INDONESIAN JOURNAL OF NURSING PRACTICES OPEN ACCESS Volume 8, Issue 1, June 2024, p. 56-67

Nurses' Perceptions of Pediatric Palliative Care with Cancer: A Qualitative Study

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Article Info
Online : http://journal.umy.ac.id/index.php/ijnp
ISSN : 2548 4249 (Print)
: 2548 592X (Online)
DOI :10.18196/ijnp.v8i1.19333

Article History
Received : 27 July 2023
Revised : 19 May 2024
Accepted : 04 June 2024

Abstract

Background: Pediatric palliative care (PPC) has seen significant progress in recent decades. Despite the improvements in care, nurses still feel anxious, fearful, and hesitant in providing PPC. More research efforts are needed to identify and explore nurses' perceptions of PPC in children with cancer.
Objective: The aim of this study was to explore nurses' perceptions of palliative care in children with cancer.
Methods: This study was a descriptive qualitative study. Participants were selected using purposive sampling involving eleven nurses in a public hospital in Bandung. Data were collected using semi-structured interviews and analyzed using thematic analysis method. The research was conducted from March to April 2023.
Results: This study identified four main themes and nineteen subthemes. The themes in this study are (1) Nurses' understanding of PPC, (2) Barriers to the implementation of PPC in children with cancer (3) Nurses' needs and expectations for PPC improvement, and (4) Roles and responsibilities of nurses in PPC.
Conclusions: This study explored the clinical reality of nurses providing PPC to children with cancer in one of the hospitals in Indonesia. The findings suggested that addressing these challenges could lead to significant improvements in pediatric palliative care practices in the hospital setting.

Keywords: cancer; nurse; pediatric palliative care; perception

INTRODUCTION

Pediatric Palliative Care (PPC) is defined as specialized medical care for children with serious illnesses, focusing on improving the quality of life for both the child and the family. It is a holistic approach that aims to prevent and alleviate physical, emotional, and spiritual suffering of children with serious illnesses, involving the prevention and relief of pain, symptoms, and stress (Benini et al., 2022; Sekse et al., 2018; WHO, 2018). The main goal of PPC is not to make patients recover, but to offer them the best possible health and quality of life regardless of their illness (Szabat, 2020; WHO, 2018).

PPC is implemented by a multidisciplinary team consisting of nurses, pediatricians, pharmacists, social workers, spiritual leaders, and psychologists (Marston et al., 2018; Weaver & Wichman, 2018). Nurses play a major role in PPC care teams by identifying symptoms and needs, distributing and managing care resources, supporting and advocating for patients, and educating patients and their family members (Larocque et al., 2017; Toqan et al., 2022). PPC's knowledge and skills among nurses will definitely affect the quality of care offered (Toqan et al., 2022; Weaver & Wichman, 2018). Nurses know limited principles and skills of pediatric palliative care (Fadare et al., 2014; Peng et al., 2017). Nurses expressed difficulties when dealing with situations related to the end of life and death of patients (Kang et al., 2022; Yu & Bang, 2015). Specifically, nurses have reported experiencing difficulties when dealing with end-of-life patients and the anger of patients' family members, communicating with end-of-life patients and their family members, and providing care with insufficient knowledge and resources (Kang et al., 2022).

(Georgadarellis et al., 2022) conducted a study that revealed a concerning lack of understanding among health professionals, including nurses, regarding the communication of information pertaining to the condition of children with cancer. Furthermore, nurses consistently express feelings of being ill-prepared, anxious, and overwhelmed when caring for patients with palliative care requirements (Devitt & Hara, 2021; Donohue et al., 2018). Understanding nurses' perceptions is crucial as it directly impacts their practice and the quality of care they provide to pediatric cancer patients. The way nurses perceive palliative care significantly influences their ability to effectively address the physical, emotional, and spiritual needs of these patients, which is vital for achieving optimal care outcomes (Ehibhatiomhan et al., 2022; Georgadarellis et al., 2022).

