

Symptoms, Suffering and Palliative Care at the End of Life in Children with Cancer to Synthesis Best Evidence for Practice: A Meta Analysis

Vasantha Kalyani*, S.K. Mohanasundari**

*Assistant Professor ** Nursing Tutor, College of Nursing AIIMS, Rishikesh.

Abstract

Objective: To review various studies to identify Symptoms and suffering perceived by children at the end of life with cancer and the need of palliative care. *Purpose of Review:* Symptoms and suffering perceived by children at the end of life with cancer and identifying Paediatric palliative care, is an important aspect of care of children with life-threatening illnesses like cancer. We review recent publications with implications for care of these children. *Data sources:* The following database were searched i.e published research papers from different sources such as original journals, E journals and electronic database for example Pubmed, Medline, etc. The search of literature was archived by searching the references using several key words related to title and subject of the review. Literature was also archived from online Journal of American academy of pediatrics and general search portal such as Google search. Only articles written in English were included. The following keywords were used in combinations: symptoms of cancer, palliative care, end of life in children with cancer etc. *Study Selection:* Studies were eligible if 1) studies conducted on perspective of parents on suffering of their children due to cancer only were included in this study (there were many studies that evaluated the psychological and physical symptoms experienced by children with cancer at end of life were included), 2. The need of palliative therapy for children with end of life care was evaluated. 3. The studies were published in refereed journal were evaluated. However few studies were found that dealt with palliative care for children with cancer at end of their life's, and all studies that evaluate palliative care were included. There were 10 studies met our criteria and were selected. *Data Synthesis:* Results of the studies were measured in terms physical and psychological symptoms and sufferings of children with at end of life, and palliative care provided as well as palliative care needed for children with cancer at end of life. All studies reviewed have shown that children with cancer is suffering with more physical and psychological symptoms apart from physical pain at end of their life that was not addressed properly by health care professional and need more palliative care. *Conclusion:* The result of research review support that the children with cancer suffer from fatigue, poor appetite, dyspnea, status epileptics and commonly suffering from pain, and psychological sufferings. these sufferings are not addressed adequately by health care professionals and need more palliative care and need additional systematic study, improved education and support for staff members, and continued development of more effective and compassionate delivery of pediatric palliative care.

Keywords: Palliative Care; Cancer Children; Meta Analysis; End of Life Care.

Introduction

Cancer is the leading cause of non accidental death

Reprint Request: Vasantha Kalyani, Assistant Professor, College of Nursing AIIMS, Virbhadrha Road, Rishikesh, Uttarakhand 249201.

E-mail: vasantharaj2003@gmail.com

© RED FLOWER PUBLICATION PVT. LTD.

in childhood. There has, however, been little evaluation of the overall experience at the end of life of children who are dying of cancer or of their symptoms other than pain. A number of studies have demonstrated that among adults, the quality of care at the end of life is suboptimal. For example; one study of elderly patients found that there was considerable suffering at the end of life, with up to

25 percent of patients experiencing moderate-to-severe pain in the last three days of life. It is not known whether the experiences of dying children are similar.

Suffering is a complex multifaceted phenomenon, which has received limited attention in relation to children with terminal illness. The care of children at the end of life may be particularly complex. For most children with cancer, the primary goal of treatment is to achieve a cure. Considerations of the toxicity of therapy, the quality of life, and growth and development are usually secondary to this goal. As a result, it may be difficult for physicians to change their focus even when there is little hope of a cure. Unfortunately, about 25 percent of children with cancer eventually die of their disease. Studies reviewed that Children who are receiving potentially curative treatment are more likely to die in hospital (where they will receive intensive care) than those receiving palliative treatment that are more likely to die at home or in a hospice. High-quality palliative care is now an expected standard at the end of life. Yet it is not known whether the care of children with cancer meets this standard. Palliative care is philosophy of care that evolved from the hospice philosophy to meet the gaps in care for seriously ill and dying patient. Palliative care is appropriate for children with wide range of condition even when cure remains a distinct possibility. Primary care provider should be taught to recognise a child's need for palliative care, to assess the emotional and spiritual needs of the child and family, to facilitate advanced care planning, to assess and manage the child's pain and symptoms, to provide to a specialist.

