



PALLIATIVE CARE IN PEDIATRIC ONCOLOGY: NURSING CONTRIBUTIONS

CUIDADOS PALIATIVOS EM ONCOLOGIA PEDIÁTRICA: CONTRIBUIÇÕES DA ENFERMAGEM

CUIDADOS PALIATIVOS EN ONCOLOGÍA PEDIÁTRICA: CONTRIBUCIONES DE LA ENFERMERÍA

Leonardo Bigolin Jantsch¹, Eliane Tatsch Neves², Andrea Moreira Arrué³, Greice Machado Pieszak⁴, Bruna Gheller⁵

ABSTRACT

Objective: to analyze the trends of scientific production about palliative care in pediatric oncology. **Method:** it is an integrative review performed in the databases MEDLINE and LILACS, in February 2012, with the definition of the following research question: what has been published about palliative care to children with cancer? It was utilized the key-words "palliative care", "child" and "cancer", using the Boolean AND operator, and has not been defined time frame. Were used full text articles available as inclusion criteria, and, as exclusion criteria, publications in the form of theses and dissertations, manuals and booklets. We performed a full reading of the articles for the application of the criteria for inclusion or exclusion. The *corpus* of the research consisted of eight articles submitted to Bardin content analysis. **Results:** four themes emerged from the data: the profile of child with cancer in palliative care, the health professional facing the palliative care and the dying and death process in pediatric oncology; the family facing the child with cancer in palliative care and the palliative care in pediatric oncology. **Conclusion:** the theme is contemporary and it requires the preparation of nurses to work in this area. The development of palliative care focuses in hospitals and support houses. It is recommended the development of research in this thematic, in order to subsidize the practice and to qualify the palliative care in pediatric oncology. **Descriptors:** children; neoplasms; palliative care, pediatric nursing.

RESUMO

Objetivo: analisar a tendência da produção científica sobre cuidados paliativos em oncologia pediátrica. **Método:** revisão integrativa realizada nas bases de dados LILACS e MEDLINE, no mês de fevereiro de 2012, com a definição da seguinte questão de pesquisa: o que tem sido publicado sobre cuidados paliativos à criança com câncer? Utilizaram-se as palavras-chave "cuidados paliativos", "criança" e "câncer", empregando o operador booleano AND, e não foi delimitado recorte temporal. Utilizaram-se como critérios de inclusão: artigos completos e disponíveis na íntegra; como critérios de exclusão, publicações em formato de teses e dissertações, manuais e cartilhas. Foi realizada a leitura na íntegra dos artigos para a aplicação dos critérios de inclusão e exclusão. O *corpus* da pesquisa constituiu-se de oito artigos submetidos à análise de conteúdo de Bardin. **Resultados:** quatro eixos temáticos emergiram dos dados: o perfil da criança com câncer em cuidado paliativo; profissional de saúde frente aos cuidados paliativos e o processo de morrer e morte em oncologia pediátrica; a família frente à criança com câncer em cuidados paliativos e os cuidados paliativos em oncologia pediátrica. **Conclusão:** a temática é contemporânea e exige o preparo do enfermeiro para atuar nessa área. O desenvolvimento dos cuidados paliativos está centrado em hospitais e casas de apoio. Recomenda-se o desenvolvimento de pesquisas nessa temática, a fim de subsidiar a prática e qualificar o cuidado paliativo em oncologia pediátrica. **Descritores:** Criança; Neoplasias; Cuidados Paliativos; Enfermagem pediátrica.

