

# Parental View of Palliative Care in Children with Cancer: Integrative Review

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## Abstract

The purpose of this integrative review is to describe parents' views and needs when it comes to palliative care in children with cancer at this critical phase. Ten published studies of a literature search in PubMed, Science Direct and CINAHL were included in this review. The analysis resulted in six themes: 1) good information and understanding of palliative care; 2) support by specialists in pediatric oncology; 3) respect as a knowledgeable expert; 4) emotional and psychological support; 5) effective communication and 6) roles of actions. Professional nurses and health care professional teams should be concerned about parents' views and the need for palliative care for their children with cancer. They should also understand the child and their parents as the center of individual care. Further studies need to be performed in this area.

**Keywords :** pediatric palliative care, children with cancer, parents' views, parents' needs

The term "Children with cancer" is used to define cancer in patients aged less than 18 years of age. Pediatric cancer is relatively rare and sometimes considered as a familial disorder. The incidence rate of children diagnosed with cancer was approximately 200 per million children around the world.<sup>1</sup> Fortunately, children cancer represented between 0.5% and 4.6% of all cancer diagnosed. WHO reported that about 80% of children with cancer survived for 5 years.<sup>1,2</sup> Cancer is a life-threatening illness and a life-limiting condition, which significantly causes long-term effects, and can lead to both physical and psychological distress for children and their family.<sup>3</sup> Long-term involvement of children with cancer may have many stressful and negative impacts on daily living, parental roles, family dynamics and quality of life for their parents.<sup>4</sup> Oncology treatments are important for improving the survival rate in children with cancer.<sup>5</sup> However, many families still need supportive care from health care providers while their children are receiving palliative care.

Palliative care is an essential part of treatment in children with cancer from diagnosis establishment throughout the end of their life and bereavement period.<sup>1</sup> Pediatric palliative care is a comprehensive tool designed to improve the quality of life of children and their parents with life-threatening conditions.<sup>1,6</sup> Palliative care considers the children and parents as the center of a unit, focuses on prevention and relief of suffering as well as physical, psychological, social and spiritual needs.<sup>6</sup> The aim of palliative care in children is to improve quality of life and to support the children and also their families to live as normal a life as possible throughout the illness trajectory.<sup>1,7</sup>

When a child with cancer is admitted for the first time into palliative care, it is the parents who will be the most important primary care-givers. They will be confronted with difficult situations and numerous problems such as symptoms of the disease itself, chemotherapeutic agents and their side effects, family and social problems, family income<sup>8,9</sup> and a high risk for long term psychological effects.<sup>10,11</sup>

In children's cancer, parents are increasingly required to play the role of caregiver.<sup>12</sup> Parents are needed to enhance collaboration with health care teams. When the care of their children has been developed based on the parents' needs, after the parents have received adequate information, parents may experience fewer burdens in their roles. Consequently, they are expected to be a positive impact on children's and parent's life quality.<sup>13</sup>

Previous integrative reviews on parents' views of palliative care in children with cancer at the end of life stage, revealed that information, communication and the relationship between health care professionals and their parents was not sufficient and the onward effect on the quality of care for their children was significant.<sup>14</sup> Few previous published studies have considered how parents of pediatric cancer patients deal with the experience of pediatric palliative care. The results of this integrative review serve as a basis to guide future intervention studies in training parents, main care givers and healthcare professionals in pediatric palliative care according to the need of parents who are the main care-givers in children with cancer.

### Purpose

The purpose of this integrative review is to describe parents' views and needs of palliative care in children with cancer.

### Method

This study used an integrative literature review method to extend qualitative studies. The analysis of the literature was conducted using six literature review steps including: 1) selecting a topic; 2) searching the literature; 3) developing the argument; 4) surveying the literature; 5) critiquing the literature and 6) writing the review.<sup>15</sup>

The search of this study was seen in terms of parent's perceptions with a combination of pediatric palliative care, palliative care in children, palliative care in pediatric oncology, palliative care in children with cancer and qualitative research. The following electronic databases were searched: PubMed, CINAHL and Science Direct.