Generalist and specialists alike can and should provide palliative care. When needed. At a minimum the team can include a well trained primary

physician, ac care coordinator and in some cases, a bereavement specialist, in addition a support should be available from specialist such as child psychologist and child life specialist to deal with psychological problems faced by children and family.

Once a need for palliative care is identified primary provides have a central role in initiating critical discussion about the trajectory of illness and about advance care plan

This present systematic review of various studies was undertaken to identify symptoms, suffering and need for palliative care at the end of life in children with cancer to synthesis best evidence for practice.

Material and Methods

The systemic review was conducted using the wide variety of literature of the subject of study i.e published research papers from different sources such as original journals, E journals and electronic database for example Pubmed, Medline, etc. the search of literature was archived by searching the references using several key words related to title and subject of the review. Literature was also archived from online Journal of American Academy of Pediatrics and general. Only articles written in English were included. The following keywords were used in combinations: symptoms of cancer, palliative care, end of life in children with cancer .

Objectives

To review various studies to identify Symptoms and suffering perceived by children at the end of life with cancer.

Table 1: Literature search

Database	No. of studies	No. of study selected	Key words
Pubmed	11	6	Sufferings and symptoms of children with cancer at end of life, Palliative care
Medline	4	2	Sufferings and symptoms of children with cancer at end of life, Palliative care
American academy of pediatrics	7	3	Sufferings and symptoms of children with cancer at end of life, Palliative care

To review the need regarding palliative care at the end of life in children with cancer.

Inclusion Criteria

Studies were included if it met the following criteria:

1. Studies conducted on perspective of parents on

suffering of their children due to cancer only were included in this study.

2. The need of palliative therapy for children with end of life care were evaluated.

3. The studies were published in refereed journal were evaluated

4. The paper were available in English

Exclusion Criteria

Studies were excluded if:

1. Studies on chemotherapy for children with cancer at end of life
2. Studies on radiation therapy for children with cancer at end of life.
3. Studies on surgical management for children with cancer at end of life.
4. Studies on incidence of cancer in children

Results

The result of systematic review identifies that, the focus of pediatric oncology research was principally on the binary outcome: death or survival. As survival rates improved, attention turned to reducing the toxic effects of therapy. However, there are very few data looking at palliative care outcomes. In addition, it is important to distinguish between symptoms that occur at the end of life from those that occur in children with cancer during their treatment, whether they survive or not. It is important to differentiate the symptoms that are caused by the disease from those that occur from treatment.

Collins and colleagues conducted a study to define the most prevalent symptoms in children with cancer used the Memorial Symptom Assessment Scale (MSAS) to prospectively assess children referred to Memorial Sloan-Kettering Cancer Center over a 12-month period. The study population consisted of 190 English-speaking children aged 10-18 years, of whom 160 patients consented to be tested and 159 completed the MSAS 10-18 using a 4-5-point scale. Greater than 35% of patients experienced clinically significant lack of energy, pain, drowsiness, nausea, cough, lack of appetite, and psychologic symptoms (sadness, nervousness, worrying, and irritability). The most distressing symptoms were difficulty in swallowing, mouth sores, pain, and insomnia. There is a marked difference in the number of symptoms between inpatients (12.7 ± 4.9 symptoms) versus outpatients (6.5 ± 5.7 symptoms). Children with solid tumors or who received recent chemotherapy experienced more symptoms. Finally, pain was reported in 84.4% of the inpatient group.