RESUMEN

Objetivo: Analizar la tendencia de la literatura científica sobre los cuidados paliativos en oncología pediátrica. **Método:** Se realizó una revisión integradora en la bases de datos MEDLINE y LILACS, en febrero de 2012 con la definición de la siguiente pregunta de investigación: lo que se ha publicado acerca de los cuidados paliativos a los niños con cáncer? Se utilizaron las palabras clave "cuidados paliativos", "niño" y "cáncer", usando el operador booleano AND, y no fue limitado marco de tiempo. Se utilizaron los siguientes criterios de inclusión: artículos completos y disponibles en la plena, los criterios de exclusión, las publicaciones en forma de tesis y disertaciones, manuales y folletos. Se realizó una lectura completa de los artículos para la aplicación de los criterios de inclusión y exclusión. El corpus de la investigación consistió en ocho artículos sometidos a análisis de contenido de Bardin. **Resultados:** Cuatro temas emergieron de los datos: El perfil de los niños con cáncer en cuidados paliativos, profesional de salud face los cuidados paliativos y el proceso muerte y el morir en oncología pediátrica, la familia del niño con cáncer en cuidados paliativos y los cuidados paliativos en oncología pediátrica. **Conclusión:** El tema es contemporáneo y requiere la preparación de las enfermeras para trabajar en esta área. El desarrollo de los cuidados paliativos se centra en los hospitales y casas de apoyo. Se recomienda el desarrollo de la investigación sobre este tema, con el fin de subsidiar la práctica y calificación de los cuidados paliativos en oncología pediátrica. **Descriptores:** niño, neoplasias, cuidados paliativos, enfermería pediátrica.

¹Acadêmico de Enfermagem da Universidade Federal de Santa Maria-UFSM. Integrante do Grupo de Pesquisa Cuidado à Saúde das Pessoas Famílias e Sociedades. Santa Maria (RS), Brasil. E-mail: leo.jantsch@hotmail.com; ²Enfermeira Pediatra. Doutora em Enfermagem. Professor Adjunto do Departamento de Enfermagem e do Programa de Pós-Graduação em Enfermagem da Universidade Federal de Santa Maria (UFSM). Membro do Grupo de Pesquisa Cuidado à Saúde das Pessoas Famílias e Sociedade. Santa Maria (RS), Brasil. E-mail: elianeves03@gmail.com; ³Enfermeira. Mestranda pelo PPGEnf/UFSM. Integrante do Grupo de Pesquisa PEFAS. Bolsista REUNI. Santa Maria (RS), Brasil. E-mail: andrea.mor@hotmail.com; ⁴Enfermeira. Mestranda pelo PPGEnf/UFSM. Integrante do Grupo de Pesquisa PEFAS. Santa Maria (RS), Brasil. E-mail: greicepieszak@gmail.com; ⁵Acadêmica de Enfermagem da Universidade Federal de Santa Maria- UFSM. Santa Maria (RS), Brasil. E-mail: gheller.bruna@gmail.com

INTRODUCTION

Cancer is defined as a group of diseases presenting an uncontrolled growth of cells, which can penetrate one or several parts of living tissues.¹ The disease is accounted for 15.6% of deaths in Brazil, in 2009, and it's considered the fifth leading cause of death at the age of one to 19 years old.²

The pediatric cancer has been gaining attention for its high mortality and lack of knowledge about its etiology. The main cancers affecting this age group are leukemias, tumors of the central nervous system (CNS) and lymphomas.¹

Children's neoplasms are different from adult cancer on the site of primary involvement and mainly by nonspecific symptoms. Sometimes they are confused and mistakenly treated as other diseases common to the age, thus having a delayed diagnosis.¹

The treatment of childhood cancer is outlined by a multidisciplinary team, aiming to increase survival, minimize late effects of medicalization and reintegration of the child in social context. Therapeutic modalities include surgery, radiotherapy, chemotherapy and hormone therapy.³

Therapy over the decades has showed to be efficient, it facilitated the early diagnosis, advances and standardization of treatment and use of protocols. However, despite the tendency to survival, there is a group of children for whom cure is not achieved.³ Given what was exposed, it is necessary and essential to care for this child, offering him the right to enjoy a minimally decent life, in which they develop palliative care.³

Palliative care has emerged with the purpose of mitigating the effects of previously incurable disease, or provide a service for those who are helpless and can not be nurtured by curative medicine.⁴

The World Health Organization (WHO) defines palliative care as a way to approach committed to improving the quality of life of patients and families affected by diseases that threaten the lives.⁵ The decision to appeal to palliative care and abandon curative treatment is done when the child can no longer be treated by therapies succeeding in range, then the relief of symptoms becomes priority.³

In pediatric approach, the palliative care involves a series of multidisciplinary care, targeted not only the physical aspects of the child, but also extends its sphere emotional, spiritual and family support.