Articles had to meet the following inclusion criteria for this review: 1) Focus on perspectives and experience of parents on aspects of pediatric palliative care; 2) empirically examine these perspectives using qualitative methods 3) be published in an English peer-reviewed journal; 4) limit of human subjects and 5) be published between January 2007 and March 2017. A total of 56 articles that met these criteria were selected. (Figure 1)

Articles were excluded if they did not focus on and discuss parents' views and the care needs of their children with cancer. A total of ten articles were finally included in this review and selected.

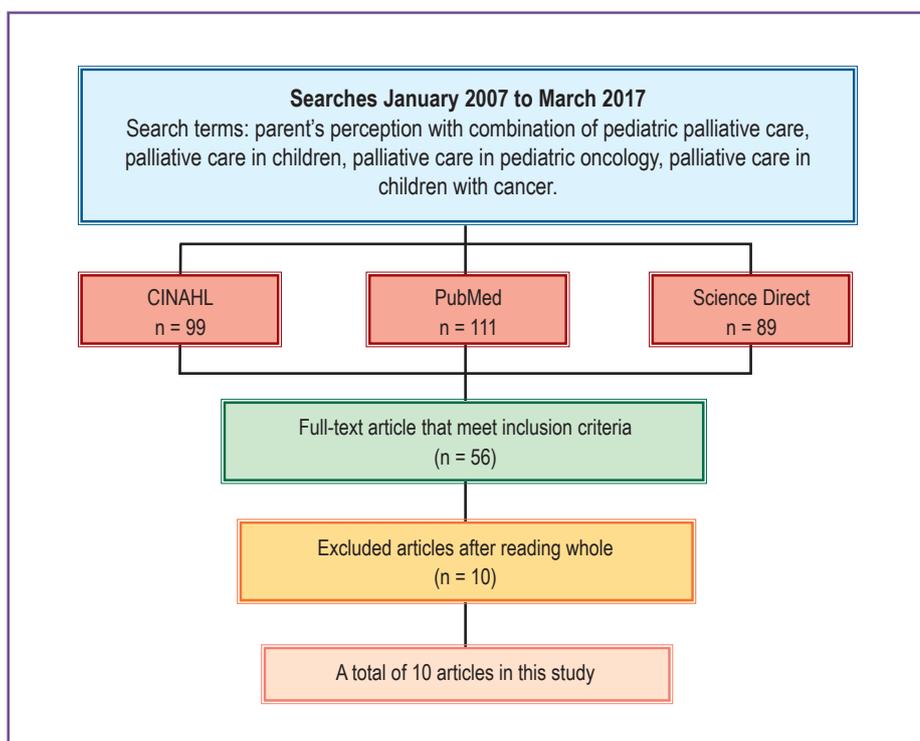


Figure 1: Flow chart of search strategy.

Results

1.1 Study characteristics

Study design

The ten qualitative studies included in this study used open-ended interviews (n = 2),<sup>3, 16</sup> semi-structured interviews (n = 2),<sup>17, 18</sup> in-depth interviews (n = 3),<sup>19-21</sup> focus group (n = 2)<sup>22, 23</sup> and semi-structured interviews combined with focus group (n = 1)<sup>24</sup> to obtain parents' perspectives on pediatric palliative care for their children with cancer. The articles in this review were analyzed for content analysis and thematic analysis (n = 7), psychological phenomenological approach (n = 1) and a grounded theory data analysis (n = 2).

Location

The majority of these studies were performed in hospitals in the United Kingdom, Ireland, Australia, Netherlands, Brazil and the United States of America.

Participants

All studies included parents of children with cancer and an oncological diagnosis of children as participants and represented the views of 187 parents.

1.2 Synthesis

The findings identified by the synthesis are shown in Table 1. Studies identified parental perspective on helpful and supportive care of palliative care for their children with cancer.

