Global Academic Nursing Journal

REVIEW ARTICLE

Pediatric palliative care in nursing: resignification from an integrative review

Cuidados paliativos pediátricos en enfermería: resignificación a partir de una revisión integradora

Cuidados paliativos pediátricos em enfermagem: ressignificação a partir de uma revisão integrativa

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How to cite this article:
Vargas LR, Loyola ABM, Silva WGR, Mattos CM, Silva MLL, Ramos MM, Silva ACR, Freitas JG, Abreu RS, Machado PRF. Pediatric palliative care in nursing: resignification from an integrative review. Glob Acad Nurs. 2022;3(3):e264. https://dx.doi.org/10.5935/2675-5602.20200264

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Chief Editor: Caroliny dos Santos Guimarães da Fonseca
Executive Editor: Kátia dos Santos Armada de Oliveira

Submission: 03-09-2022
Approval: 03-31-2022

Abstract

The aim was to promote reflections, based on the bibliographic survey, in relation to death and dying and care and caregivers. Integrative literature review through the Virtual Health Library platform, carried out in August 2021. Thirteen articles were analyzed that met the determined inclusion criteria. Among the selected articles, the national studies covered 76.92% of the theoretical framework used and the approaches mainly emphasized the need for inclusion and active participation of the whole family in palliative care, the indispensability of strengthening the nurse's bond with his client and the autonomy of this professional through internal and/or ethical dilemmas. It is concluded that the implementation of palliation education for nursing students and nurses should receive greater emphasis in order to provide means for the personal and professional growth of these individuals.

Descriptors: Child; Palliative Care; Nursing; Hospice and Palliative Care Nursing; Medical Oncology.

Resumén

El objetivo fue promover reflexiones, a partir del levantamiento bibliográfico, en relación a la muerte y el morir y el cuidado y los cuidadores. Revisión integrativa de la literatura a través de la plataforma Biblioteca Virtual en Salud, realizada en agosto de 2021. Se analizaron 13 artículos que cumplieron con los criterios de inclusión determinados. Entre los artículos seleccionados, los estudios nacionales abarcaron el 76,92% del referencial teórico utilizado y los abordajes enfatizaron principalmente la necesidad de inclusión y participación activa de toda la familia en los cuidados paliativos, la indispensabilidad de fortalecer el vínculo del enfermero con su cliente y la autonomía de este profesional a través de dilemas internos y/o éticos. Se concluye que la implementación de la educación en paliación para estudiantes de enfermería y enfermeros debe recibir mayor énfasis a fin de proporcionar medios para el crecimiento personal y profesional de estos individuos.

Descriptores: Niño; Cuidados Paliativos; Enfermería; Enfermería de Cuidados Paliativos al Final de la Vida; Oncología Médica.

Resumo

Objetivou-se fomentar reflexões, a partir do levantamento bibliográfico, em relação à morte e ao morrer e aos cuidados e cuidadores. Revisão integrativa da literatura através da plataforma Biblioteca Virtual em Saúde, realizada em agosto de 2021. Foram analisados 13 artigos que atenderam aos critérios de inclusão determinados. Dentre os artigos selecionados, os estudos nacionais contemplaram 76,92% do referencial teórico utilizado e os enfoques enfatizaram, principalmente, a necessidade de inclusão e participação ativa de toda a família nos cuidados paliativos, a indispensabilidade do fortalecimento do vínculo do enfermeiro com seu cliente e a autonomia deste profissional mediante dilemas internos e/ou éticos. Conclui-se que a implementação do ensino da paliação para graduandos de enfermagem e enfermeiros deve receber maior ênfase a fim de fornecer meios para o crescimento pessoal e profissional destes indivíduos.

Descritores: Criança; Cuidados Paliativos; Enfermagem; Enfermagem de Cuidados Paliativos na Terminalidade da Vida; Oncologia.