Factors that predispose to the use of palliative therapy is grounded in diagnostics that reveal a condition, whether it be limiting, life-threatening or terminal, and treatment can begin when the disease is diagnosed, concomitant with or without curative treatment.^{3,6}

From this perspective, one wonders whether what has been published about palliative care to children with cancer. To respond to this question, it was elaborate as objective to analyze the trend of scientific literature on palliative care in pediatric oncology.

METHOD

It is an integrative review, with a descriptive approach of the results. The integrative review aims to gather and synthesize results of research on a specific topic in a systematic and orderly manner. Being an instrument for deepening the knowledge of the subject investigated, allowing the synthesis of multiple published studies and general conclusions about a particular area of study.⁷

The search was conducted *online* through the portal of the Virtual Health Library (VHL) in databases from Latin American and Caribbean Health Sciences (LILACS) and International Literature in Health Sciences (MEDLINE), in the month of February 2012. We used the key words "palliative care", "child" and "cancer", using the Boolean operator AND, and was not bounded time frame.

It was found 16 articles in LILACS and 50 in MEDLINE, totalizing 66 productions. Were used full text articles available as inclusion criteria, and, as exclusion criteria, publications in the form of theses and dissertations, manuals and booklets. We performed a full reading of the articles for the application of the criteria for inclusion or exclusion.

For the productions analysis, it was used the Bardin content analyzes, which consists on analyzing the communication from systematic analysis techniques in order to deduce, in the description, messages and contents from established knowledge.⁸

The first step of analysis was the pre-analysis, in which up to the choice of the body of research. After the first stage, with the research corpus set, occurred the beginning of the second stage of analysis. That's when it is made the material exploration. With the results of this step, data can be systematized, grouping them into categories of affinity.

Finally, the third and final stage, where relief information obtained in the previous steps present themselves, quantifying and demonstrating the results.⁸

Figure 1 shows the productions with the identification code, journal, author and title of the articles selected in this study.

RESSULTS AND DISCUSSION			
Code	Periodical	Authors	Title
A1	Journal of Pediatric Hematology/Oncology	Klopfenstein KJ, Hutchison C, Clark C, et al.	Variables Influencing End-of-Life Care in Children and Adolescents
A2	Journal of Clinical Oncology	Tang ST, Hung YN, Liu TW, et al.	Pediatric End-of-Life Care for Taiwanese Children Who Died As a Result of Cancer From 2001 Through 2006
A3	Pediatr Blood Cancer	Fraser LK, Miller M, Mckinney PA, et al.	Referral to a Specialist Paediatric Palliative Care Service in Oncology Patients
A4	Revista Gaúcha de Enfermagem	Costa TF, Ceolim MF.	A enfermagem nos cuidados paliativos à criança e adolescente com câncer: revisão integrativa da literatura
A5	CANCER Supplement	Whittam EH.	Terminal Care of the Dying Child Psychosocial Implications of Care
A6	Escola Anna Nery Revista de Enfermagem	Avanci BS, Carolindo FM, Góes FGB, et al.	Cuidados paliativos à criança oncológica na situação do viver/morrer: a ótica do cuidar em enfermagem
A7	Online Brazilian Journal of Nursing	Lopes VF, Silva JLL, Andrade M.	A percepção de profissionais de enfermagem sobre os cuidados paliativos ao cliente oncológico pediátrico fora de possibilidade de cura: um estudo na abordagem fenomenológica das relações humanas
A8	Journal of Pediatric Psychology	Hinds PS, Brandon J, Allen C, et al.	Patient-reported Outcomes in End-of-Life Research in Pediatric Oncology

Figure 1. Publications on palliative care in pediatric oncology - period 1993-2011 - LILACS and MEDLINE.
Source: Elaborated by authors. Brazil, 2012.