Limited research has been conducted on obstacles to PPC, with the majority of current studies relying on quantitative research approaches. Nevertheless, in order to gain a deeper comprehension of the contradictions present in PPC, like delays and lack of referrals despite its positive effects, qualitative research might be more suitable as it enables a more nuanced exploration of nurses' perspectives and reasons.

Therefore, the purpose of this study was to explore nurses' perceptions of palliative care in children with cancer in Kenanga Room 2 Hasan Sadikin Hospital, Bandung.

METHOD

This study used a descriptive qualitative design to obtain an overview of nurses' perceptions of PPC in Kenanga Room 2 of RSHS in Bandung. In selecting participants, the researcher was assisted by a research assistant, named the head of Kenanga 2 room. The research assistant helped select participants who fit the inclusion and exclusion criteria for the interview.

The participants were interviewed using a semi-structured approach, wherein the interview commenced with open-ended questions. The nature of the questions was subject to change, omission (if they were deemed irrelevant to the participants' perceptions), or the emergence of new questions, depending on the responses and the researcher's inquiry to enhance the depth of the description. The interview guidelines for this particular study were formulated based on the interview guidelines proposed by DeJonckheere and Vaughn in 2019. The interviews were conducted over a span of 7 days, involving a total of 11 participants. The duration of the interviews varied from 22 minutes to 58 minutes, with an average duration of 36 minutes. Throughout the interviews, the researcher utilized a voice recorder and field notes to document noteworthy observations, as well as verbal and non-verbal expressions that held significance during the interview process. All interviews were transcribed verbatim, encompassing the exact wording used by the participants, including any informal language styles and non-verbal expressions.

Then the data analysis process was carried out manually without the help of software and simultaneously with the data collection process. The researcher paid close attention to the participants' body language to be able to find important meanings. The data analysis used in this research is thematic analysis method. The reporting of this research is based on the Consolidated Criteria for Qualitative Research Reporting (COREQ) which consists of 32 items.

Sample and setting

In qualitative research, participants are selected who can inform the best of research questions and increase understanding of the phenomenon under study. This research used purposive sampling technique. The sampling technique was initiated by delineating certain characteristics of the intended participants based on the inclusion criteria, followed by the application of the exclusion criteria (Table 1).

Considering the data saturation process, eleven nurses were selected to be interviewed regarding their perceptions of PPC. The number of participants was determined when the data were saturated, where no further new information emerged in the code list. The decision was reached after engaging in discussions among the research team. Despite the attainment of data saturation at the ninth participant, an additional two participants were added to ensure the saturation of the data.

Table 1. Participants Inclusion and Exclusion Criteria

Inclusion criteria	1) Participants were nurses in the selected ward 2) Participants are in good health, have cognitive capacity and the ability to express themselves verbally, not in a condition that makes the interview process difficult. 3) Participants volunteered to participate in the study. 4) Participants filled out the informed consent.
Exclusion criteria	Participants do not speak Indonesian (can only speak local language).

Ethical acknowledgement

This study was ethically approved by Health Research Ethics Committee of Central General Hospital. Dr. Hasan Sadikin Bandung with the number LB.02.01/X.6.5/56/2023.

RESULT

This study involved eleven people. All the participants were female. The age ranged from 27 to 50 years old. A total of 3 people (27.3%) had the last education of Diploma (D3) in nursing and as many as 8 people (72.7%) had the last education of Nurse Profession Program (Ners). A total of 3 people (27.3%) had 20-30 years of clinical experience as a nurse, 4 people (36.3%) had 1-5 years of experience, and 4 people (36.3%) had 9-20 years of experience.

