

Information Needs among Parents of Cancer Children: A Systematic Review

Ikeu Nurhidayah^{1,4}, Nani Nurhaeni², Isna Hanifah³, Allenidekania²

¹ Postgraduate Program, Faculty of Nursing, Universitas Indonesia, Depok, West Java Indonesia 16424

² Pediatric Nursing Department, Faculty of Nursing, Universitas Indonesia, Depok, West Java Indonesia 16424

³ Faculty of Nursing, Universitas Padjajaran, Bandung, West Java Indonesia 45363

⁴ Pediatric Nursing Department, Faculty of Nursing, Universitas Padjajaran, Bandung, West Java Indonesia 45363

✉Email: ikeu.nurhidayah@unpad.ac.id

ABSTRACT

Background: When a child is diagnosed with cancer, parents are affected, especially if they are unprepared and do not understand the illness. Parents' informational needs are frequently expressed and vary, so identifying parent needs is critical before providing health or nursing interventions. **Aims:** This review aimed to identify the information needs of parents of children with cancer. **Method:** PubMed, Medline, and CINAHL were applied to conduct electronic searches. The terms "information needs", "parent", "cancer", and "child" were combined using Boolean expressions "OR" and "AND". The inclusion criteria were non-experimental studies published in English within the last 10 years (2011-2021). Risk of bias assessment was conducted for each included study using the Joanna Bridge Institute critical appraisal tools. After identification and screening, the articles were filtered according to the criteria with a total of 15 articles included in this study. Furthermore, data extraction and synthesis were carried out. Narrative synthesis is used by collecting information on the findings of the article to be grouped into themes of finding problems. **Results:** Four themes emerged based on the results of the analysis: types of information needed; information formats; provision of information; and sources of information. **Conclusion:** This study concluded that parents require accurate information that addresses their specific information needs and is appropriate for their child's cancer stage. The provision of balanced written and verbal information, as well as information that is complete, accurate, and reliable, makes it easier for parents to increase their knowledge about caring for their children.

Keywords: Cancer, Children, Information needs, Parents.

INTRODUCTION

Almost every organ or tissue in the body can develop cancer, which is a group of diseases where abnormal cells grow out of control, attack nearby organs, and spread throughout the body (WHO, 2018). Cancer also attacks various age groups including infants, children, men, and adolescents. According to the World Health Organization (2021), it is estimated that 400,000 children and adolescents aged 0-19 years are diagnosed with cancer each year.

There is a need for psychosocial services for parents and caregivers because studies show that families are impacted by the illnesses that children suffer from (Kearney, Salley and Muriel,

2015; Brand, Wolfe and Samsel, 2017). Depending on how serious the condition is, different families of children with cancer have different needs. Families worry that their children won't be able to get well. Parents talk about how their child's diagnosis and treatment have caused stress in their lives (Kerr *et al.*, 2007). As a result, providing the right kind of supportive care to parents is critical in helping them cope with the stresses associated with their children's cancer diagnosis and treatment (Kerr *et al.*, 2007).

Supportive care is defined as the provision of health care needs for patients in seven need domains, which include information needs, practical, spiritual, psychological, social, emotional, and

physical needs during the prediagnostic period, diagnostic period, treatment period, and follow-up period, which includes survivorship, palliative, and bereavement care (Pelentsov, Laws and Esterman, 2015). Information needs have been identified as a generally unmet need for supportive care for patients living with cancer including pediatric cancer patients, friends, and family (Thiessen *et al.*, 2020).

Parents of cancer children have a fundamental need for knowledge to manage the psychosocial effects of their child's illness, to be aware of condition progression, and to comprehend the care provided to their children (Brand, Wolfe and Samsel, 2017). Child care and knowledge are essential in facilitating child care (Motlagh, Mirzaei-Alavijeh and Hosseini, 2019). Knowing the diagnosis, course of treatment, and potential complications can help parents feel more at ease, less anxious, and possess self-control (Motlagh, Mirzaei-Alavijeh and Hosseini, 2019).