Regarding the country of origin of products, three are Brazilian, four North American and one from Taiwan. The time frame comprised the years 1993 to 2011, as described in Table 1:

Table 1. Distribution of articles from 1993 to 2011. Brazil, 2012.

Publication Year	Frequency
1993	1
2001	1
2007	1
2009	1
2010	2
2011	2
Total	8

In Table 1 it was found that the subject under investigation is emergent and contemporary, because the years 2010 and 2011 concentrated 50% of production.

Regarding the approach of the selected studies, two were literature reviews and six field researchs, among these there are two with quanti-qualitative character, two quantitative and two qualitative. About the fields, it was found that three of the articles reported to characteristics of children with cancer; four, the health care team facing this situation; and five had the care applied in the context of the thematic study.

Based on the data analyzed, four themes emerged: the profile of children with cancer in palliative care; palliative care in pediatric oncology; family of the child with cancer in palliative care and the health professional in the face of palliative care and dying and death in pediatric oncology.

♦ Profile of children with cancer in palliative care

In one study, the prevalence of children in need of palliative care was higher in females presenting with 53.7%, the mean age was 9.3 years and the main diagnoses were central nervous system (CNS) tumors, followed by the other solid tumors such as leukemias and lymphomas.^{A1}

Similar results to the above study showed that the average age was eight years old, but there was disparity regard to sex, because 63% of affected children were boys.⁹

In Brazil, the tumors that most affect the pediatric age group are leukemias, followed by lymphomas and CNS tumors.^{1,10} These discrepant results may be related to the geographical and population difference in the studies.

In the analyzed studies, palliative care

Jantsch LB, Neves ET, Arrué AM et al.

began to emerge when curative therapies were suspended without division of milestone.⁸ Some of the patients received palliative care in their last three days of life.^{A2}

The aggressive care such as chemotherapy, cardiopulmonary resuscitation and intensive care, were present at the end of life of most children, who died in a hospital.^{A1-A2} These data agree with researches conducted with adult patients, where approximately 55% of cancer patients die in hospitals.¹¹ Statistics that could be modified by the benefits of palliative care.

There is, moreover, that from the children who died from the disease, only 37% were referred for palliative care services.^{A3} The site considered suitable for palliative care was the child's home where the family company, the environment pleasant and how to care become more welcoming and provide better quality of care.^{A1, A5}

Despite the low levels of technology, different socioeconomic levels, and lack of knowledge to perform the care, studies show that is at the patient home, with his family, that the child is relieved, comforted and receiving family affection, that could not receive if you were being cared for elsewhere.¹²

Home care should be based not only on a careful and routines established by conduct, nor to make a theoretical/technical way, but rather on a more human and intimate care (family and child). However, we emphasize the importance of the procedures that make palliative care and that are offered by the home caregiver.¹³

The technique of doing, that makes up care, is part of a whole set of actions that should be based on humanized care. To do so, humanization is no longer a practice adopted during patient care, but should be based on a holistic view exchange of knowledge, experiences and feelings.¹⁴

One advantage described, for palliative care be performed at home, is the child's participation in family routines and shared care between family members and friends, encouraging opportunities for communication and participation within the family.^{A5}

♦ Health professional in face of palliative care and death and dying process in pediatric oncology

The perception of health of the child in palliative care has emerged significantly in the publications. The most often cited

Palliative care in pediatric oncology: nursing...

professional in literature^{A6-A7} was the nurse that acts directly on patient care.¹⁵

The nurse was quoted as the professional who are faced daily with death¹⁶ and, thus, shall treat it as inevitable, however, the feeling of failure and impotence before the disease is present in the daily work of this professional.^{A6-A7} Situation becomes less aggressive as the nurses have more experience and professional experience.^{A6}

Death is an event that follows the life of the professional nurse, and her experience may serve as a tool for coping. Most nurses face the death of the patient without therapeutic possibilities as part of a natural process. This mode of perception is not representative of the professional nurse as "cold", but as a caregiver seeking ways to adapt to different situations of care.¹⁷

The process of death and dying is much discussed and questioned, because the sight of death is loaded with symbolism, is socially constructed, imbued with values and meanings that depend on the historical, cultural, economic, and political environment in which the subject is found¹⁸. This reality demonstrates the different ways of facing death, and proves the uniqueness of perception and coping process of death/dying, which are interpreted by the health professional involved.