Introduction

Childhood is a phase of exploration and play, which brings with it the expectation of a healthy and happy future. However, this is lost in the uncertainties and anxieties triggered by the impact of the diagnosis of chronic or terminal diseases and their treatments, which affect the child in the physical, cognitive and psychosocial scope. The illness also causes multiple changes in their daily routine, such as the imposition of restrictions and isolation, the need for recurrent hospital visits, aggressive therapies and, in some cases, serious side effects that cause intense suffering, all of this added to the emotions of fear, sadness, anger and guilt, especially[1].

Realizing the process of refusing death and withdrawing from life, the Palliative Care (PC) aspect arises, originating from the term "palium", which means mantle, cover or protect. Therefore, its objective is to reduce pain and suffering, covering the moment of diagnosis and, above all, the moment of discovering the impossibility of applying a curative medicine. In other words, this approach aims to restore the quality of life of patients and their families - as they actively experience and participate in the entire health/disease process - through early identification, correct assessment, treatment of pain and other physical, psychosocial and spiritual problems[2,3].

As care is at the heart of Nursing, it is up to it to provide mechanisms to help the child and their families adapt to the changes in life caused by the disease(s), emphasizing the importance of the nurse as a member of the multidisciplinary team in the CP, as a provider of biopsychosocial assistance from the holistic view developed throughout their professional training. In addition, it is essential to establish effective communication, including with the child, depending on their ability to understand what is happening, and the provision of care focused on the particularities of each one, essential components in the promotion of health and the true caution[4].

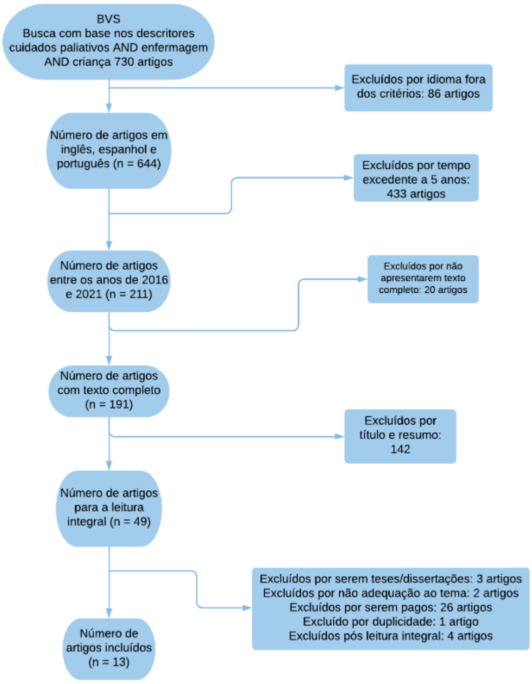
Considering these aspects, the need arises to prepare health professionals to face death from the beginning of their graduation, in higher education institutions, as a way of combating the model currently used in the light of biological logic. One of its great strengthening agents was the technological advance observed during the 20th century, which solidified the practice of therapeutic obstinacy, transforming it into a resource that causes suffering from the prolongation of life at all costs, through the feeling of '' false hope'' and comfort provided to the patient and their relatives[4,5].

In this way, it is understood that such a resource highlights the difficulty of accepting the end of life, both by family members and by health professionals themselves, in the face of direct contact with genuine vulnerability, especially when it comes to a premature interruption, even in the childhood. Therefore, we seek to understand the impact and benefits generated from the implementation of PC at the time of diagnosis in pediatrics, for all individuals involved, including care. This article aims to promote reflections, based on the bibliographic survey, in relation to the benefits brought by the implementation of palliative care for children and caregivers in the process of death and dying.

Methodology

This is an integrative review study, a research method that synthesizes the past literature on a given topic, enabling the synthesis and analysis of the scientific content already produced regarding the investigated subject. This methodology follows certain steps to obtain the selected articles, which are listed below[6].

Figure 1. Flowchart for the selection of articles for the integrative review. Rio de Janeiro, RJ, Brazil, 2021



Initially, the guiding question of the research was elaborated: “what are the benefits brought by the implementation of palliative care for the child, their families and professionals involved in their treatment?”. Then, articles related to the theme were searched in the bibliography and, for this, the Virtual Health Library (VHL) platform was used using the following Descriptors in Science and Health (DeCS): "Palliative Care", "Nursing" and " Child".

