic in the day-to-day care, although there is the recognition of its necessity and its importance in the scenario of pediatric hospitalization. Despite all the advantages offered by palliative care, there is still resistance in patients and family members, and also in healthcare professionals.

Discussion and Results

Nursing performance in palliative care was addressed by the articles that originated the study in six dimensions: Nursing Role, Experience in Palliative Care, Quality of Care, Communication Skills, Education on Palliative Care and Nursing Feelings, as shown in Figure 1. When it comes to the nursing work in palliative care, holistic care is relevant as an attribute to nurses. The study showed that the main tasks in the care were to perform the Nursing consultation, the rounds in the hospital beds, the physical examination and the anamnesis, as well as the invasive procedures, besides the active listening in relation to patients' complaints.

The nursing professional is essential as a member of the multiprofessional team, assisting the patient in his most basic needs, such as the evaluation and management of pain and its biological, physical, psychosocial and spiritual needs. Once enrolled in the palliative care area, nurses can improve the quality of life of their patient as well as of their family members, leading to a more dignified survival and a more peaceful death process. When referring to the experiences of nurses in palliative care, it was verified that there are situations in which these professionals, within the palliative care team, do not have attributions as coordinators of care. Although they have great influence and importance in the quality of care, Nursing professionals have shown that their work is still considered invisible and not valued compared to other professionals members of the healthcare team, influencing their active voice and limiting their participation in decision-making [6].

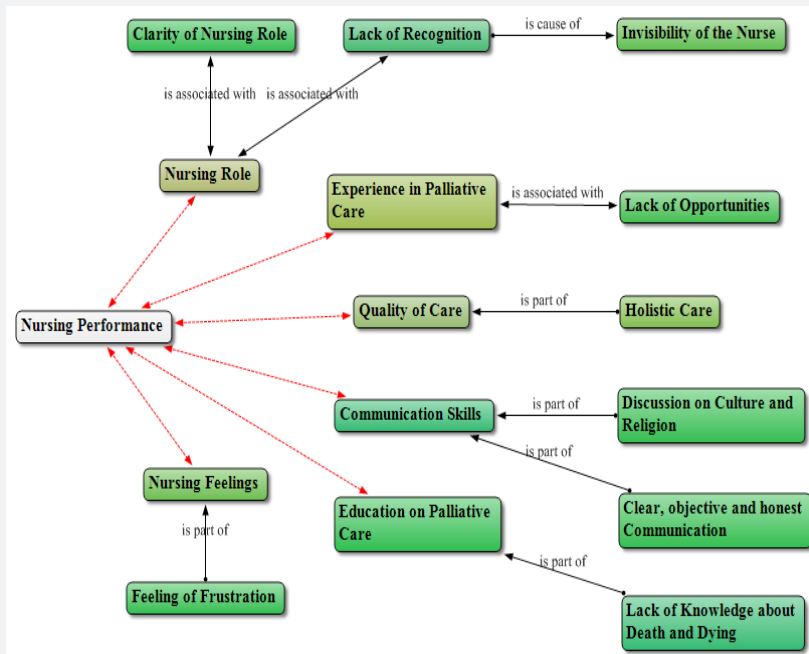


Figure1: Nursing Performance in Palliative Care.
Source: Elaborated by the author using resources from *Atlas.ti*, 2018.

In order to gain experience in the provision of palliative care, it is necessary to experience it in the day-to-day care. Another barrier in pediatrics is the lack of opportunities to engage in palliative care cases due to their limited number. Generally, the most experienced nurses are assigned to the cases, leaving the new nurses without the opportunity to work their palliative skills. There is a lack of promotion of palliative care education in the healthcare institution, making the staff currently afraid to position younger professionals to deal with children and develop their own experiences [7]. It was also identified the need to work on the communication skills with those involved in the process of care. Clear, objective and, above all, honest communication is of great importance for adherence to treatment, whether by the family and the patient, or by the healthcare team as a whole.

Another attribution of the Nursing team is to communicate with the patient and his family about other aspects of human life inherent in their well-being, such as culture and religion, while medical staff tends to focus on family treatment options and decisions. Oncology nurses reported that their roles were viewed as merely supportive of medical decisions, generating tensions and uncertainties about their actual assignments [8]. There is an urgent need to clearly highlight the attributions of Nursing, both in the palliative team and to generalist nurses, so that this invisibility does not occur and makes it difficult to perform care for those who need it the most [6]. Palliative care education is extremely important for the quality of Nursing care, but there is still great fragility regarding the knowledge about the process of death and dying, especially in pediatrics. The professionals themselves acknowledge the need for continuing education in palliative care and terminally-based care, as well as communication skills and teamwork [9,10].

Nurses experience feelings of frustration about the lack of education and training opportunities in palliative care and terminally ill care, resulting in a Nursing team unprepared to deal with difficult situations and discussions. The lack of opportunities to promote education in palliative care becomes a barrier to the provision of qualified care [6-8].

Conclusion

The scientific evidences described in this integrative literature review point to significant negative aspects regarding palliative care. Not only are they inherent to Nursing, many of these aspects involve the multidisciplinary healthcare team, where many interventions are still needed to improve the coexistence in the work environment so that the patient is not harmed. Despite the relevance of the theme in the healthcare scenario, it was observed in the production of this literature review the scarcity of publications that responded explicitly to the pre-established research question. It is indispensable the need for new publications that address the work of Nursing within the multidisciplinary palliative care team in a more enlightened way, along with contributions to soften the perceived interferences.

Conflict of Interest

The authors declare that there was no conflict of interest during the production of this article.

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