Original Article

Providing Ethical Care for Children with Cancer: Nurses' Perspectives

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Abstract

Background: Diagnosing a child with cancer is one of the most intense and challenging experiences that a family can face. Caring for children with cancer is one of the most challenging areas of the nursing profession, technically and emotionally, and nurses face various ethical issues in this regard. This study aims to explore nurses' perceptions of providing ethical care for children with cancer. **Materials and Methods:** This study applied a qualitative design and a purposive sampling method. Participants included 21 nurses with experience in caring for children with cancer. Data were collected using semi-structured interviews and analyzed using inductive content analysis. **Results:** Data analysis revealed three categories and seven subcategories. First, barriers to providing ethical care (subcategories: parents making decisions instead of the child, cultural misinterpretations, and reference to fortune-tellers). Second, facilitators of providing ethical care (subcategories: family hopefulness and parents' religious background). Third, approaches for providing ethical care (subcategories: the necessity of conducting research in the field of cultural backgrounds and the establishment of ethical-religious committees). **Conclusions:** This study presents some significant barriers, facilitators, and approaches to providing ethical care for children with cancer. These results are based on nurses' experiences and perceptions. All healthcare professionals can use our results to provide high-quality and ethical care for children with cancer.

Keywords: *Ethics, neoplasms, nursing care, pediatrics*

Introduction

Cancer is the second most common cause of death in children worldwide, and one percent of all cancers are diagnosed in children.[1] Each year, 300,000 children are diagnosed with cancer all over the world.[2] Although the survival rate of children with cancer has reached 80 percent in developed countries, annually, 80,000 children die of cancer worldwide.[3] In Iran, childhood cancer has a moderate prevalence. It is estimated at 48-141 cases per million people.[4]

Cancer is one of the most challenging and complex diseases regarding treatments and prognosis. This disease affects family life and brings them various social and economic challenges.[5] The survival rate of children with cancer has increased significantly since the 1970s. This increase in survival rate is due to ample advances in cancer treatments and nursing care.[6] However, cancer treatment and care pose various physical, psychological, and social challenges for children and their families.[7] Thus, diagnosing a child with cancer is one of the most challenging experiences that a family can face. In such a situation, family members may feel anger, guilt, denial, hopelessness, stress, and insecurity. So, it is vital to provide high-quality nursing care for children with cancer and their families.[8]

Indeed, nurses play a vital role in caring for and communicating with children with cancer.[9] However, caring for children with cancer is one of the most challenging areas of the nursing profession, both technically and emotionally.[10] In this regard, two significant issues affect the perceptions and attitudes of nurses regarding children with cancer: 1) the long-term and overwhelming process of caring for children with cancer and their families, and 2) confronting the ethical aspects and challenges of caring for these patients that affect their dignity and autonomy.[11] Nursing is an ethical profession. So, all nurses must follow ethical principles.[12]

It is important to note that nurses face various ethical issues and dilemmas in

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caring for children with cancer.[13] Nurses caring for children with cancer have reported these ethical issues most often: 1) Obtaining informed consent forms for starting or continuing treatment methods, 2) making decisions about the type of treatment or end-of-life care (if necessary), 3) confronting patients' suffering and pain, 4) being honest with children with patients and their families, and 5) communicating about breaking bad news.[14-16] These issues affect the quality of care and even the treatment success rate. Thus, identifying these ethical issues is crucial for improving the clinical and ethical performance of nurses.[11,17] The above content shows that providing high-quality nursing care for children with cancer is associated with various ethical issues and challenges that must be identified and addressed properly.

Studies on ethical issues experienced by nurses caring for children with cancer are limited, and their results are considerably inconsistent. For example, in a survey by Ventovaara *et al*. (2022),[18] ethical issues noted by nurses caring for children with cancer included how to communicate with children and family members about breaking bad news, shortage of time and personnel, and performing medical procedures against the will of children, however, in the study conducted by Baysal *et al*. (2019),[19] these ethical issues were different. They included making decisions about Do Not Resuscitate (DNR) orders and researching without informed consent from patients or their families. In another study by Pye *et al*. (2013),[20] nurses noted some important ethical issues in caring for children with cancer. These issues were: conflicts between patients, their family members, and healthcare professionals regarding patients' rights in making decisions about treatment options and communications between healthcare professionals.