Parents or other family members may have different preferences about the amount of information they want to hear. Most parents want a clear and simple explanation of the diagnosis and prediction of the child's future; as well as some advice on what to do next. Parents also want the opportunity to ask questions and nurses are expected to be warm and sympathetic listeners (Hockenberry, Wilson & Rodgers, 2017). While still paying attention to the psychosocial needs of the parents, it can be difficult for nurses and other health care professionals to continue to enrich references and adjust information needs for each parent at every phase and stage of the disease. Therefore, healthcare providers must be aware of the information needs of parents. The purpose of this study is to determine the informational needs of parents of cancer patients.

METHODS

This systematic review used narrative analysis. Narrative synthesis examined various issues on a specific topic by identifying, analyzing, and interpreting the body of knowledge into particular themes (Coughlan & Cronin, 2017). This approach is used to identify

the information need of childhood cancer parents. Coughlan and Cronin's (2017) steps are adapted for the review. The primary objective of this review was to answer the research question: how is parents' informational need related to cancer children?

The electronic search strategy was carried out by the first and third authors. An extensive search was conducted using index terms and keywords across three databases: PubMed, Medline, and Cumulative Index to Nursing and Allied Health (CINAHL). Multiple databases were chosen to reduce bias in study results and to broaden the scope of article searches. These three databases were chosen to expand search coverage of articles related to information needs in health settings, particularly those related to pediatric oncology. PubMed was chosen because it is a platform with over 34 million references, whereas MedLine is the largest biomedical literature database and CINAHL is a database with articles about nursing and allied health. This is also in line with the recommendations of Bramer *et al.*, 2017 dan Gusenbauer & Haddaway (2020) who stated that several databases, including PubMed, Medline, and CINAHL, are recommended for conducting systematic reviews in the field of health and nursing. An initial search on PubMed combined the main concepts from the research aims: ("child" OR "p*ediatric") AND ("parent") AND ("cancer") AND ("information* needs"). Each database's keyword truncation was done individually. The search was conducted for three months, between March to June 2021. The initial search for articles published in English with no year limit to obtain a thorough study.

The articles that met the study's inclusion criteria were written in English and related to the aims of this study, non-experimental studies (quantitative, qualitative, and mix-methods approach) were chosen. Types of childhood cancer and children's age are not limited. Only literature published between 2010 and 2021 was considered. Articles that did not have a full-text, secondary study, an experimental study, and did not explain the parents' perspective were eliminated. Importing articles and deleting duplicates were done with the

reference manager. The title and abstract were then independently reviewed by the first three authors. The complete text of the shortlisted articles was then checked against the inclusion and exclusion criteria. The Joanna Bridge Institute (JBI) appraisal tools for cross-sectional and qualitative studies were used in the quality appraisal. Any discrepancies in judgment are settled through discussion until an agreement is reached. The data extraction included the author, year of publication, country, aims, study design, sample size, instrument, and findings. Then narrative synthesis is used to analyze the findings into groups of themes.

RESULTS AND DISCUSSION

The search and screening process for studies is shown in Figure 1. Three databases provided articles from the year 2010 to 2021. After excluding duplicates 1.119 articles remained. Following the application of inclusion and exclusion criteria, 15 articles remained for quality assessment (4 articles were obtained from PubMed, 5 articles from Medline, and 6 articles from the CINAHL). The selected articles received a quality score above seven, so the study quality was acceptable.