Table 2. The Characteristics of the respondents

No	Age (year)	Gender	Religion	Final education	Length of Service	Palliative Care Training
P1	46	Female	Islam	D3	27 years 7 months	No
P2	45	Female	Islam	Ners	22 years	No
P3	30	Female	Islam	Ners	4 years	No
P4	31	Female	Islam	D3	11 years	No
P5	28	Female	Islam	Ners	3 years	No
P6	36	Female	Islam	D3	14 years	No
P7	50	Female	Islam	Ners	30 years	No
P8	27	Female	Islam	Ners	5 years	No
P9	28	Female	Islam	Ners	4 years	No
P10	43	Female	Islam	Ners	17 years	No
P11	45	Female	Islam	Ners	9 years	No

Theme 1: Nurses' understanding of PPC

The initial theme that emerged was nurses' understanding of PPC, and four subthemes were identified: quality of PPC care, interdisciplinary approach, building communication and relationships, and scope of PPC practice. Nurses' grasp of the concept is crucial for the delivery of effective PPC care (De Clercq et al., 2019). When nurses have a deep understanding of PPC and recognize how different factors are interconnected, it improves their practice in caring for pediatric patients and their families.

Table 3. Theme 1: Nurses' understanding of PPC

No	Subthemes	Sample quotes
1	Quality of PPC care	"Alhamdulillah, it's good. The nurses here always try to establish trust and communication with patients and families (P2)." "Palliative care for children is already ongoing here, but it's still not maximized. We still focus on curative care, like medicine, infusions (P8)."
2	Interdisciplinary approach	"Palliative care in this room is carried out together, there are nurses and doctors too (P9)."
3	Building communication and relationships	"Nurses always try to establish trust and communication with patients and families, starting from the patient's admission, even though the patient and family are not referred to the palliative team (P2)."
4	Scope of PPC practice	"Palliative care is end-of-life care, so most of the patients treated here are in the final stage (P9)."

Theme 2: Difficulties in implementing PPC in children with cancer

There were four subthemes in theme 2, such as nurse factors, family factors, service system factors, and other health worker factors. The first subtheme was chosen because all participants agreed the same opinion that the lack of nurses compared to the number of patients made it difficult for them to provide PPC.

Table 4. Theme 2: Difficulties in implementing PPC in children with cancer

No	Subthemes	Sample quotes
1	Nurse factors	"The problem encountered is usually that we have too many patients. So we don't have enough time (P8)." "Well, the obstacle is that, the burden, the ratio between officers and patients is not balanced (P2)."
2	Family factors	"The family is difficult to communicate. The family is still in denial, so it's difficult to communicate, difficult to educate (P6)."
3	Service system factors	"There is no pediatric-specific palliative screening yet, because so far we are still using this (for adults) (P10)."
4	Other health worker factors	"Sometimes the patient can't do anything and then the palliative care (by the doctor) is too late (P4)." "Some doctors do not propose to the palliative team from the beginning, the consul is already close to dying so it is difficult to conduct an assessment (P11)."

Theme 3: Nurses' needs and expectations for PPC improvement

In the theme of nurses' needs and expectations for PPC improvement, six subthemes emerged, namely continuing education and training, PPC consultation teams, monitoring and evaluating the quality of care, balancing nurse-patient ratios, maintaining and improving quality of life, and integrating PPC in daily practice.

Table 5. Theme 3: Nurses' needs and expectations for PPC improvement

No	Subthemes	Sample quotes
1	Continuing education and training	"Besides that, we also need training about children, the stages of child development. Because each stage of child development is different (P6)."
2	PPC consultation teams	"We also need a pediatric palliative team, especially in the pediatric room so that the care continues (P3)."
3	Monitoring and evaluating the quality of care	"Then it is also evaluated whether it is correct or not (P8)."
4	Balancing nurse-patient ratios	"Palliative care is end-of-life care, so most of the patients treated here are in the final stage (P9)."
5	Maintaining and improving quality of life	"So what patients and families really need for palliative care is all fulfilled, and they feel satisfied with what we provide. We expect satisfaction and comfort from them (P2)."
6	Integrating PPC in daily practice	"It should be given (palliative care) from the beginning (of the diagnosis). Once diagnosed, palliative care should be given immediately, especially the parents because children usually follow their parents. According to the theory, it should be given from the beginning, I also experienced it myself, my brother (P1)."