Subsequently, the following inclusion criteria were adopted: period for the publication of articles covering only the years 2016 to 2021, availability of the full text free and publications in Portuguese, English and Spanish. Duplicate articles and those that, after reading their titles and/or abstracts, did not address the topic were discarded.

When using the descriptors in the database, 730 cataloged articles were found. Following the exclusion criteria, after a complete reading of their titles and/or abstracts, 142 articles were discarded. Then, 86 texts were discarded for presenting language outside the criteria, 433 for their publication time exceeds 5 years, 20 for not having a full text, 3 for being theses and/or dissertations, 2 for not being adequate to the theme, 26 for having paid access, 1 for duplication and 4 for full reading, resulting in a total of 13 eligible articles.

Aiming at ordering, the last step was the elaboration of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart, in order to highlight how the bibliographic choice was made[7].

Results

After the full reading of the selected articles, a table was developed that includes title, authors, year, base, level of evidence - in accordance with the Oxford table - and synthesis of the results obtained in order to facilitate the collection of data from the studies.

Chart 1. Summary of results. Rio de Janeiro, RJ, Brazil, 2021

Title	Authors	Year	Base	Level of evidence	Summary of results
Cuidados Paliativos, Cuidados Compartidos	Beatriz Lozano López e María Merede Huertas Pérez.	2017	IBECS	1B	The multidisciplinary team must provide personalized care in order to improve the quality of life of patients and families.
Cuidados Paliativos em Oncologia Pediátrica na Percepção dos Acadêmicos de Enfermagem	Tuani Magalhães Guimarães, Liliane Faria da Silva, Fátima Helena Espírito Santo e Juliana Rezende Montenegro Medeiros de Moraes.	2016	BDENF / LILACS	1C	For academics, palliative care in pediatric oncology is related to the control of signs and symptoms, comfort, support, promotion of quality of life and well-being. On the other hand, some understand that palliative care aims to prolong life. They perceive the need for the multidisciplinary team to work with the child and their family.
Cuidados Paliativos em Oncologia Pediátrica: Revisão Integrativa	Ana Letícia Dias Semtchuck, Flávia Françoso Genovesi e Janaína Luiza dos Santos.	2017	BDENF / InstitutionalDB / LILACS	1C	Of the fifteen articles, twelve were published in national journals and the year 2013 was responsible for 33.3% of the publications. Two categories were created: the nursing team and the communication and relationships established.
Cuidados Paliativos em Oncologia: Vivência de Enfermeiros ao Cuidar de Crianças em Fase Final da Vida	Genáine De Fátima Alves Teixeira Fernandes Dos Santos, Patrícia Serpa de Souza Batista, Débora Rodrigues Alves de Lima, Amanda Maritsa de Magalhães Oliveira, Kalina Coeli Costa de Oliveira Dias e Brunna Hellen Saraiva Costa.	2020	BDENF / LILACS	1A	Three thematic categories emerged: nurses' perception of assistance to children with cancer in palliative care and support for family members, highlighting assistance focused on well-being and comfort; care practices used by nurses for children with cancer in palliative care, with an approach aimed at relieving pain and other symptoms; and communication of bad news and appreciation of spirituality in child care in palliative care, in the context of terminality.
Cuidados Paliativos Pediátricos: Análise de Estudos de Enfermagem	Thaís Cristina Flexa Souza, Antonio Jorge Silva Correa Júnior, Mary Elizabeth de Santana e Jacira Nunes Carvalho.	2018	BDENF	5	All articles referred to oncology and evidence for humanistic support assistance to the caregiver, control of cancer pain, engendering care with a view to recreational activities and maintaining effective communication with the team, child and family.