Table 1 provided information about the characteristics of the included studies. Studies were conducted in Iran, Jordan, Indonesia, Turkey, Swedia, Switzerland, Ireland, Norway, South Africa, New Zealand, and the United States. By region, there was one study

from Southeast Asia, four studies from the Middle East, one study from Africa, one study from Oceania, five studies from Europe, and three studies from America. Seven studies employed quantitative design (cross-sectional), while eight used qualitative design. Eleven articles categorize the child's age based on the World Health Organization (WHO) age range (0-19 years), with several periods of the child's age beginning with newborns (0-1 years), children (2-10 years), and teenagers (11-19 years). Eleven studies included parent participants who had children with both solid tumors and hematological cancer, two studies involved parents of children with hematological cancer, one study involved parents of children with solid tumors, and one study did not provide information about the type of childhood cancer. Thirteen studies discussed information needs about childhood cancer in general, one study discussed nutrition information needs, and one study discussed parents' information needs about Complementary and Alternative Medicine (CAM).

Table 2 summarized the findings of the narrative synthesis from each study. Because it involved both qualitative and quantitative studies, the findings were written in narrative form. Based on the findings, there were four themes obtained related to the research question. The main theme that emerged from the findings were: 1) the types of information needs; 2) the format of information; 3) the provision of information; and 4) the source of information.

Table 1. The Information Needs of Parent.

Authors and Year	Findings
Motlagh et al., (2019)	Parents of leukemia children have the greatest need for information about medical care (60,06%) and physical care, specifically how to care for their child in pain (60,46%).
Vetsch et al., (2015)	Parents receive more types of verbal information than written information, even though written information is very important for parents to receive because verbal information is sometimes forgotten by parents. Health workers still do not fully provide complete information to parents regarding follow-up care and long-term effects (late effects). The type of information received by parents regarding information related to disease, treatment, and long-term effects is as follows: <ul style="list-style-type: none">Verbal information: disease (91%), treatment (88%), follow-up (85%), long-term effect (74.6%);Written information: disease (39.6%), treatment (45.5%), follow-up (27%), long-term effects (19%);No information: disease (2.6%), treatment (15%), follow-up (5.8%), long-term effects (16.9%).

Authors and Year	Findings
(Aziza, Wang and Huang, 2019).	Parents reported information needs are related to their child's condition, including the fear that their child's condition will deteriorate, unexpected recovery, a lack of support services, a poor prognosis, and the desire to receive the best medical care possible.
Arabiati & Altamimi (2013)	The most frequently reported information needs are the need to know when a side effect occurred (93.9%), what type of treatment the child received (93.9%), and the possible outcome of the child's disease (92.8%). The lowest level of need is for how to provide information to children (14%), followed by how to regulate children's emotions (24%).
Arpaci et al., (2018)	Parents' information needs regarding children's nutrition, including food-drug interactions (58%), food-disease interactions (52.2%), neutropenic diet (46.4%), food preparation (21.7%), and timing (when should a neutropenic diet be started) (25%). Parents report a lack of information and demand comprehensive and consistent information.
(Hovén et al., 2018)	Parents' information needs for long-term effects (late effects), access to psychological assistance, and follow-up care have not been met. Parents who received written information were more satisfied with ($x^2 = 33.81, p < .001$), it is found the information to be more useful than parents who did not receive written information ($x^2 = 23.69, p < .001$).
Kessel et al., (2013)	The three most important information needs of parents of children with cancer are discussing short-term side effects (98.4%), the first steps of treatment (96.8%), and the importance of the doctor explaining that parents do not cause the child's illness (90.3%). Parents also prefer a written information format (84%).
Maree et al., (2016)	Parents of children with cancer want to learn more about the disease and its causes and any information specific to their child's cancer.
Rodgers, et al. (2016)	Parents' ability to process information is influenced by their perceptions of how much and how quickly information is provided. Because of the large and rapid flow of information from health workers, parents find it difficult to process information during their child's diagnosis and discharge. Parents prefer information that is consistent and provided by the same information provider, or information that is uniformly provided.
Smith et al (2019)	Parents prefer a balance of verbal and written information formats. Parents prefer to receive information from health professionals gradually; they want to hear information about their child's diagnosis apart from their child; and they want their children to understand the information they communicate.
Stub et al., (2021)	A total of 46% of parents used Complementary and Alternative Medicine (CAM), although they stated that they did not receive information about CAM at the hospital and would appreciate it if a health professional worker did. The majority of parents (95%) want to know about the most recent evidence-based information on vitamins and supplements, as well as techniques to reduce chemotherapy side effects, boost the immune system, and fight cancer. Furthermore, parents want advice on how to help their families, cope with life, and reduce anxiety in their children and themselves.
Kastel et al., (2011)	According to the family's experience, there are many barriers to getting information from health professionals, including families believing that the time provided by health professionals for providing the information is sometimes insufficient; families must sometimes wait until the time of the next treatment/therapy to get answers to questions; it is difficult for the family to meet with the doctor; and sometimes the family believes that too much information is provided, causing the family to become confused.
Kilicarlan-toruner & Akgun-citak, (2013)	Parents seek information regarding their child's illness, prognosis, treatment, side effects, and challenges with care delivery.