Wolfe and colleagues examined retrospectively the symptoms that children experience at the end of life. They interviewed, over a 1-year period parents of children who died. One hundred sixty-five families were identified, 143 were located, 107 agreed to participate, and 103 English-speaking parents were interviewed either by phone (98) or in person (5) to

recall, through a questionnaire, the experiences of their child at the end of life. The average age of the children at death was 10.8 ± 6.7 years, and that of the parents at the time of the interview was 4.3 ± 7.7 years. Fifty-one percent of the children died at home, and of the 49% of children who died in the hospital, 45% died in the intensive care unit. The parents were asked whether their children experienced the following symptoms: fatigue, pain, dyspnea, poor appetite, nausea or vomiting, constipation, or diarrhea. The most common symptoms the parents reported were fatigue (nearly 100%), followed by pain, dyspnea, and poor appetite (all greater than 80%). Of all the symptoms, fatigue, pain, and dyspnea were by far the most common in causing a great deal of suffering at the end of life. Regardless of the seven symptoms that parents were asked about, palliative treatment was inadequate, because children continued to suffer. The two most common symptoms treated were pain (76%) and dyspnea (65%), with only 27% and 16% benefiting from the treatment. Less than 20% of patients with fatigue were treated, and very few were reported to derive benefit from the treatment. Finally, of the seven symptoms screened for, only pain, dyspnea, nausea or vomiting, and diarrhea were mentioned in the patient's chart, whereas the treatment team failed to recognize fatigue, poor appetite, and constipation. Despite the failure of the health care team to recognize or treat effectively symptoms at the end of life, the parents rated the care given by the oncologist (81%), nurse (90%), and psychosocial staff (77%) as good to excellent. Clearly, parent satisfaction is an inadequate indicator of quality palliative care.

A Qualitative descriptive study with semi-structured interviewed mothers and fathers of hospitalised children (0-16 years old) with a terminal illness in Granada (Spain). Of 13 parents were interviewed. They described children's suffering as manifested through sadness, apathy, and anger towards their parents and the professionals. The isolation from their natural environment, the uncertainty towards the future, and the anticipation of pain caused suffering in children. The pain is experienced as an assault that their parents allow to occur.

A study was conducted to explore the psychological experiences of children with brain tumours at the end of life: parental perceptive. Twenty-four parents of children diagnosed at less than 18 years of age with a brain tumor, and who died between 2 and 12 years prior, were approached for this qualitative, retrospective study. Three main domains were identified that describe parents' perceptions of their child's psychological experiences:

(1) intrapsychic changes—those processes within oneself, and encompassing internal aspects of a person such as cognitive and emotional variables; (2) interpersonal interactions—those interactions between oneself and others, including being treated like their same aged healthy peers and maintaining relationships with others; and (3) posttraumatic growth—those positive personal changes that can occur as the result of a significant struggle or hardship.

A descriptive study was conducted to analyse Critical Situations in Children, Adolescents and Young Adults with Terminal Cancer within the Home Setting. The records of 133 children cared by paediatric palliative care team (PPCT) from 01/1998-12/2009 was analysed. The majority of children who died sustained no critical situation. In 38 (28.6%) pts 45 critical situation occurred. These accumulated towards the end-of-life (62.2% within the last week). About two-thirds were anticipated. There was no clustering of critical situation during the night/weekend. Leading symptoms were neurological. In 4 critical situations pre-hospital emergency physician was alerted. 5 children were readmitted to hospital. Most critical situation (88.9%) could be controlled in the home setting. Despite anticipation, a relevant number of children developed critical situation, which needed either additional medical intervention or other support by the PPCT. Considering the distressing and suffering character of status epilepticus and dyspnoea, it is important to thoroughly address these conditions in palliative care.