Dinâmica Musical na Sensibilização dos Acadêmicos de Enfermagem Frente aos Cuidados Paliativos em Oncologia Pediátrica	Cintia Fonseca Nunes, Liliane Faria da Silva, Fátima Helena do Espírito Santo, Fernanda Garcia Bezerra Góes e Juliana Rezende Montenegro Medeiros de Moraes.	2018	BDENF / LILACS	1A	The dynamics favored reflection on coping strategies and improvement of childcare, in addition to reinvigorating the health team. It mobilized reflection on empathy, unpreparedness and lack of opportunity to experience pediatric oncology and grief, as a way of approaching the practice. The possibility of its use in professional practice was also raised.
Existential Experience of Children with Cancer Under Palliative Care	Jael Rúbia Figueiredo de Sá França, Solange de Fátima Geraldo da Costa, Maria Emília Limeira Lopes, Maria Mirian Lima da Nóbrega, Patrícia Serpa de Souza Batista e Regina Célia de Oliveira.	2018	MEDLINE	1B	From the analysis of the theme of the empirical study, the following thematic categories emerged children experiencing fear, sadness, anguish and insecurity in the face of the diagnosis and children experiencing the fear of their family disintegrating due to the possibility of dying.
Familiares Vivenciando Cuidados Paliativos de Crianças com Câncer Hospitalizadas: uma Revisão Integrativa	Cristineide dos Anjos, Rose Mary Costa Rosa Andrade Silva, Eliane Ramos Pereira, Carlos Eduardo Peres Sampaio, Marcos Andrade Silva e Eliane Cristina da Silva Pinto Carneiro.	2021	LILACS	1A	The sample consisted of 13 articles, originating two categories: the impact of palliative care for children with cancer on family dynamics and multidisciplinary care, especially by nurses, for the family of children with cancer.
Nursing Interventions in Palliative Care in Pediatric Oncology: An Integrative Review	Amanda Danielle Resende Silva e Sousa, Liliane Faria da Silva e Eny Dórea Paiva.	2019	BDENF / LILACS	1B	It was noticed that performing music therapy, massage, playful application, early consultation of palliative care, social interventions and physical exercises for the resolution of a specific symptom promotes better results.
Obstinação Terapêutica sob o Referencial Bioético da Vulnerabilidade na Prática da Enfermagem	Cláudia D'Arco, Carla Maria Maluf Ferrari, Luciane Vasconcelos Barreto de Carvalho, Margareth Rose Priel e Luciane Lucio Pereira.	2016	LILACS	1C	Passivity was evidenced in the face of medical decision, difficulty in facing terminality, negative perception of therapeutic obstinacy, negative feelings regarding the terminality of the young person and the child and recognition of the nurse's role in relation to terminality.
Pediatric Palliative Care Nursing	Terrah Foster Akard, Verna L. Hendricks-Ferguson e Mary Jo Gilmer.	2019	MEDLINE	1A	It was concluded that nurses perform ideal roles to provide pediatric palliative care and serve as leaders for the advancement of science.
Profissionais de Enfermagem: Compreensão Sobre Cuidados Paliativos Pediátricos	Edna Regina Verri, Natalia Aparecida Santana Bitencourt, Jéssica Aires da Silva Oliveira, Randolfo dos Santos Júnior, Hélida Silva Marques, Mariana Alves Porto e Debora Grigolette Rodrigues.	2019	BDENF	1A	Difficulties related to understanding the philosophy and goals of palliative care and difficulty in working with pediatric patients who are under this care were demonstrated on the part of the professionals, highlighting the feelings of failure and sadness when dealing with the situation. Therefore, as coping strategies, the affective distancing of the patient and his family, spirituality and the offering, to the patient, of a differentiated and humanized care are used.
Provision of Palliative and Hospice Care to Children in the Community: A Population Study of Hospice Nurses	Erica C. Kaye, Melanie Gattas, Ashley Kiefer, Jason Reynolds, Kristina Zalud, Chen Li, Zhaohua Lu e Justin N. Baker.	2019	MEDLINE	1C	Five hundred and fifty one nurses were interviewed in 71 hospices. Nurses reported feeling somewhat or very uncomfortable providing services to children during the disease trajectory and at the end of life in all domains.