It seems that nurses caring for children with cancer face various ethical issues in different situations. Possible causes of this difference and inconsistency of study results could be differences in healthcare systems, collaboration and communication between healthcare professionals, cultural and spiritual attitudes of healthcare professionals, children, and their family members, age and developmental stage of the child, and the hospital's management system. On the other hand, we found no study on nurses' perceptions regarding providing ethical care for children with cancer in Iran. Thus, considering that nurses in different countries and situations may experience different ethical issues, the present qualitative study was conducted to explore nurses' perceptions regarding providing ethical care for children with cancer.

Materials and Methods

This qualitative study started in May 2023 and applied the conventional content analysis method. Content analysis is a systematic method used to reach the depth and breadth of the description of the phenomenon. This method is suitable for examining people's experiences and attitudes towards a particular subject.[21]

Participants included nurses working in the Ayatollah Kashani Hospital oncology unit in Shahrekord, Iran. In Shahrekord City, there is only one oncology unit, and all oncology patients, including children, are referred to this ward. Inclusion criteria were: willingness to participate in the study, having at least a bachelor's degree in nursing, having at least six months of working experience in the oncology ward, and having expertise in providing care for children with cancer. It seems that six months of working experience can be enough to acquire proper insights regarding different aspects and issues related to the job (including ethical issues). However, as shown in Table 1, the least working experience of participants in this study was two years. The exclusion criteria were Unwillingness to continue participating in the study. Sampling was performed using the purposive method and continued until data saturation was reached.

Data were collected using in-depth, face-to-face, semi-structured interviews with participants. Before interviews, the study objectives, reasons for recording interviews, the voluntariness of participation in the study, and the confidentiality of the information and participants' identities were described for each participant. Also, permission to record interviews was obtained from all participants. Participants' demographic data were also evaluated. Participants were asked to choose their preferred

Table 1: Demographic characteristics of participants

Participant no	Age (years)	Gender	Education	Working experience (years)
P1	28	Female	Bs*	3
P2	34	Female	Bs	6
P3	44	Female	Bs	10
P4	27	Female	Bs	3
P5	48	Male	Msc**	16
P6	34	Female	Msc	5
P7	29	Female	Bs	2
P8	38	Female	Bs	5
P9	30	Female	Bs	4
P10	35	Female	Bs	5
P11	40	Female	Bs	8
P12	29	Female	Bs	3
P13	46	Female	Bs	9
P14	35	Female	Bs	7
P15	44	Female	Bs	11
P16	26	Male	Bs	2
P17	31	Female	Bs	4
P18	37	Female	Bs	5
P19	42	Female	Bs	9
P20	37	Female	Bs	6
P21	38	Female	Bs	9

*Bachelor's degree. **Master's degree

time and place for interviews. They all preferred the personnel restroom.

Interviews began with open questions and continued with probing questions about the desired phenomena [Table 2]. Interviews continued until the interviewer was sure she understood the concepts presented by participants. The duration of interviews varied between 45-90 minutes. All interviews were conducted by the same interviewer (H.H.). Interviews continued until reaching in-depth, reliable, and sufficient data. All interviews were recorded using an MP3 recorder. Each participant was interviewed once. There was no need to repeat the interview with any participant. Interviews were conducted in morning and evening shifts. Immediately after each interview, the researcher listened to the recording several times. Then, the interviews were transcribed word by word as soon as possible. By doing so, the interviewer obtained some insight and feedback for the next interviews and could decide about the adequacy of data and reaching data saturation. Data saturation was reached after 21 interviews.

Data analysis was performed using qualitative content analysis with an inductive approach. Inductive content analysis is useful for obtaining reliable and valid results from written data to develop new knowledge, insights, scientific facts, and clinical guidelines. Organizing qualitative data for inductive content analysis includes open coding, creating categories, and abstraction.[22] In the present study, analysis units included parts of the handwritten text of interviews related to the study's objectives. After choosing analysis units, data analysis started with repeatedly reading the texts, aiming at immersing in the data, and making sense of the data as a whole. In the open coding step, elementary ideas were extracted from the written text of interviews. Then, these ideas were listed. To do so, each interview text was read by the researcher word by word repeatedly, and then, all codes that were possibly related to study objectives were written at the margin of the texts as notes. After initial note-taking, the researcher listened to recorded interviews again to ensure no critical point was missed. Generally, the researcher listened to recorded interviews and read the written text of interviews repeatedly.

