

Research Article

Exploration of the Strategies of Iranian Nurses in Providing Palliative Care to Children with Cancer: A Qualitative Study

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Abstract

AIM: This study aimed to explain the strategies of Iranian nurses in providing palliative care to children with cancer.

METHOD: This study is a qualitative research with an approach to the conventional content analysis. The main participants were nine nurses working in ward pediatric oncology. Also based on data analysis, five parents of children, two children, one social worker, one physician, one psychologist, and one nutritionist were also included. Data were collected through semi-structured interviews and observation and were analyzed by the Elo and Kyngäs approach. Lincoln and Guba criteria were used for the trustworthiness of data analysis.

RESULTS: Three conceptual categories were developed with qualitative analysis: "prevention and relief of pain and physical symptoms", "spontaneous compassion", and "strengthen parental resilience"; that were derived from the main categories: "attention to precautionary considerations," "friendly relationship of nurses with parents of children, create enjoyable moments, spontaneous assistance," "facilitate coping with current situation, perceived confrontation with child death."

CONCLUSION: In this study, the results showed that nurses' strategies in providing palliative care to children with cancer were a combination of professional and spontaneous strategies.

Keywords: Children with cancer, Iran, nurses' strategies, palliative care, qualitative study

Introduction

Pediatric palliative oncology in the early stages of the disease in children with cancer integrates the principles of palliative care (Snaman et al., 2018). During palliative care of children with cancer, nurses are responsible for identifying symptoms, evaluating treatments, coordinating care, ensuring clear communication, developing realistic care goals, and ensuring that the patient, family, and other team members understand the prognosis, the strengthening of a hope sense, preparing the family for the possibility of child death, supporting, caring, and educating families (Docherty et al., 2012; Ogelby & Goldstein, 2014; Ranallo, 2017).

Nurses have an effective role in palliative care team. The results of a study showed that in nursing care, while paying attention to the effects of the pediatric cancer on family, cultural, spiritual, communication, ethical standards, and other issues such as cancer symptoms and treatment, the importance of hope and family mourning were considered (Foster et al., 2010). Nurses' understanding of the caring needs of children and parents' needs due to cancer disease, focusing on comfort and pain management, and appreciating the children and their parents'

spirituality had dominant roles in palliative care (Dos Santos et al., 2020).

The implementation of palliative care can depend on cultural factors (Mardani et al., 2015), and nurses' actions will be effective when they are appropriate to the socio-cultural context of each country (Gysels et al., 2012), given that exploring nurses' strategies helps identify child care deficiencies and try to address them, in this study too researchers wanted to know what nurses do to provide palliative care to children with cancer, in other words, the researchers wanted to explore the nurses' experiences in this issue and since experience cannot be explored in a quantitative method, another research method should be used. So, since the qualitative approach searches for the latent meaning beyond the participants' lived experiences (Campbell, 2014). We used a qualitative method to explore nurses' strategies for providing palliative care to children with cancer.

Research Questions

1. What were nurses' experiences in providing palliative care for children with cancer?

2. What strategies were used by nurses for providing palliative care to children with cancer?

Method

Study Design

The present study was a qualitative study of content analysis with a conventional approach (Hsieh & Shannon, 2005). The research environment was the pediatric oncology ward of a Referral hospital in Semnan.

Sample

Sampling was initially done purposefully, and participants at first were nurses. A nurse with more experience caring for children with cancer was selected as the key informant. Then, based on the data obtained from the analysis with children, parents, and other health care providers, individual interviews were conducted. Inclusion criteria included having the consent to participate in the study, the experience of caring for a child with cancer, and speaking Persian. Withdrawal or reluctance of the participants to participate in the study was considered as an exclusion criterion. Sampling is continued until data saturation (Holloway, 2005), that is, sampling continued until new data did not appear and category attributes were completed. Finally, with nine nurses, one social worker, one psychologist, one nutritionist, one doctor, two children, and five parents, sampling was completed.

Data Collection

Data were collected through observation (Gold, 1957; Vahedifard, 2010) and semi-structured, in-depth and individual interviews from December 2019 to 2021. The first four interviews were conducted in person at the participants' workplace and home but because of the coronavirus disease 2019 (COVID-19) pandemic conditions, interviews were not conducted in person and based on the convenience and desire of the participants, interviews were conducted at home or at their work place. The researcher first asked the warm-up questions about participants' personal information and then asked the main research question. The first interview began with a general question such as "can you explained me about your caring with a cancerous child?" Then, the after questions were designed according to the interview guide, and participant's speak. The interviews were recorded and then transcribed. Interviews lasted between 50 until 70 minutes.