Another striking feature of nursing is the bond building with the child and his family. This is because of the great periods of (re) hospitalization.¹⁹ Some nurses compare the patient/client with a family member.^{A6} Owning bond and emotional attachment hinders the separation and action towards the dying.²⁰ But it is known that the bond built between professional nursing and patient and family also provides benefits, human relationship supports the belief in the improvement and provides support in difficult times.²¹

It is critical that health professionals have technical and scientific knowledge about the physiological growth, psychomotor development, cognitive skills, as well as culture, language and behavior for each age group in order to have more precision in evaluations aimed at children, involving also the care technologies to the technical-scientific knowledge.^{A4, A7-A8}

♦ Family of the child with cancer in palliative care

In the view of parents that kept their children in palliative care until death, palliative therapy represented continuous

Jantsch LB, Neves ET, Arrué AM et al.

comfort for the child.^{A7} During this process the family plays an important role, both in health restoration at the time of receiving the diagnosis and/or stages of treatment.²² For these factors, it becomes paramount family participation in the palliative approach.^{A7}

It's the family that accompany the child, therefore, instruct it, insert it and hear it with the sensitivity of the perception of their needs becomes indispensable, because the welfare of the family is directly reflected in the welfare of the patient and the reverse is also true.²²

For an effective care is of paramount importance the family presence in the care process.²³ It is important that the family, along with the professional team creates care strategies to improve the welfare of the patient's physical and mental, as well as balance and family structure. The moment the family handles together, the child becomes smoother and safer.²⁴

Another relevant factor is about the information regarding the prognosis of the disease; when they are withheld to family members, it causes a false hope and understanding of the clinical picture of the child.^{A2, A5, A7} However, when the child receives an aggressive curative care, family trusts and invests in treatment, for lacking of situational awareness. Therefore it is essential to communicate clearly and effectively the binomial family/health care team.

According to a study, health professionals, especially doctors, are reluctant to deal with the family, either because they think it is a task they can take a long time, either because they feel unprepared to provide this support.²⁵ Questions that deal directly with life/death of the child, such as non-resuscitation, withdrawal of treatment and autopsy, which are potential problems, are not well treated by their parents, arising ambiguities in the understanding, which sometimes lead to wrong decisions.^{A5}

The active participation of family in these decisions is needed, because the terminal phase is long remembered, with each family faces the situation within their cultural and religious context, and supported by their own desires, capabilities and resources.

At the terminal moment is expected to offer the patient the necessary conditions for its realization, and palliative care is characteristic not only to cover the physical dimension, such as emotional, and spirituality, faith and religion also sources of welfare and quality of life.²⁶

Palliative care in pediatric oncology: nursing...

Often, in the child's family in palliative care, there is a change in family dynamics that may cause suffering to the brothers. This suffering can be related both to isolation and loss of attention, as the grieving to see their brother or sister sick.^{A5} Therefore, the child having a support at school is important because, when present difficulties in social interaction, will have a support.²⁷

Another important factor is the suffering of mourning against the imminent death of the family, a situation that must be addressed by the team with the family. It is important to talk about the end of life, and create coping strategies to deal with the child's death.^{A5} One way to alleviate this moment becomes the closer relationship between patient and family, with a view to an improved quality of life and quality of death. The family who was talked to is aware of the gravity of this moment and situational, assimilating the possibility of the existence of the order and preserve the effectiveness.²⁸

♦ Palliative care in pediatric oncology

The specificity of palliative care provided to children with cancer was found to be prevalent. Moreover, these treatments did not differ from the care of children in therapeutic treatment. Another feature is that this care does not differ according to cancer found, however it must be individualized in order to meet the specific demands of each user.^{A1, A6}