Table 2: Questions used in interviews

Question	Probing question
Could you please tell us about your experience working with cancer children and their parents?	Please explain more
What problems did you face during your care?	Please give me an example
What were the obstacles in providing ethical care?	Please explain more
Tell us about your most unpleasant experiences with ethical challenges.	Please explain more
What strategies do you suggest to improve ethical care in children with cancer?	Please give me more information

In the next step (categorization), extracted codes were classified and related subcategories based on their differences and similarities. The abstraction step was conducted after categorization and identifying relevant subcategories. Abstraction aims at formulating a general description of the research topic. For doing abstraction, each category was named using a content-characteristic word. Then, subcategories with similar concepts were grouped as categories and categories were grouped as main categories. Figure 1 presents the flowchart of the study process.

Four criteria are proposed for ensuring the reliability and validity of results obtained in qualitative studies, including credibility, dependability, confirmability, and transferability.[23] We applied these four criteria to achieve the trustworthiness of the results. To ensure credibility, we presented the obtained results to the participants and asked them to express their opinions regarding the concordance of our findings with their experiences and what they said in their interviews. To ensure the dependability of the results, faculty members of the nursing school who had expertise in qualitative research were asked to evaluate the data analysis process and the obtained results and tell whether they were accurate or not. Researchers kept all documents and data during all steps of the study process to ensure the confirmability of results. Also, evaluating the obtained results by academic faculty members improved confirmability. We applied the purposive sampling method, interviewed various participants, and used direct quotes and examples in interviews to ensure the transferability of the results.

Ethical consideration

This study is approved by the ethics committee of Shahrekord University of Medical Sciences, Shahrekord, Iran (ethics code: IR.SKUMS.REC.1402.020). All participants signed an informed consent form before participating in the study. Before any interview, the researcher (H.H.) described the study objectives, study protocol, voluntariness of participation in this study, and confidentiality of data (including participants' demographic data) to each participant. Each participant asked for permission to record the interviews.

Results

In total, 21 oncology nurses who had experience in providing care for children with cancer participated in this study; two of them were male, and 19 of them were female. Two participants had an MSc degree in nursing, and the rest had a bachelor's degree in nursing. Table 1 presents the demographic characteristics of the participants.

After analyzing qualitative data, 689 codes were extracted, which were categorized into three categories and seven subcategories. These categories included barriers to providing ethical care (with three subcategories:

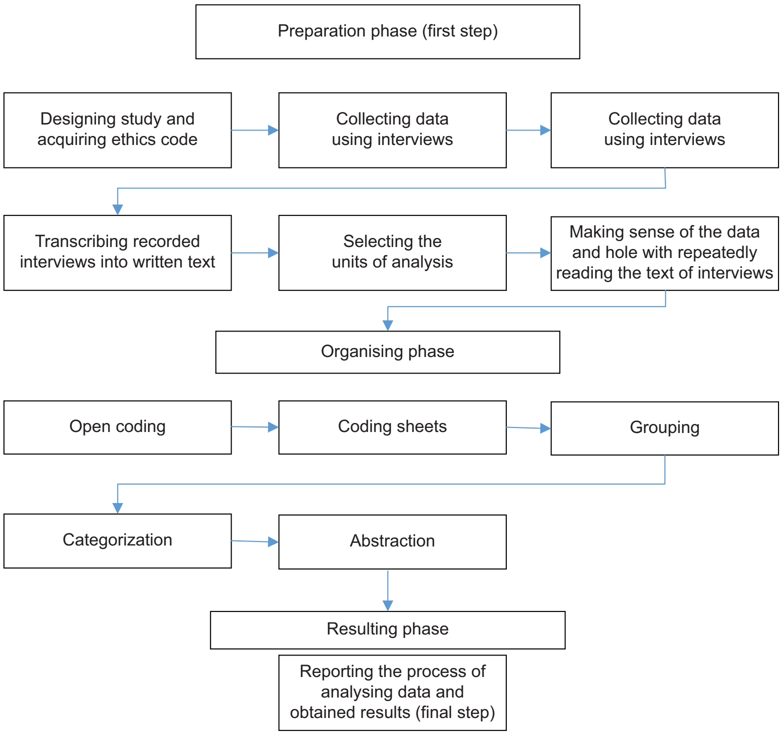

Figure 1: Study flowchart

parents making decisions instead of the child, cultural misinterpretations, and reference to fortune tellers), facilitators of providing ethical care (with two subcategories: family hopefulness and parents' religious background), and approaches for improving ethical care (with two subcategories: the necessity of conducting research in the field of cultural backgrounds and organization of ethical-religious committees). These categories and subcategories are shown in Figure 2 and described below.