Statistical Analysis

The Elo and Kyngäs approach was used to analyze the data (Elo & Kyngäs, 2008). The researcher transcribed the interviews into written text and then reads the text to understand what is happening. Then, the whole interview was considered as a unit of analysis. Words, sentences, and paragraphs were then considered as meaning units, and the meaning units were named according to their meaning by the code. After that, the codes were compared based on similarities and differences and classified as abstract categories. Finally, with deep reflection and constant comparison of categories with each other, the content hidden in the data was introduced as the main categories. To manage the data, the MAXQDA 2018 software was used.

Rigor of the Data

Lincoln and Guba criteria were used for the trustworthiness of data analysis (Lincoln & Guba, 1986). In this regards, techniques such as memo writing, immersing in the data, member-checking, and evaluation by a awareness person in qualitative analysis (peer-checking) were used.

Ethical Considerations

This study was approved by the ethics committee of Semnan University of Medical Sciences, Semnan, Iran (No: IR.SEMUMS.REC.1398.224). The aim of study was explained clearly to the participants. Informed consent was obtained voluntarily, as the participants can freely withdraw from the study. Also, the anonymity of the participants was considered strictly.

Results

Twenty participants participated in this study. Demographic information of the participants in this study is given in Table 1. Three conceptual categories were developed with qualitative analysis: "prevention and relief of pain and physical symptoms", "spontaneous compassion", and "strengthen parental resilience". These conceptual categories were derived from main categories and subcategories Table 2.

Prevention and Relief of Pain and Physical Symptoms

Due to unpleasant effects of cancer in the children, the nurses tried to provide strategies for relief of pain and physical symptoms. This main category included "management of the symptoms and effects of treatment" and "attention to precautionary considerations." With regard to the management of the symptoms, nurses used pharmacological and nonpharmacological methods, for example, the nurse said about pharmacological method: "If the children were in a lot of pain, we inject apotel" (P16: Nurse), and about the nonpharmacological method another said: "We calm them down more psychologically, we calm the environment for them" (P6: Nurse).

Also nurses for attention to precautionary considerations performed different strategies. For example, with regard to pay

Table 1.
Demographic Information of the Participants in This Study

Variable	Frequency (Percentage)
Sex	Female: 16 (80) Male: 4 (20)
Age (years)	Less than 18 years old: 2 (10) 18–30 years old: 5 (25) 30–40 years old: 9 (45) More than 40 years old: 4 (20)
Education	Student: 2 (10) Less than a bachelor: 4 (20) Bachelor: 9 (45) Master and more: 5 (25)
Work experience of health care providers	Less than 6 years: 9 (69.24) 6–12 years: 2 (15.38) 12–18 years: 2 (15.38)
The length of time the children were in palliative care	Less than 2 years: 1 (50) 2–4 years: 1 (50)

Table 2.
 Extracted Main, Generic, and Subcategories Based on Participants' Experiences

Conceptual Categories	Main Categories	Subcategories
Prevention and relief of pain and physical symptoms	Management of the symptoms and effects of treatment	Pharmacological relief Nonpharmacological relief
	Attention to precautionary considerations	Emphasis on immunodeficiency Pay attention to safety tips Emphasis on nutritional and care precautions
Spontaneous compassion	Friendly relationship of nurses with parents of children	Establish an emotional relationship Continuity of telephone communication Continuity of face-to-face communication
	Create enjoyable moments	Holding birthday for children Giving gifts to children Provide favorite foods for children
	Spontaneous assistance	Financial assistance Providing personal items for mothers Multitasking coordination for medication preparation
Strengthen parental resilience	Facilitate coping with current situation	Encourage communication with God Explain the nature of the disease Explanation of medications and their side effects
	Perceived confrontation with child death	Separation of the dying child from others in the ward Inform parents of the their child's impending death Facilitate parents and relatives' meeting with the child

attention to immunodeficiency issue, the nurse said that I say: "Wash your hands. Use gloves. Wear a mask. Do not meet anyone else. If someone has got a cold, do not visit the child at all. Do not take the child out" (P11: Nurse). A mother about pay attention to safety points mentioned that, the nurses told us that: "Raise the bed railings. Do not throw medicines in the blue bucket" (P9: Mother), also about the importance of nutrition precautions a nurse stated, "For their nutrition, we told them to disinfect the ingredients and wash the fruits well, not to use raw vegetables. For their nausea, we used to say, to use something cold, not to use things that make the gastrointestinal tract movements faster, stimulants—spices, these should be consumed less, fast food and those which have additives should not be consumed" (P14: Nurse), too regarding nurses' strategy to take care precautions, a child said: "they say be careful when you walk not to hit your head, do not injure your body" (P3: The child).