Authors and Year	Findings
Coyne et al., (2016)	Parents expect open and honest communication when it comes to sharing information. When presenting information to families, healthcare workers must keep an open mind, be attentive to the information required, and take a flexible approach.
Aburn & Gott, (2014)	When their child is first diagnosed, some parents experience a lack of understanding regarding diagnosis and therapy because they are unable to assimilate the information resulting from a diagnosis that surprises and confuses them. Parents believe that the health education provided by health workers meets their needs to a large extent; they feel supported by staff and have the opportunity to ask questions at any time; however, there are some gaps in information regarding food safety and infection.

The Types of Information

According to the study's findings, there were two types of information needs (based on dimensions and the stage of children's cancer). Cognitive needs, affective needs, situational needs, social integration, personal integration, and hope are all characteristics of information needs among parents of cancer children, according to the dimension (Katz, Gurevitch & Haas; Tan, 1981; Miranda dan Tarapanoff, 2008; Yusup dan Subekti, 2010; Christina & Nuraeni, 2018). Parents must receive health education to address cognitive needs such as answering previously unknown questions, understanding their child's condition, and making the best decisions for their children. The findings of the included studies described a wide range of cognitive needs, such as the need for diagnosis, prognosis, treatment for pain, infection, long-term and short-term effects, follow-up care, nutritional needs, Complementary and Alternative Medicine (CAM) needs, and needs for mental problems in children and parents.

Parents also require information about affective needs. A qualitative study conducted by Stub et al. (2021) describes how parents require information to support their children and families, and specific strategies to reduce anxiety in children. Another study conducted in Indonesia by Aziza et al. (2019) depicts the need for situational needs. According to the study, parents believe in destiny and the power of God as a coping mechanism for anxiety and stress caused by a lack of information and their child's poor condition.

Aziza et al. (2019) described the need for information about social integration. That study concluded that parents need friends, relatives, and religion to cope with anxiety and

depression caused by a lack of information or education. Furthermore,

because Indonesia is a community-oriented country, parents require support and assistance from those around them (Aziza et al., 2019). All health workers must pay attention to meeting the social integration needs of parents by assisting them in remaining connected to their social environment. A qualitative study conducted by Stub et al. (2021) also demonstrates the need for hope. Some parents report that they require quality-of-life information to help their children. Parents express their hopes and expectations for their children's health. In this case, health professionals must provide full support to parents to remain optimistic about their child's condition's progress.

The information needs of parents of children with cancer vary depending on the child's stage of disease, which includes the diagnostic, treatment, and survival phases. During the diagnostic phase, parents are frequently taken aback by their child's diagnosis, necessitating detailed information on diagnosis, therapy, and side effects (Kilicarslan-toruner and Akgun-citak, 2013). They require information on how to manage the child's anxiety, how to care for the child's physical and nutritional needs, treatment complications, coping abilities, new treatment methods, and the child's prognosis during the treatment phase (Kilicarslan-toruner and Akgun-citak, 2013). Meanwhile, during the survivorship phase, parents need information on how to manage late effects, continuing education for their children, rehabilitation services, access to psychological services, and the need for follow-up (Hovén et al., 2018; Vetsch et al., 2015).