Table 1: Summary of Articles Included in Integrative Review

Author (Year)	Aim/objective	Design and sample	Main findings (Parental needs in palliative care)
Konrad SC. 2008 <sup>16</sup>	Explored parents' views on qualities of supportive palliative care in their children from health care professional	Qualitative study - 12 parents of children with cancer - Open-ended interviews	- From mothers' assessments of care providers found that communication and interpersonal relationship competencies were identified as most influential.
Monterosso, et al. 2009 <sup>17</sup>	Parent perspectives on extent of service provision, and facilitators and barriers to supportive palliative care	Qualitative study - 19 parents of children with cancer - Semi-structured interviews	- All parents suggested health care providers should care for their children at home. - Perspectives on palliative care that are difficult to understand. - Expectation of health professionals to have specialist pediatric knowledge and experience in oncology. - Parents of children with cancer felt well informed by health professionals.
Seth T. 2010 <sup>19</sup>	- To explore parental perceptions and parental views about suffering from cancer in their child; about disease, prognosis and treatment. - To explore parental view on decision making and beliefs for treatment in palliative care of their children.	Qualitative study - 23 parents of cancer with cancer patients in the age mean age 13 years - In-depth interviews	- Most parents appreciated truthfulness in diagnosis, prognosis other information and counseling from physicians and health care team. - Most parents said that both parent and health care team should decide together when to stop curative treatment.
Weidne, et al. 2011 <sup>24</sup>	To identify and define the key components of care for parents in their children with cancer	Qualitative study - 29 parents of children with cancer - Semi-structured interviews and focus group	- Parents wanted good and appropriate information for guidance to make decisions about their children with cancer and palliative care received. - Parents wanted the health care team to respect their role as expert caregivers of their children. - Most parents identified communication as an important element of care.

Author (Year)	Aim/objective	Design and sample	Main findings (Parental needs in palliative care)
Robert, et al. 2012 <sup>22</sup>	To understand and describe experience of parents as the main caregiver faced with their children with cancer who had received pediatric oncology treatment at a pediatric cancer center	Qualitative study - 14 parents of children with cancer age 10 years - Focus group	From parents' study, identified four major themes of palliative care: 1) Standards of care 2) Communication 3) Emotional care 4) Social support
Coyne, et al. 2014 <sup>3</sup>	To explore parental perspectives on children's participation in decision-making process in palliative care from their own perspectives at pediatric oncology unit.	Qualitative study - 22 parents of children receiving cancer treatment age 7-16 years - Open-ended interviewing	- Identified core theme "it has to be done". - The categories which identified parents' roles in the decision-making process: 1) Best interest of their child in process. 2) Assessing their child's ability for participation in decision-making process. 3) Allowed choices but not the decision to decline treatments. 4) Sometime lacking involvement in treatment decisions. 5) Lacking participation any 'real' decisions.
Neilson et al. 2015 <sup>18</sup>	To describe the role of the general health care providers in children with cancer and receiving palliative care from the views of parents who were the most important caregivers of their children.	Qualitative study - 11 parents of children with cancer - Semi-structured interviews	- Parents' viewpoint was that the general health care providers' role is to provide support and medical care. - General health care providers' time pressures influenced the level of engagement with the parents and influenced the ability to learn during palliative care. - Lack of familiarity with the family and parents influenced their level of interaction. - Parent's lack of clarity of their general health care providers' role influenced the opportunities for support for their children.
Boss, et al. 2015 <sup>23</sup>	To describe parent concerns on "Pediatric Medical Orders for Life-Sustaining Treatment" as the program to increase discussion between parents and health care provider about treatment, encouragement of parents and meeting childrens' needs	Qualitative study - 10 parents of children with cancer age 10 years - Focus group	- The best time to discuss the program would be starting from hospital admission to 24 hrs. after discharge. - Would be empowering the parents to feel central to their children's care. - Requiring communication skills, children and family centered care. - Parents require active listening, empathy and face to face conversations or interaction without electronics such as mobile phones. - Parents require continuity of children patient care in hospital and at home.