The characteristics of palliative care provided to children with cancer emphasize comfort, welfare and applicability under the most humane way possible, with the presence of cuddle, look, word and listening to the needs of the patient and his family.^{A6, A7}

Another feature was pointed out by research analgesia, to diminish the pain and suffering of these children. It is essential that staff knows the analgesic techniques in order to provide better resolution in attendance.^{A1, A6-A7} It was part listed the attitudes of health professionals and parents facing the painkillers are permeated by fear or ignorance with respect to the dependence on medication or incorrect dosage, sometimes causing an under-medication and thus the suffering of child.^{A1}

Analgesia is a way of providing palliative care and also implies, in the association's attention, conversation and affection as an additional measure of comfort to the end of life. It is worth noting that these measures should be applied carefully not only the child but also his family.²⁹

According to the literature, include to

Jantsch LB, Neves ET, Arrué AM et al.

palliative care home care such as massage, psychotherapy and hypnosis, and analgesia medication that is prescribed by the doctor.^{A4} In this sense, palliative care provided to children with cancer must meet the biopsychosocial needs of families and children, respecting their particularities, beyond beliefs and values.^{A4}

We highlight the need to provide relief from pain and symptoms of cancer, associating the biopsychosocial and spiritual needs of individuals in palliative care³⁰, in other words, give voice to their personal beliefs and values.

CONCLUSION

The issue of palliative care in pediatric oncology is contemporary, with current and relevant publications. The role of nurses was evident in the studies, being prevalent in the literature, a result which demonstrates the importance of care provided. In addition, professionals working with this clientele stressed feeling of frustration, helplessness, sadness and attachment.

The place where palliative care is provided remains focused on hospital-medical model. This result may reflect the recent introduction of the theme in the setting of care to children with cancer, being the hospital the reference place of care. But it was indicated that the most appropriate place is home.

The research subjects of most studies were the professional caregiver and child in the situation of palliative care. There was a gap in relation to the home caregiver and family about the situation of death/dying, and the greater objectivity in the face of the real needs for the child and his family in this context.

It is recommended the development of research in order to support the practice and qualifying palliative care in pediatric oncology. And more investment in job training for the development of palliative care, based on ethical principles and that the humanization of care is essential in caring for terminally ill children.

REFERENCES

1. Ministério da Saúde (Brasil). Instituto Nacional do Câncer. Particularidades do câncer infantil: Brasília. Ministério da Saúde; 2008.
2. Ministério da Saúde (Brasil). DATASUS. Departamento de Informática do SUS: Brasília. Ministério da Saúde; 2010.

Palliative care in pediatric oncology: nursing...

3. Camargo B, Kurashima A. Cuidados Paliativos em Oncologia Pediátrica: o cuidar além do curar. 1ª ed. São Paulo(SP): Lemar; 2007. p.19-44.
4. Firmino F. Implantação de Serviços de Cuidados Paliativos:Nossos Marcos Históricos. Revista Prática Hospitalar [Internet]. 2005 Sept-Oct [cited 2011 Oct 28]; (41). Available from: <http://www.praticahospitalar.com.br/pratica%2041/pgs/materia%2028-41.html>
5. World Health Organization (Organização Mundial da Saúde- OMS). National cancer control programs: policies and managerial guidelines. 2rd ed. Geneve: OMS; 2002.
6. Pessini L. Cuidados Paliativos: Alguns Aspectos Conceituais, Biográficos e Éticos. Revista Prática Hospitalar [Internet]. 2005 Sept-Oct [cited 2012 Jan 20];8(41). Available from: <http://www.praticahospitalar.com.br/pratica%2041/pgs/materia%2021-41.html>.
7. Cordeiro AM, Oliveira GM, Rentería JM, Guimarães CA. Revisão sistemática: uma revisão narrativa. Rev Col Bras Cir (online) [Internet]. 2007 Nov-Dec [cited 2012 Jan 19]; 34(6): 428-431. Available from: <http://www.scielo.br/pdf/rcbc/v34n6/11.pdf>
8. Bardin L. Análise de Conteúdo. Lisboa: Edições 70 LDA; 1977.
9. Amaral, BA. Cuidados paliativos e controle de sintomas em oncologia pediátrica [Internet]; 2011.[cited 2011 Nov 01]. Available from: <http://www.oncopediatria.org.br/content/cuidados-paliativos-e-controle-de-sintomas-em-oncologia-pedi>.
10. Diniz AB, Regis CA, Brito NP, Conceição LS, Moreira LMA. Perfil epidemiológico do câncer infantil em população atendida por uma unidade de oncologia pediátrica em Salvador-Bahia. Rev ciênc méd boil [Internet]. 2005 May-Aug [cited 2012 Feb 20];4(2):131-9. Available from: <http://www.portalseer.ufba.br/index.php/cm/bio/article/view/4185/3451>
11. Ramirez A, Addington-Hall J, Richards M. The carers. BMJ (Ed. Port.). 1998; 324:1291-2.
12. Melo LBC, Lima BSS, Tomaz MT, Trezza MCSF. Construindo um cuidado: a família e o seu familiar em regime de Cuidados Paliativos oncológicos no domicílio. Congresso internacional de Cuidados Paliativos; 2010 Oct; São Paulo. São Paulo. Academia Nacional de Cuidados Paliativos; 2010.
13. Florani CA. Cuidados paliativos no domicílio: desafios aos cuidados de crianças