Spontaneous Compassion

Nurses out-of-duty did things that were more due to their sense of compassion toward children. This main category included "friendly relationship of nurses with parents of children," "creating enjoyable moments," and "spontaneous assistance."

The frequent hospitalizations of children inadvertently caused the nurses to have a friendly relationship with the children's parents; for example a mother said: "Now our relationship has become a state of friendship" (P9: Mother). This friendly relationship with parents was not limited to the time of the children's hospitalization; the continuity of communication was seen during the days when the children were at home or after their death by telephone and in person. In this regard, the nurse said: "The child who I said died I am still in connection with his mother. We are going out together" (P1: Nurse).

Because children are deprived of happy games due to illness, to improve the children's mood, the nurses tried to provide happy moments for them. In this regard, the nurses mentioned the following strategies: "We celebrate birthdays for children" (P5: Nurse) or "Sometimes we give presents to children apart from the birthday party" (P11: Nurse), even the nurses tried to make the children happy by satisfying their simple desires. For example, a mother said: "My boy tells the nurses I want an ice cream, they will buy it for him" (P7: Mother).

Spontaneous assistance was the nurses' another strategy. Since most of the families did not have good financial resources and it was difficult for them to buy drug and food, nurses helped families. A nurse in this regard stated: "We help a little financially. We have a group that announces, for example, what the children need and we raise money for them every month, whenever necessary, and give it to the family" (P5: Nurse). Also a mother said: "when my daughter had lost extremely weight due to chemotherapy complications such as anorexia, nausea and vomiting; we had to provide expensive nutritional supplements. Since we had not enough money, the our required costs were paid by the nurses" (P9: Mother).

Also, nurses sometimes provided personal items for mothers if needed. A nurse said: "I remembered a mother in ward, she had brought few clothes here, we for her bought clothes" (P11: Nurse). Another strategy that the nurses in this study did spontaneously and willingly was that they made extra-duty coordination to prepare children's medicine. In this regard, a nurse said: "I'm in contact with the nurses from other hospitals. I say if you have this medicine, I will send the patient and you give her your medicine. (P1: Nurse).

Strengthen Parental Resilience

These conceptual category was include two main categories of "facilitate coping with current situation" and "perceived confrontation with child's death". Nurses tried to facilitate parental adjustment to the current situation, or to prepare for imminent death of the child.

Reliance on religious capacities was one of the strategies of nurses to facilitate coping with current situation. A mother said: "Sometimes I would get nervous, I would wash, I would cry, someone would talk to me and tell me to say a prayer you'll be fine" (P16: Mother). The nurses believed that by explaining the disease to the child and their parents, they could better cope with the current situation, so the nurse said: "Usually, parents do not have information about the disease first we explain the disease to them" (P8: Nurse). Also, the nurses educated parents about medications' care, and managing the their potential side effects in order to enhance parents' knowledge for better coping with child's conditions. For example, the nurse said: "We were explaining about the medication to the mothers" (P11: Nurse) or a mother said: "They told us about the side effects of the medications" (P9: Mother).

When nurses felt that the child was near to die, they were gradually preparing the family for this phenomenon, in this regard a nurse said: "When the child is in near death, we explain to the family and when a child is on the imminent death, we do not keep him in the ward because of adverse influence on others" (P2: Nurse). Also meeting was without restriction for parents and relatives. For example, the nurse about this strategy said: "We had to reduce the strict limitations that allowed only the parents had to be in the room of the person who was dying" (P14: Nurse).

Discussion

This study aimed to explore the strategies of Iranian nurses in providing palliative care to children with cancer. The first main category this study included, "management of the symptoms and effects of treatment" and "attention to precautionary considerations." About management symptoms especially pain, different studies confirm this result for example Aghaei et al. (2021) mentioned the importance of focusing on reducing the physical suffering of cancer patients in palliative care (Aghaei et al., 2021). In another study, some nonpharmacological methods were used to control pain (Sabeti et al., 2021). However, more studies are still needed to pay more attention to the pain management of children by using nonpharmacological methods.

Attention to precautionary considers was another nurses' strategy. Nurses explained the health needs of the child to the parents so that they could take better care of the child. Borneman et al. (2015) mentioned the importance of education in palliative care for patients and family caregivers (Borneman et al., 2015) which can indicate the importance of this strategy of nurses. Habimana et al. (2019) stated that a standard educational program for cancer patients is accompanied with increase the knowledge of patients and satisfaction in patients and nurses (Habimana et al., 2019). So, it seems the enhancement of parents' knowledge to health needs of their child can lead to

acquiring the independence sense, and improving the child and parents' quality of life.