Author (Year)	Aim/objective	Design and sample	Main findings (Parental needs in palliative care)
Kars, et al. 2015 <sup>20</sup>	To explain and describe the parents' actions in handling and expressing "the voice of the child."	Qualitative study 34 parents with cancer during palliative care In-depth interviews	Three aspects were identified from the parents' need to represent the "voice of the child." 1) The context in which parents had access to "the voice of their child" 2) The strategies they used to get insight into the child's inner perspective 3) The parent's ability to take into account their child's perspective
Arruda-Colli, et al. 2015 <sup>21</sup>	To examine the different perspectives of caregiver experiences of parents of children with relapsed cancer.	Qualitative study - 13 parents as the main caregivers of children with recurrent cancer - In-depth interviews	Parent's experiences were reported in three major themes: 1) Giving meaning to palliative care 2) Lack of control 3) Perception of threat to their children

### 1.3 Findings

A wide range of important palliative care strategies especially for children cancer was addressed in these reviews. Most of the investigators explored parents' views on the quality of palliative care for their children with cancer not only in physical problems but also in emotional, psychological, and spiritual support. Some of the investigators explained parents' experiences of palliative care for their child after diagnosis with cancer and relapsed cancer.<sup>21-24</sup>

*The findings of the review are described in six themes*

#### Theme 1: Good information and understanding of palliative care

Many review studies in this study identified the perspective of parents when it comes to good information.<sup>3,17,19</sup> They preferred health care teams to share information about palliative care including diagnosis, prognosis, and treatment because palliative care was difficult to explain and understand.<sup>17,19</sup> They wanted to have a better understanding and to gather more information in the early stages of the cancer trajectory<sup>17,19</sup> and they also needed health care providers to empower them to feel central to their children's care.<sup>23</sup> They appreciated when positive or negative information in diagnosis and prognosis was transferred into care management decisions made by health care providers.<sup>16</sup>

Some parents' understanding of palliative care is only to keep a child comfortable and help their child to a peaceful death.<sup>17</sup> Many parents stated that they didn't have many choices about the cancer therapy for their children because the treatment and care in palliative care was necessary for their child's survival and better quality of life<sup>3</sup> and palliative care is as important for children as family centered care.<sup>23</sup> Some

studies found that parents with poor understanding of their role in palliative care may influence parents' management of care.<sup>18</sup> Moreover, parents need to understand not only the information on cancer treatment, but also to learn the process of their role as a caregiver to improve the quality of their child's care.<sup>18,21</sup>

#### Theme 2: Support by specialists in pediatric oncology

Many parents viewed the health care professional as being an expert, with specialized knowledge, with unique knowledge about pediatric oncology and experienced in cancer care and therapy for their children.<sup>3</sup> Parents were happy to be guided, trusted and had confidence in their health professionals.<sup>3,18</sup> The parents were satisfied with their healthcare provider team who had a special ability to care for their children with cancer and specialist support available for 24 hour.<sup>18</sup> In one study, parents appreciated healthcare providers who were confident and had advanced knowledge in palliative care of their children's health especially in cancer service care.<sup>16</sup>

#### Theme 3: Respected as a knowledgeable expert

Several studies described parental perspectives and views of palliative care in their children with cancer as a need to be respected as an expert in their child's care.<sup>3,20,24</sup> Parents wanted healthcare professionals to respect their role as experts on their children because of their intense involvement in their child's life.<sup>24</sup> They knew their child better than their child's doctor and could understand what their child wanted or what was appropriate for their child.<sup>3,20</sup> One study revealed that the parents wished to be seen as the voice of their children, representing their children's feelings, perceptions, needs and wishes, leading to the best care for them and tailored to their children's needs.<sup>20</sup>