National studies cover 76.92% of the theoretical framework used, followed by the United States of America (USA), which represent 15.38% and Spain, responsible for the remaining 7.70%. Most of the selected articles were published in 2019 and the level of evidence "A", which consists of systematic reviews, with the highest degree of recommendation, was the most prominent. It is also noticed that the approaches emphasize, mainly, the need for inclusion and active participation of the whole family in the PC, the indispensability of strengthening the nurse's bond with his client and the autonomy of this professional through internal and/or ethical dilemmas.

Discussion

Neoplasms are the second leading cause of death among children and adolescents and the most frequent tumors in these age groups are leukemias, lymphomas, neuroblastomas, Wilms tumor, retinoblastomas, sarcomas, osteosarcomas and germ tumors. In view of this, the care of children with cancer comprises a complex activity, as it encompasses imprecision regarding the cure, establishing a great feeling of impotence and frustration on the part of the family, interdisciplinary team and even society[8-10].

Terminal illnesses, culturally, have always been associated with suffering and death. Beliefs and values based on Western society, unlike Eastern culture (where the process of death naturally integrates the life cycle), reinforce the idea of the sacredness of life, culminating in the association of death with fragility and failure. However, this represents not only the extinction of the species, but the destruction of the body itself[5,11].

On the other hand, palliative care considers death as a natural process, not accelerating or delaying it, but aiming at improving the quality of life, a factor that has an extremely positive influence on the course of the illness. In this way, the care purpose in this context is not the search for a cure, but the provision of care that provides true support, information and comfort. Currently, it is estimated that 1,200,000 children/year would be indicated for palliative care[2,5,6,11-13].

In this context, the team should focus its assistance on physical and emotional aspects, cultural, religious and ethical values, in addition to the material and human resources available, always aspiring to quality of life with a focus on well-being and respect, since, by accepting care, the patient trusts the caregiver and responds to the treatment, demonstrating awareness of the aptitude, commitment and attention given by the professional[2,4-6,9,10].

There are several studies that emphasize the need and benefits of family participation in the care of hospitalized children, especially at this moment of adaptation to the new health-disease condition in palliative care, which can be represented by highly disturbing moments in the face of the diagnosis, since this puts her in the face of uncertainties and apprehension regarding the future and the possibility of the death of her loved one[1,9,11,12].

The family impact is mainly caused by long periods of hospitalization, frequent (re)hospitalizations, aggressive therapy and limitations in understanding the diagnosis. Therefore, the emergence of the bond between professionals, the child and the family occurs naturally, being strengthened by the affective relationship of trust, friendship and admiration, in addition to the mutual learning inherent in human interactions[1,10,12,13].

Thus, when caring for a child without a therapeutic perspective, family members are also taken care of - who constitute their fundamental support network, through conversation and other actions that provide comfort and consolation for suffering, even if through small actions. The empathetic look, the therapeutic touch and active and qualified listening are essential because they act as measures of comfort and well-being in this phase of so much suffering[1,9-11].

That said, studies recommend that the nurse becomes the link between the patient, the family and the multidisciplinary team, as he mentors several functions, participating in the child's and family's disorders, making them able to know and have a broad view of all their needs, from the singularity, offering support, reception and help to overcome a difficult time[1,5,6,10,12,14].

In addition, there is great difficulty in communicating bad news and complications to family members and the child during treatment, which can become the most difficult part of care due to the confrontation of feelings of the child, the family and the professional himself. A careful observation is recommended for the development of the best method for each patient and the need for attention to the reactions expressed for the personalized planning of the approach is highlighted[1,9,10,15].

This communication link can be built through activities such as music, drawing, painting, toys, electronic games, fun/educational videos, theater and the initiative to read stories or tales, in which a significant improvement is observed in the ability of expression of the child. The analysis of the studies pointed out that children need this care, in addition to physical care, so that they are perceived except for their illness, so that they feel welcomed as human beings and not as sick[4,6,10,13,15].

Music therapy, for example, has significantly reduced the stress and anxiety of the entire multidisciplinary team, emphasizing aspects of humanity and compassion. Some authors confirm that the playful interaction with children undergoing cancer treatment reduces the need to use sedatives during radiotherapy sessions, in addition to being fundamental in guiding and preparing for the exhausting procedures they will face[6,13].