Jantsch LB, Neves ET, Arrué AM et al.

Palliative care in pediatric oncology: nursing...

dependentes de tecnologia. J pediatr (Rio J) [Internet]. 2010 Jan-Feb [cited 2012 Jan 20]; 86(1): 15-20. Available from: http://www.scielo.br/scielo.php?pid=S0021-75572010000100004&script=sci_arttext

14. Santana JBC, Campos ACV, Barbosa BDG, Baldessari CEF, Paula KF de, Rezende MAE, et al. Cuidados paliativos aos pacientes terminais: percepção da equipe de enfermagem. Bioethikos Centro Universitário São Camilo [Internet]. 2009 [cited 2012 Feb 20]; 3(1): 77-86. Available from: <http://www.saocamilo-sp.br/pdf/bioethikos/68/77a86.pdf>

15. Costa CR, Fontoura EG, Servo MLS, Rosa DOS. Significado de cuidar/cuidado sob a óptica dos estudantes de enfermagem. Rev enferm UFPE on line [Internet]. 2012 Jan [cited 2012 Apr 20]; 6(1):149-55. Available from: http://www.ufpe.br/revistaenfermagem/index.php/revista/article/view/2095/pdf_784

16. Kovács MJ. Sofrimento da equipe de saúde no contexto hospitalar: cuidando do cuidador profissional. Mundo saúde [Internet]. 2010 [cited 2012 Dec 20];34(4):420-9. Available from: http://www.saocamilo-sp.br/pdf/mundo_saude/79/420.pdf

17. Furtado AMO, Souza SRS, Ramos JS, Ferreira CAM. O enfermeiro frente ao paciente fora de possibilidades terapêuticas: dignidade e qualidade no processo do morrer. Enferm glob [Internet]. 2011 Apr [cited 20 Feb 2012]; 22:1-8. Available from: http://scielo.isciii.es/pdf/eg/v10n22/pt_administracion6.pdf

18. Covolan NT, Correa CL, Hoffmann-Horochovski MT, Murata MPF. Quando o vazio se instala no ser: reflexões sobre o adoecer, o morrer e a morte. Rev bioét. 2010; 18(3): 561-71.