The Information Format

The majority of parents reported a lack of written information provided by health workers in four studies (Hovén et al., 2018; Kästel et al., 2011; Rodgers et al., 2016; Vetsch et al., 2015). According to Vetsch et al. (2015), parents primarily received verbal information from health practitioners and desired additional written information formats such as booklets. This is consistent with the findings of Rodgers et al., (2016), who discovered that parents prefer written information to ensure the consistency of information provided by multiple informants (health providers), particularly when it comes to providing drugs to their children. Aburn & Gott (2014) also explain parents' desire for a balance of verbal and written information formats. Health workers can provide more written material in the future because the written format can help parents recall the information provided by health workers. Written information is expected to strengthen the delivery of information verbally. Individual long-term follow-up plans, including a treatment summary, should be provided to each patient, preferably in written format, according to parents, who expect written information in the form of a simple booklet that can be carried anywhere (Hovén et al., 2018; Vetsch et al., 2015).

The Provision of Information

The method of providing information to parents must be tailored to their specific requirements. According to Coyne et al. (2016), parents expect health workers (informants) to be sensitive to what parents want and provide information openly and honestly based on family needs. Customized information using lay language and terminology can help parent process information more easily (Kilicarşlan-toruner and Akguncitak, 2013). Providing information tailored to the culture and beliefs of the family can also benefit parents (Aburn and Gott, 2014). Information should also be provided in a flexible manner, such as by adjusting the condition and time of parent and child (Coyne *et al.*, 2016). Several studies have found that some parents prefer to receive diagnosis or prognosis information separately from their children because their children are too young to understand the diagnosis or prognosis (Arabiat and Altamimi, 2013; Smith *et al.*, 2019). When providing

information, health workers must pay attention to the situation and location to respect parents' decisions about transferring information from health workers to their children.

When providing information to parents of children with cancer, health workers must pay more attention to the issue of time. Aziza et al., (2019); Kästel et al., (2011); Smith et al., (2019) believe that health workers spend too little time providing information. Parents prefer that information be provided gradually from the diagnosis phase to the survivorship period because they cannot process large amounts of information in a short period (Rodgers et al., 2016). Parents will be more likely to receive and retain information if it is delivered gradually, consistently, and uniformly to other health professionals (Rodgers *et al.*, 2016; Smith *et al.*, 2019). Nurses, like all other health professionals, must manage the timing and consistency of information. This is intended to ensure that information is only provided to parents when necessary, and that information provided to parents is not excessive or confusing.

The Source of Information

Health professionals (doctors, nurses, oncologists), relatives, friends, and the internet are all sources of information for parents of children with cancer. Despite rapid technological advancement, some parents rarely use the internet to obtain information about their child's condition. Parents, according to Vetsch et al. (2015), view the internet as a less trustworthy source of information. Moreover, Aburn and Gott (2014) discovered that parents are hesitant to use the internet as a source of information because they believe it is frightening and contains inaccurate information about children's cancer. The government and stakeholders must establish a credible online source that provides accurate and reliable information to parents.

CONCLUSION

The information needs of parents of cancer children will vary depending on their child's condition. The provision of information needs that parents desire refers to cognitive needs (knowledge about diagnosis, prognosis, care and

treatment, long-term effects, follow-up care, nutrition, complementary and alternative medicine, and mental health of parents and children); affective needs (how parents deal with anxiety, fear, and anger in their children); situational needs (information based on parents' beliefs about what is best for their children); personal and social integration needs (regarding self-esteem and reduce feelings of guilt) and hope. To meet the needs and preferences of cancer parents and children, information delivery must be able to adjust several aspects (how to provide information, sources of information, and information format). Nurses and other health workers must assist and facilitate parents in obtaining information based on their children's needs and conditions. Also, educators, nurses, and other health professionals must assess parents' information needs related to their condition.

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