Therefore, it appears in research that recreation rooms, playrooms and actions such as the "Doctors of Joy" have a great influence on palliative care in pediatrics, generating a cozy environment, stimulating interactions with other individuals and allowing moments in their routine, where the child diverts his focus from the illness and just enjoys his childhood[4,6,10,14].

It is also noteworthy that some children have limitations to perform certain activities, and animal therapy is a strong ally in their treatments due to the reduction of anguish from the association of an already existing bond with their dear pets. The United States, for example, adopts this model of animal-assisted interventions for its easy implementation, low cost, and evident improvement in commitment and participation in procedures[15].

Another notorious factor is pain, which, considered the fifth vital sign, characterizes 78% of the symptoms in children with cancer, significantly affecting their quality of life. Therefore, it requires adequate prevention and treatment, since in the terminal phase it can represent up to 90% of the symptoms. It is evident that one of the main actions of nurses for palliative care is pain control[6,9,10,14].

Regarding pharmacological treatment, it is used to significantly reduce pain and its proper management should be a priority in planning. Non-pharmacological methods and the aforementioned therapies do not replace therapy with analgesic medication, since pain receives emotional influences, especially in childhood, where vulnerability is greater. It is understood that the involvement of the team with the patient and the family provides the relief of symptoms in a better way, since comforting the patient encompasses care[2,4,6,9,14].

It is worth noting that care for children with cancer requires care and emotional balance, because when the professional is faced with the diagnosis of a child without a therapeutic perspective, he is faced with the paradox of interruption of the natural line of life, which triggers feelings of insecurity, sadness, helplessness, frustration, pain and pity. Thus, when faced with the process of losing the patient, they are often forced to reflect on the limits that perpetuate the invincibility of death[2,5,9,10,16].

In this field of action, there is a great physical and emotional exhaustion of health professionals, in addition to the difficulty of experiencing grief and the lack of training to deal with the family members of their patients. Nurses commonly report feeling unprepared to act in the care of oncological children and their families, referring to a need for psychological support in order to deal with work situations[5,6,10,12,16,17].

Thus, it is essential to insert palliative care as part of the university curriculum in health and continuing education, with a view to meeting the diverse learning needs of professionals who face care at the end of life. Knowing the concepts related to the implementation of palliative care, as well as the process of finitude, allows a better understanding of personal values and beliefs in this process[1,2,4-6,9,10,12,15,17].

In addition to the difficulties inherent in the current practice of the profession, there is a lack of freedom of conduct for nursing professionals, due to the absence of appropriate legal support and due autonomy for decision-making involving the truly dignified death of the child, which results in enormous difficulty in performing the functions[2,5,6,10,13].

In short, they are faced with an important dilemma: the belief about the best conduct to be taken and the legal consequences of their actions. Faced with this, nurses are forced to perform care they do not agree with and to assume a defensive posture that prevents adequate involvement and bonding, thus causing their distance from patients and families, attitudes contrary to the essence of their professional practice and, mainly palliative care[2,5,10].

Conclusion

It is inferred that although palliative care is a topic of significant relevance today, unfortunately there is still a considerable delay in relation to its implementation as a care model. This fact is directly related to the perpetuation of the belief in “curative medicine” and to the late adoption of this aspect, which took place only in the 1980s, in the southern region of the country, at the Clinical Hospital of the Federal University of Rio Grande do Sul.

Therefore, the reflection of these factors in the education promoted to nurses is evident, not only by higher education institutions, but by continuing education itself, which does not provide them with resources for the association of humanistic theory with practice, resulting in a large deficit educational, lack of autonomy in the face of decisions and psychological structure to deal with the daily situations of the job, even facilitating the Burnout Syndrome.

There is an urgent need for the wide dissemination of this aspect of health and its concepts, which help those involved so much. It is imperative to implement the teaching of palliation for nursing students and nurses, in order to provide means for their personal and professional growth and improvement of care, putting into practice the principles that guide the profession.

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