Category 1: Barriers to providing ethical care

This category included three subcategories: parents' refusal to start necessary treatments for their child, cultural misinterpretations, and reference to fortune-tellers.

Analysis of nurses' statements showed that some parents deny their child's disease. In such situations, parents may refuse to start required treatments. Denying the child's disease and delaying treatments can lead to disease progression or even the child's death. Generally, nurses stated that ignoring the children's rights to receive necessary treatments from their parents could cause significant distress to other family members and healthcare professionals.

A nurse said: "*A 14-year-old boy was hospitalized with neck lymphadenopathy. His father said my son has no cancer; he has consumed cortone and is much better now. All nurses said this is because of cortone drugs, but he didn't accept and discharged his son with his consent. Later, the disease metastasized, and they came back with a terrible condition. The oncologist prescribed chemotherapy, but the child's father refused that. The patient said to us, please do chemotherapy for me, for God's sake; I don't want to die……. The patient died after a while*" [N14].

The results of this study showed that cultural misinterpretation is another barrier to providing ethical care for children with cancer. In this regard, some families may think that a child's cancer is due to their sins and faults during life; they also may relate a child's cancer to their lack of faith. Sometimes, relatives and friends also have such attitudes.

A nurse said: *"One parent was crying and said I think I have lost my faith or committed a sin, and this (disease) is the sequel of my sins"* [N3].

Another participant stated: *"Other people think the same and say the child's cancer is because of their parents' sins. This misunderstanding is annoying and makes me distressed and confused"* [N1].

Most participating nurses stated that some parents refer to a fortune-teller to gain hope for their child's disease and seek cures. Parents facing the most complex and challenging life situation (diagnosing their child with cancer) experience considerable frustration and disappointment. They may see a fortune-teller instead of oncologists, hoping that the fortune-teller can cure their child in a transcendence and supernatural manner. Fortune-tellers often inspire parents with delusive hope, and this can lead to delayed treatments and progression of the cancer.

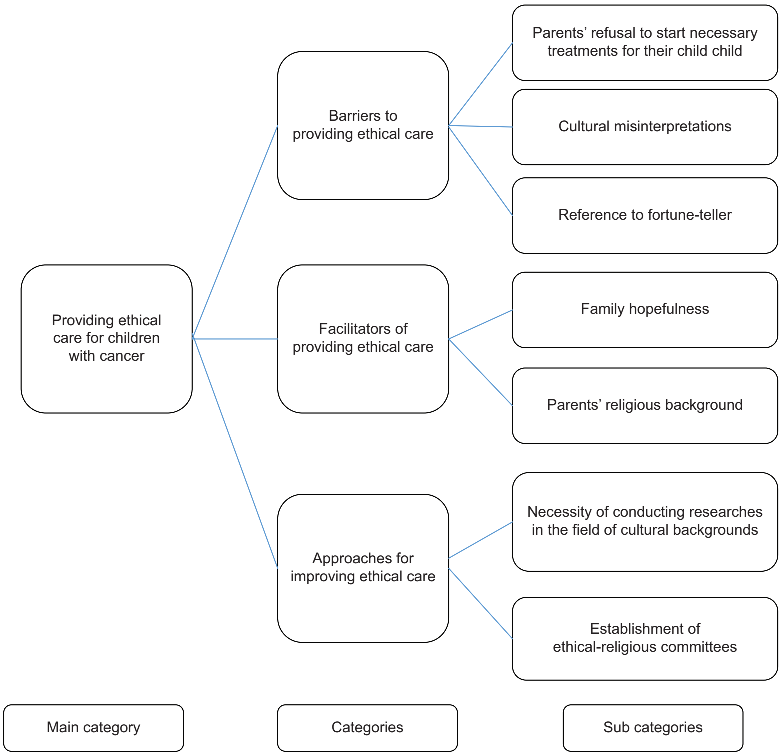

Figure 2: Categories and subcategories extracted from data analysis

A nurse said: *"I saw parents whose oncologist told them their child has cancer, but they visited a fortune-teller instead of starting necessary treatments. The fortune-teller gave them a handwritten prayer and said to place that beside the patient, and it would cure the child's disease. The child's parents became hopeful and didn't start treatments. After a while, the child's condition got worse, and the cancer was metastatic"* [N19].

Another participant said: *"…These actions (referring to fortune-tellers) cause harm to the child; what sin has the poor child committed?"* [N7].