Theme 4: Roles and responsibilities of nurses in PPC

There are six subthemes in this theme, namely: providing psychosocial support, providing spiritual support, effective communication, health promotion and education, discharge planning, and dying and post-death care.

Table 6. Theme 4: Roles and responsibilities of nurses in PPC

No	Subthemes	Sample quotes
1	Providing psychosocial support	"Support is provided from all aspects, from psychological, spiritual, knowledge (P2)"
2	Providing spiritual support	"Patients is dying definitely need palliative care, especially in communication, spiritual support (P1)."
3	Effective communication	"Don't use medical words, so use their language (P2)."
4	Health promotion and education	"Palliative care nurses can provide education to families (P4)."
5	Discharge planning	"The role of the nurse is to approach, then to the nursing aspect of course, related to patient responses, then related to preparation, especially the patient's family who decides to finally homecare or be treated at home (P11)."
6	Dying and post-death care	"This dying patient must be accompanied (P1)."

DISCUSSION

The participants expressed favorable opinions regarding the standard of palliative care (PPC) provided in their room, notwithstanding the belief of certain participants that the actual standard of PPC differed from the theoretical norms and necessitated enhancement. According to participants, the theoretical framework suggests that cancer patients should start receiving palliative care from the moment of diagnosis. However, in practice, palliative care is typically initiated only when the patient's condition deteriorates. Moreover, participants noted that pediatric palliative care is contingent upon the completion of screening by a physician. Nevertheless, there are still healthcare professionals who mistakenly perceive palliative care as solely applicable to patients in the terminal stages of illness. Counseling sessions are frequently conducted late in the disease trajectory and close to the time of death, whereas early involvement has been shown to alleviate patient suffering (Szymczak et al., 2018; Sawin et al., 2019).

The provision of pediatric palliative care at the time of diagnosis or treatment can significantly improve the quality of care. According to McNeil et al. (2023), participants have advocated for the prompt utilization of PPC services from the onset of diagnosis. Research conducted by Ho et al. (2018), Salins et al. (2022) and McNeil et al. (2023) highlights the significance of early incorporating PPC in the care of children with cancer in order to enhance the quality of life for both patients and their families. Moreover, the level of care provided is also contingent on nurses' comprehension of the theoretical and practical aspects of PPC. To address this, the implementation of the Pediatric Palliative Care Education Workplace Intervention has been proposed to enhance pediatric nurses' understanding and perception of palliative care. This intervention aims to equip nurses with the knowledge required to accurately define palliative care and to promote palliative care consultations, as evidenced by the study conducted by (James et al., 2022).

Studies have highlighted the significance of adopting a team-based approach in Pediatric Palliative Care (PPC). There are several studies showing that an interdisciplinary approach to PPC can improve the quality of care provided to children with life-threatening conditions and their families (Fields et al., 2023; Rico-Mena et al., 2023). This collaborative approach can lead to an improvement in health professionals' skills, confidence, and ability to handle personal grief, enhance their knowledge, attitudes, and competencies in PPC, and cater to the diverse needs of parents with children facing life-threatening conditions (Friedrichsdorf & Bruera, 2018; Weaver & Wichman, 2018; Cho-Hee et al., 2022).

Participants also reported that the palliative team provides consultation to children with cancer according to the screening results. With the existence of the palliative team, room nurses have an understanding that PPC is a team task so that participants do not see the need to practice PPC. But, in our findings, the hospital had a palliative team but no pediatric-specific palliative team. The hospital's palliative team consists of pediatricians, psychiatrists, psychologists, nurses, general practitioners, and medical rehabilitation doctors. Unfortunately, only one nurse from room Kenanga 2 was part of the hospital's palliative team. However, she could not be involved in this study because she was on leave.