#### Theme 4: Psychological support for parents and their children

From this review, psychological support was identified in four out of ten studies.<sup>16,21,22,24</sup> Parents described their needs and their family's needs for counseling from an expert healthcare team.<sup>22</sup> Parents were distressed by the suffering caused when facing a new treatment or new invasive procedure for their children with an awareness of their children's psychological reaction such as fear or anxiety.<sup>20</sup> Most parents stated they were satisfied with providing psychological support and guidance in response to the child's psychological signs identified by professionals.<sup>20,22</sup> Additionally, parents who expressed their emotional suffering should be aware of the emotional implications, and learn the strategies to help and empower them.<sup>21</sup> A single mother needs healthcare professionals as a team to be concerned with her well-being and to regularly check if she needs emotional support.<sup>16</sup> Psychological support can reduce parental stress and empower parents coping with various stressful events.<sup>20,22,24</sup>

#### Theme 5: Effective communication

Effective communication was identified by parents in many studies.<sup>17,22,23</sup> Parents required realistic, honest and wide-open communication with healthcare and medical professionals about the prognosis and treatment of their children.<sup>17</sup> Many parents appreciated having enough time with healthcare providers for discussions about their children's care. Furthermore, they required empathy from the healthcare team.<sup>22</sup> Some parents stated that honesty and trust in healthcare professionals is needed to provide good and effective communication.<sup>23</sup> Healthcare teams would approach palliative care discussions by using active, deep listening, and face-to-face conversations without electronic devices such as on the phone, which is the critical point to improve effective communication.<sup>17,22</sup> The essential information about their children's care, that the parents received in the process of effective communication, might reduce parents' feeling of powerlessness and provide them with resilience to control their feelings of uncertainty during the palliative care for their children.<sup>17</sup>

#### Theme 6: Roles of actions: Parents act more than health care professionals

Parents were faced with the difficult decision between giving treatment or denying treatment to their child.<sup>3,17,19</sup> The roles in decision-making were mostly the domain of parents in both major and minor decisions.<sup>3,19</sup> Major decisions were made mostly by the health care professionals after discussion with parents of the children.<sup>3</sup> Parents stated that they wished the health care providers would always listen to them, bring them into every decision-making process.<sup>17</sup> Their children would be allowed to be involved in small decisions, because this was essential in building trust and strong relationships, making the palliative care trajectory to proceed easily.<sup>3</sup>

## Discussion

The main result in this review shows that there were six important themes: good information and understanding of palliative care, support by specialists in pediatric oncology, respect as a knowledgeable expert, psychological support to the parent and child, effective communication and roles of action. The overview of this review addresses the parental view of their children with cancer in a palliative care phase. The main focus on the views on specific care is that care provided is not only for their child but also the parent. For example, psychological support was provided to parents because of the stressful and distressing impact when facing a new treatment or invasive procedure for their child.<sup>20</sup>

Nurses and healthcare providers should be concerned with parental views on care, and find time to discuss their emotions, feelings, beliefs about their children's illness, and quality of life of their children. The components of disease information, prognosis, staging, treatment, procedures and special care for children with cancer<sup>3,17,19</sup> and understanding that good palliative care involved both physiological and psychological aspects provides their child with good quality of life and care. The services of palliative care in children cancer should improve the healthcare provider team's ability to meet the needs of parents and their children. This advanced knowledge and experience in pediatric palliative care, also enhances nurse-parent-children relationships. Moreover, the most important point is the involvement of parents, who are the main caregivers, in every process of palliative care, from the beginning of the disease and throughout the palliative care phase.

## Conclusion

This review demonstrated the parents' views and needs when it comes to palliative care when their children are diagnosed with cancer, as a life-threatening illness with life-limiting conditions. Most importantly, it is vital that health care professionals and nurses should understand parents' needs and provide special care for both pediatric patients and their parents. Parent centered or family centered care should drive the development of optimal models of pediatric palliative care for children and their families. The parents also needed to receive sufficient and good support from professional nurse and health care teams.

Most previous studies have focused on improving the training of health care professionals. A limited number of previous published studies reported training for affected children and their parents, and more research is needed. This area of future research may reveal key similarities and differences in parental views and needs. Further research may help to direct better palliative care for children and their parents during this very difficult time and to improve the quality of care and the quality of each family's life.

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