A study was conducted to describe the circumstances surrounding the deaths of hospitalized terminally ill children, especially pain and symptom management by the multidisciplinary pediatric care team. Patients in the neonatal intensive care unit, pediatric critical care unit, or general pediatric units of Vanderbilt Children's Hospital (USA) who were hospitalized at the time of death, between July 1, 2000, and June 30, 2001, were identified. Children eligible for the survey had received inpatient end of life care (EOL) care at the hospital for at least 24 hours before death. A retrospective medical record review was completed to describe documentation of care for these children and their families during the last 72 hours of life. Records of children who had received inpatient EOL care were identified (n = 105). A majority (87%) of children were in an intensive care setting at the time of death. Most deaths occurred in the pediatric critical care unit (56%), followed by the neonatal intensive care unit (31%). Pain medication was received by

90% of the children in the last 72 hours of life, and 55% received additional comfort care measures. The presence of symptoms other than pain was infrequently documented.

A study was conducted to describe and show effectiveness of the outreach team model of palliative care (PC) in allowing home death for children with incurable cancer by Children's Cancer and Leukaemia Group United Kingdom. A period of 7 months among 185 children from UK oncology centre were recruited to a prospective questionnaire survey. One hundred sixty-four children from 22 centers died (median age, 8.7 years). Around 132/164 parent's preferred home death for their children. And 68/164 parents requested no OPD or IPD visit for their children. A named individual provided on-call palliative care advice by phone or home visit in 22 oncology centres. As palliative care progressed, involvement of oncologist and social worker appeared less, whereas paediatric oncology outreach nurse specialists (POONSs) remained prominent. Home death is facilitated by this model. Professional roles change during PC and after death. An ongoing role for the oncology team in bereavement support is highlighted.

A study reviewed about Development of a paediatric palliative care program was preceded by a needs assessment that included a staff survey and family interviews regarding improving pediatric palliative care. Four hundred forty-six staff members and community physicians responded to a written survey regarding comfort and expertise in delivering end of life care. Sixty-eight family members of 44 deceased children were interviewed regarding treatment, transition to palliative care, and bereavement follow-up contact. Frequencies were generated for responses to the staff survey. Five interviewers reviewed the families' narratives and identified frequently occurring themes. Staff members reported feeling inexperienced in communicating with patients and families about end of life issues, transition to palliative care, and do not resuscitate status. Families reported distress caused by uncaring delivery of bad news and careless remarks made by staff members. Staff members reported feeling inexperienced in symptom and pain management and described occasions when pain could have been better managed. Families believed pain had been managed as well as possible despite observing their children suffer. Fifty-four percent of staff members reported that adequate support was not provided for those who treat dying children. Staff members and family members stated their desire for more support. Staff members who described their

Table 2: Major findings of the meta analysis

Category	Description
Samples	<ul style="list-style-type: none"> • Children who died due to cancer • Children who are suffering from cancer • Parents of children died and still suffering from cancer • Health care provides who care for the child with cancer
Physical symptoms and sufferings of children,	<ul style="list-style-type: none"> • Pain • Poor Appetite • Dyspnea • Status epileptics
Psychological suffering	<ul style="list-style-type: none"> • Fatigue • Sadness • Apathy • Anger towards parents and health care professionals • Isolation • Progressive neurological dysfunctions (positively or negatively)
Palliative care	<ul style="list-style-type: none"> • Advanced planning, close contact, good communication, detailed parental information, and a 24-h on-call service can reduce critical situation in children with terminal cancer. • Treatment of critical situations should focus on the child's symptoms and wishes, and the needs of the whole family. • Pediatric oncology outreach nurse specialists (POONs) (outreach team model of palliative care (PC)) show effectiveness in allowing home death for children with incurable cancer. Home death is facilitated by this model. • For Development of a pediatric palliative care program there is need for additional systematic study, improved education and support for staff members, and continued development of more effective and compassionate delivery of pediatric palliative care. • The documentation of pain and symptom assessment and management can be improved but requires new tools in interdisciplinary pediatric palliative care.

most difficult experiences caring for a dying child referenced personal pain and inadequate support most frequently.