Participants encountered challenges in establishing effective communication and fostering relationships with pediatric patients and their families. It was evident that participants had to invest significant effort and employ appropriate strategies to facilitate communication and build relationships in such circumstances. It was crucial for participants to adjust their communication style to align with the child's preferred mode of interaction. This necessitated a deep understanding of the child's developmental stage and growth milestones based on their age. Moreover, parents often grappled with denial or fear when confronted with the possibility of their child's mortality. This emotional response could manifest as reluctance to engage in discussions regarding prognosis, timelines, or coping with the uncertainties surrounding their child's health status. Consequently, parents might experience heightened levels of anxiety and fear due to the perceived lack of control over the situation. Therefore, participants were not only tasked with establishing rapport with pediatric patients but also with extending their communication and relationship-building efforts to include parents, siblings, and other family members (Akard et al., 2019; Cai et al., 2024).

The ability and perception of building relationships with pediatric patients and families can be influenced by participants' understanding of PPC, as highlighted in the studies conducted by (Beng et al., 2022) and (Bobillo-Perez et al., 2020). (Bobillo-Perez et al., 2020) propose a communication strategy for healthcare professionals to establish rapport with pediatric patients, which involves taking the time to understand their interests, hobbies, and preferences. By doing so, the child may feel more at ease and comfortable in the presence of the nurse. Additionally, nurses can effectively explain medical procedures and treatments in a manner that is easily comprehensible to the child. Allowing the child to ask questions and express their concerns is also crucial in fostering a trusting relationship. Moreover, communicating with the child using language appropriate for their level of understanding and addressing them by their first name can facilitate the development of trust with the child's parents, as suggested by (Hall & Nayar, 2014) and (Bobillo-Perez et al., 2020). The establishment of a strong relationship based on trust can significantly impact the quality of care provided to pediatric patients and their families. It can contribute to enhanced end-of-life care and foster trust among patients, families, and healthcare professionals involved in PPC (Sisk & Baker, 2019; Bobillo-Perez et al., 2020; Cho-Hee et al., 2022).

Many patients who should benefit from PPC services are not receiving them or are receiving them too late (Chong et al., 2020). Participants assume that PPC is care provided in the terminal phase, when patients are dying, or when curative treatments are no longer responding. Conceptual confusion has been identified as a significant obstacle in the effective implementation of PPC. Given the influential role nurses play in family decisions, this study offers unique insights into nurses understanding of PPC in children with cancer in the Kenanga 2 pediatric inpatient ward of RSHS.

The results showed that most participants recognized the importance of PPC and had a fairly good knowledge of its main principles and objectives. An interesting finding was that although they mentioned PPC as care to improve quality of life, participants insisted that, PPC is end-of-life care, best provided when curative treatment is no longer an option. Although most participants supported the principles of PPC, they still suggested providing training and continuing education to ward nurses as none of the participants had received specialized palliative training or education. In addition, disagreements can be resolved with guidelines for implementing PPC in clinical practice (De Clercq et al., 2019; Gott et al., 2013).

The untimely integration of PPC remains a concern at the operational level, resulting in conflict among team members. Participants believed that nurses were more proactive than doctors in encouraging PPC due to their daily contact with patients and families at the bedside. In addition, during palliative consultation, it is the nurses who often come. Nurses identified difficulties in providing care related to both caregiver and family factors. Nurses were well aware of the grief and emotional state of the family resulting in denial of the condition and death at the end of the child’s life. Equal pressure on nurses to balance the needs of the pediatric patient and the family resulted in a reluctance to disclose the news of the death. In addition, nurses also felt pressure in providing PPC due to the lack of nurses, nursing time and heavy workload. Previous research has also identified these issues (Haines et al., 2018; Ehrlich et al., 2020; Kang et al., 2022).