19. Pedro ENR, Funghetto SS. Concepções de cuidado para os cuidadores: um estudo com a criança hospitalizada com câncer. Rev gaúch enferm [Internet]. 2005 Aug [cited 2012 Feb 21]; 26(2):210-9. Available from: <http://www.lume.ufrgs.br/bitstream/handle/10183/23627/000710036.pdf?sequence=1>

20. Amaral JB, Menezes MR, Ramos JLC, Rocha MDS. Sentimentos vivenciados pelas enfermeiras durante o cuidado paliativo de idosos hospitalizados. J Nurs UFPE on line [Internet]. 2011 May [cited 2012 Feb 20];5(3):729-33. Available from: http://www.ufpe.br/revistaenfermagem/index.php/revista/article/view/1630/pdf_485

21. Silva ALP. O acompanhamento psicológico

a familiares de pacientes oncológicos terminais no cotidiano hospitalar. Interação psicol [Internet]. 2003 [cited 2012 Jan 20];7(1):27-35. Available from: <http://ojs.c3sl.ufpr.br/ojs2/index.php/psicologia/article/viewFile/3204/2566>

22. Ferreira NMLA, Souza CLB, Stuchi Z. Cuidados paliativos e família. Rev Cienc Méd [Internet]. 2008 Jan-Feb [cited 2012 Feb 20];17(1):33-42. Available from: <http://www.puc-campinas.edu.br/centros/ccv/revcienciasmedicas/artigos/v17n1a4.pdf>.

23. Mendes JA, Lustosa MA, Andrade MCM. Paciente terminal, família e equipe de saúde. Rev SBPH [Internet]. 2009 [cited 2011 Dec 30];12(1):151-73. Available from: <http://pepsic.bvsalud.org/pdf/rsbph/v12n1/v12n1a11.pdf>.

24. Souza ES, Escobar EMA. Importância da participação dos pais nos cuidados durante a hospitalização de seus filhos. Rev Enfermagem UNISA [Internet]. 2000 [cited 2012 Feb 20];1:104-7. Available from: <http://www.unisa.br/graduacao/biologicas/enfer/revista/arquivos/2000-24.pdf>.

25. Neto IGA. Conferência familiar como instrumento de apoio à família em cuidados paliativos. Rev Port Med Geral [Internet]. 2003 [cited 2012 Feb 12];19:68-74. Available from: <http://www.apmgf.pt/files/54/documentos/20080304114613156224.pdf>.

26. Peres MFP, Arantes ACLQ, Lessa OS, Caous CA. A importância da integração da espiritualidade e da religiosidade no manejo da dor e dos cuidados paliativos. Rev psiquiatr clín (São Paulo) [Internet]. 2007 [cited 2012 Feb 07];34(1):82-7. Available from: <http://www.hcnet.usp.br/ipq/revista/vol34/s1/82.html>.

27. Wilkinson S, Croy P, King M, Barnes, J. Are we getting it right? Parents' perceptions of hospice child bereavement support services. Palliat med. 2007;21:401-7.

28. Nucci NAG. A Criança e a morte: construindo significados. Congresso internacional de Cuidados Paliativos; 2010 Oct; São Paulo. São Paulo. Academia Nacional de Cuidados Paliativos; 2010.

29. Pontes CM, Kurashima AY. Criança com Câncer: Revisão da literatura sobre sinais e sintomas presentes na fase de cuidados paliativos. Rev soc bras enferm ped [Internet]. 2009 July [cited 2012 Feb 22];9(1):27-31. Available from: http://www.sobep.org.br/revista/images/stories/pdf-revista/vol9-n1/v.9_n.1-art4.revi-

Jantsch LB, Neves ET, Arrué AM et al.

Palliative care in pediatric oncology: nursing...

[crianca-com-cancer-revisao-de-literatura-sobre-sinais.pdf](#).

30. Santos MCL, Pagliuca LMF, Fernandes AFC. Cuidados paliativos ao portador de câncer: reflexões sob o olhar de Paterson e Zderad. Rev. Latino-Am. Enfermagem [Internet]. 2007 Mar-Apr; 15(2):[about 5 p.]. Available from: http://www.scielo.br/pdf/rlae/v15n2/pt_v15n2a24.pdf.

Sources of funding: No
Conflict of interest: No
Date of first submission: 2012/04/30
Last received: 2012/06/04
Accepted: 2012/06/05
Publishing: 2012/07/01

Corresponding Address

Leonardo Bigolin Jantsch
Rua Turvo, 216 – Centro
CEP: 98640-000 – Crissiumal (RS), Brasil