Discussion

Palliative care includes the control of pain and other symptoms and addresses the psychological, social, or spiritual problems of children (and their families) living with life-threatening or terminal conditions. But health care professional were less aware in perceiving the suffering of the children with cancer than the parents. Clinical research concerning the effectiveness and benefits of pediatric palliative care interventions and models of service provision should be promoted. In addition, information about pediatric palliative care that is already available must be effectively disseminated and incorporated into education and practice. So that health care professionals can easily recognize the suffering of the children and plan for appropriate palliative care.

Conclusion

The result of research review support that the children with cancer suffer from fatigue, poor appetite, dyspnea, status epileptics and commonly suffering from pain, and psychological sufferings

like fear, sadness, apathy, and anger towards their parents and the professionals caused due to isolation from their natural environment, the uncertainty towards the future, and the anticipation of pain. Most children and parents preference is home to spend their end of life only need on-call palliative care advice by phone or home visit than outpatient visit or inpatient admission because Children who received cancer-directed therapy during the end-of-life period suffered from a greater number of symptoms than those who did not receive treatment. And these sufferings are not addressed adequately by health care professionals and need more palliative care and need additional systematic study, improved education and support for staff members, and continued development of more effective and compassionate delivery of pediatric palliative care.

References

1. World Health Organization. *Cancer Pain Relief and Palliative Care in Children*. Geneva, Switzerland: World Health Organization; 1998.
2. American Academy of Pediatrics, Committee on Bioethics, Guidelines on forgoing life-sustaining medical treatment. *Pediatrics*. 1994; 93: 532-536.
3. American Academy of Pediatrics, Committee on Bioethics, Ethics and the care of critically ill infants and children. *Pediatrics*. 1996; 98: 149-152.

4. Fleischman AR, Nolan K, Dubler N, et al., Caring for gravely ill children. *Pediatrics*. 1994; 94: 433-439.
5. Frager G (1997) Palliative care and terminal care of children. *Child Adolesc Psychiatr Clin North Am*.6:889-909.
6. Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd ed. New York, NY: Oxford University Press; 1998 Collins JJ (1996) Intractable pain in children with terminal cancer. *J Palliat Care*. 12:29-34.
7. Sirkia K, Hovi L, Pouttu J, Saarinen-Pihkala UM, (1998) Pain medication during terminal care of children with cancer. *J Pain Symptom Manage*. 15:220-222
8. Cassel CK, Foley KM. *Principles for Care of Patients at the End-of-Life: An Emerging Consensus Among the Specialties of Medicine*. New York, NY:Milbank Memorial Fund; 1999
9. Fagen TS (1982) Music therapy in the treatment of anxiety and fear in terminal pediatric patients. *Music Therapy*. 2:13-23.
10. American Academy of Pediatrics, Committee on Bioethics (1995) Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 95:314-317.
11. Nitschke R, Humphrey GB, Sexauer CL, Catron B, Wunder S, Jay S (1982) Therapeutic choices made by patients with end-stage cancer. *J Pediatr*. 101:471-476.

Instructions to Authors

Submission to the journal must comply with the Guidelines for Authors.

Non-compliant submission will be returned to the author for correction.

To access the online submission system and for the most up-to-date version of the Guide for Authors please visit:

<http://www.rfppl.co.in>

Technical problems or general questions on publishing with IJPN are supported by Red Flower Publication Pvt. Ltd's Author Support team (<http://www.rfppl.co.in>)

Alternatively, please contact the Journal's Editorial Office for further assistance.

Publication-in-Charge

International Journal of Practical Nursing

Red Flower Publication Pvt. Ltd.

48/41-42, DSIDC, Pocket-II

Mayur Vihar Phase-I

Delhi – 110 091

India

Phone: 91-11-22754205, 45796900, Fax: 91-11-22754205

E-mail: redflowerppl@gmail.com, redflowerppl@vsnl.net

Website: www.rfppl.co.in