Spontaneous compassion as main category included "friendly relationship of nurses with parents of children," "create enjoyable moments," and "spontaneous assistance." About nurses' friendly relationship with parents, the nurses established friendly relationships with parents during discharge and even after the death of children. In this regard, a study showed that continued communication of healthcare professionals with parents who have lost their children by cancer was associated with positive consequences such as low levels of long-term grief (Van der Geest et al., 2014). Also, in Beutler et al.'s (2014) study, which dealt with parents' experiences of the actions of healthcare providers when their child died, five main themes were reported, which were staff perspectives and effects, follow-up care, continuous contact, communication, attention to parents and continuity of care (Butler et al., 2014). These findings were somewhat similar to the strategies taken in the present study for parents after the death of their child in the process of palliative care. The reason for this can be justified by the fact that these strategies were taken to help parents to better cope with the death of their child and condition after it, so that parents do not suffer from grief disorders and to continue their normal life.

Also sometimes, the nurses tried to keep the children happy and fun, for example with playing. In this regard, a study showed that one of the coping strategies of children with cancer undergoing chemotherapy was to engage in fun activities (Sposito et al., 2015). Also, Soares et al. (2014) conducted a study titled playing by nursing staff in palliative care for children with cancer. Their results showed that play enables children with cancer to integrate palliative care into the care they receive (Soares et al., 2014). In the present study, due to the small number of children with cancer, nurses had more time to play with the children and create happy moments for them, but may be in crowded hospitals with few nurses, there may be no time for nurses to play with children, that it can be a flick for the authorities to hire more nurses in order to have enough time to perform this useful and effective strategy in order to improve the quality of life of children.

Financial support was the most crucial help to the parents and was performed as spontaneous assistance by nurses. A study found that paying attention to the well-being of parents of children with life-limiting illnesses is essential. These parents are vulnerable to financial problems due to their child's illness (Koch & Jones, 2018) and this result can confirm the importance of nurses' strategy. The study of Williams-Reade et al. (2015) is somewhat similar to our finding because in their study, the importance of the role of nursing managers in meeting financial needs in palliative care for children was pointed out (Williams-Reade et al., 2015).

Strengthen parental resilience which included "facilitate coping with current situation" and "perceived confrontation with child death" was another strategy of nurses in this study. Spirituality is a basic necessity in providing high quality palliative care (Ferrell et al., 2013) and is a vital factor in cancer patients

facing with their disease and improving their quality of life from the diagnosis to death (Puchalski, 2012). Also in the palliative care service package in the NICU (2020), the importance of such things as inviting parents to be patient, praying for the sick baby, and being satisfied with fate was mentioned (Heidarzadeh et al., 2020). Although, based on this study, it can be said that the nurses' involvement in religious matters was considered part of the privacy of children and their families, and therefore they avoided getting into this issue too much. But considering the strong role of religion in improving the quality of life, it is felt that nurses need to receive the necessary training in this regard so that they can better meet the needs of children and their families in the field of religion.

Nurses also tried to improve the conditions for children and parents to cope with this phenomenon by explaining the disease, treatment, and related side effects at the beginning of the treatment period. In this regard, a study showed that coping in the early stages of cancer treatment in children and adolescents may be an important goal to increase the adaptation of these children (Compas et al., 2014). Another study suggested that children with cancer undergoing chemotherapy should be coped with a variety of conditions, including hospitalization and medications side effects (Sposito et al., 2015).

Perceived confrontation with child death was another category. Accordingly in the last days of life, nurses prepared parents to confrontation with their child's death by strategies such as informing parents about the imminent death of their child. In this regard, Lima et al. (2019) stated that to tell the bad news to parents in the palliative care unit, parents and specialists were in the same room and then, what happened were reviewed (Lima et al., 2020). Also in the last days of the child's life, meeting parents and relatives with the child was facilitated, in this case in a study, items such as limiting barriers to family visits with the dying child and the possibility of parents spending time with their child and preparing family for child death was mentioned (Johnston et al., 2020).

Study Limitations

The limitation of this study was that due to the COVID-19, some of the interviews were not conducted in face-to-face, and electronically assumed.

Conclusion and Recommendations

Nurses' strategies in providing palliative care to children with cancer were a combination of professional and spontaneous strategies. Also, Nurses is focused on the patients' comfortness. They try to eliminate pain until the children have been a qualified life. So, palliative care is needed to percept the child and parents' needs. However, It is suggested more studies to investigate or explore the nurses' and parents' challenges in palliative care process.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Semnan University of Medical Sciences, Semnan, Iran (IR.SEMUMS.REC.1398.224).

Informed Consent: Written informed consent was obtained from nurses, parents and children who participated in this study.

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