All participants unanimously agreed that the primary obstacle hindering the provision of optimal pediatric palliative care (PPC) is the insufficient number of nurses in hospitals, resulting in an overwhelming workload. To address this issue, one proposed solution is to establish partnerships with palliative care teams, thereby enabling the delivery of comprehensive care to pediatric cancer patients (C & K, 2016). Additional research suggests that adopting a family-centered care approach can effectively balance the healthcare system's requirements with those of the child and their family (Kokorelias et al., 2019; Salins et al., 2022). By implementing a family-centered care approach in pediatric palliative care, various benefits can be achieved, including improved communication, addressing physical, emotional, and spiritual needs, empowering families, reducing hospitalizations, enhancing patient outcomes, providing better family support, reducing healthcare costs, increasing healthcare provider satisfaction, fostering community support, and enhancing overall healthcare system efficiency (Margaretha et al., 2021). Furthermore, another study highlights the significance of enhancing working conditions, such as staffing levels and workload, to mitigate nurse turnover (Haines et al., 2018).

Participants reported that they perceived difficulties and had expectations for a solution to deal with these difficulties. Moreover, the barriers encountered by the participants also highlighted cultural taboos regarding death. Self-reflection of one's morals, values, and beliefs enables nurses to practice safely without becoming overwhelmed by the challenges of caring for dying patients and their families (Rost et al., 2020; Porter et al., 2021). However, nurses opinions and beliefs that it is taboo to discuss a patients poor prognosis with the family have been previously identified as a barrier to providing care (Kilcullen & Ireland, 2017; Rost et al., 2020; Porter et al., 2021). For nurses, perhaps developing self-reflection has the potential to encourage nurses to engage in discussions about aspects of care that conflict with their personal values, which in turn may help alleviate moral distress.

Family is identified as a key focus of PPC, presenting a significant challenge in the successful implementation of PPC initiatives (Rosenberg et al., 2019). Participants highlighted barriers associated with family factors, particularly in their interactions with patients and families from diverse cultural and religious backgrounds. Currently, there is a lack of research exploring how ethnic and religious minorities perceive and comprehend the concept of palliative care (De Clercq et al., 2019). Participants expressed difficulties in delivering PPC to patients and families with varying cultural and religious backgrounds, underscoring the communication challenges faced by nurses. The diverse values, beliefs, and customs across different cultures can influence how patients and families interpret and respond to healthcare services (Alsalamah et al., 2022). Nurses may encounter misunderstandings and confusion due to their unfamiliarity with these cultural differences, as evidenced in previous studies (De Clercq et al., 2019; Gu et al., 2022; Sommerbakk et al., 2016).

Cultural practices and spiritual beliefs play a fundamental role in the lives of many individuals, and delivering high-quality care necessitates healthcare providers to possess awareness and sensitivity towards these aspects (Weaver et al., 2016; Haines et al., 2018). The present study highlights the importance of establishing connections with the community in which the family resides, as well as the significance of cultural sensitivity in the provision of palliative care. Additionally, it reveals that families may reject the child's condition and prognosis, posing a challenge. (Eklund et al., 2018) reported that the Family Talk Intervention can effectively address these concerns and offer support. This intervention involves a structured dialogue between the healthcare team and the family, with the aim of enhancing the family's comprehension of the child's condition and prognosis, and encouraging their active involvement in the decision-making process.

CONCLUSION

This study described the clinical reality of nurses providing PPC to children with cancer in one hospital in Indonesia. This study can provide a better understanding of how nurses perceive palliative care in children with cancer. The nurses identified several components that influence the provision of PPC to pediatric patients with cancer. The findings of this study can help inform relevant initiatives and strategies to improve clinical nurses' performance and ability to deliver PPC care, so that the quality of PPC can be continuously improved in the future.

ACKNOWLEDGEMENT

The authors would like to thank their lecturers and colleagues for their contributions and support for the study. They are also grateful to all the reviewers who have provided their valuable input to the manuscript and helped finalize this paper.

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