Category 2: Facilitators of providing ethical care

This category had two subcategories: family hopefulness and parents' religious background. Nurses' statements showed it is easier to care for hopeful families. Their hopefulness facilitates the process of anti-cancer therapies and related care, as they seek treatments and follow their child's condition carefully. Furthermore, a strong religious background increases family hopefulness and is another facilitator of providing ethical care for children with cancer.

In this regard, a nurse stated: "From communications with hopeful families and evaluation of the process of their child's treatments, I have realized that they encourage their child and follow the treatment process carefully and repeatedly."

One participant stated that: *"During several years of working in the oncology unit, I have realized that religious families are more hopeful. They have faith in God and seek treatments with reliance and trust in God."* [N11].

Another nurse said: *"If we make disappointed families hopeful and even improve their religious attitudes, they can better tolerate the child's difficult treatment process"* [N2].

Category 3: Approaches for improving ethical care

This category had two subcategories: the necessity of conducting research in the field of cultural backgrounds and the establishment of ethical-religious committees.

Healthcare professionals face various ethical challenges in caring for children with cancer because these children are considered unable to make decisions about their health. Thus, their parents make all essential treatment decisions. In our country, Iran, many important decisions, such as cancer treatments, are made based on religious (Islamic) beliefs. This may be challenging for families and healthcare professionals who are not aware of the religious principles regarding the specific situation. In this regard, conducting research in the field of the cultural and religious background of society and developing guidelines for providing ethical care for children with cancer based on research results seems crucial. Furthermore, it is recommended that ethical and religious committees be established in medical centers. Such committees can support families and healthcare professionals in making ethical decisions. They can also develop regional guidelines.

A nurse said: *"A child with cancer was hospitalized in our ward and was under mechanical ventilation. There was no hope for successful treatment or recovery. We had a shortage of ventilators, and another patient needed* *mechanical ventilation. On the one hand, there are no specific instructions or guidelines for such situations. On the other hand, the child's parents stated that life and death are in God's hands, and discontinuing treatments means interference in God's work and discretion. We healthcare professionals were unable to react to this attitude because we didn't know what to say or what to do."* [N20].

Similarly, another nurse stated: *"Of course, there are several issues related to providing ethical care for children with cancer that are left unanswered…"*[N8, N1]

Other participants have stated that: *"only we, the nurses who care for children with cancer, can understand what difficult ethical challenges we face every day"* [N2] *and "If there were specialized committees in each hospital that provide ethical and religious consultation, it could be very helpful. Even we, the nurses, could benefit from the opinions of specialists in the field of ethical and religious issues and make the best possible decisions"* [N6].

Discussion

We explored nurses' perceptions regarding providing ethical care for children with cancer. Three categories were extracted from nurses' statements: barriers to providing ethical care, facilitators of providing ethical care, and approaches for improving ethical care.

Parents' refusal to start necessary treatments for their children is one barrier to providing ethical care for children with cancer. Delegating decision-making authority exclusively to parents may lead to delays in starting treatments, progression of the disease, and even child death. This is inconsistent with the authority and beneficence principles of bioethics. On the other hand, in challenging situations, like diagnosing a child with cancer, an important question arises: Do the child's parents have the ability and authority to be the sole decision-makers?

The process of decision-making by parents of children with cancer and influencing factors has been evaluated in some research. In a qualitative study by Bartholdson *et al*. (2015),[7] nurses providing care for children with cancer reported that parents play a crucial role in deciding about starting or terminating treatments and care in the present and future. They stated that conflicting attitudes between healthcare professionals and parents can create ethically challenging situations. The study has reported deciding on treatment levels for children with cancer as an ethical problem, which is similar to our results. Salvador *et al*. (2020)[24] evaluated the preferences of parents of children with cancer regarding their role in treatment decision-making. Results of their study revealed that 45/2% of parents preferred a passive collaborative role (physicians making the final decision after the parent's input), 27/2% preferred a collaborative role (parent and physician sharing the decision), 21% preferred a passive role (physician alone making the final decision), and 6/6% preferred an active collaborative role (parent making the final decision after physician's input). None of the participants preferred an active role (parent alone making the final decision). These results show that many parents of children with cancer don't prefer to be the final decision-maker and need information, instruction, and collaboration with healthcare professionals to make decisions in such challenging situations. In another qualitative study by Alahmad *et al*.,[11] nurses providing care for children with cancer reported decision-making and consenting in pediatric cancer as an ethical challenge. These participants stated that decisions should be made through a collaboration between healthcare professionals, parents, and children.

Based on the above-mentioned content, it can be said that making decisions about necessary treatments for children with cancer is extremely challenging. As study results demonstrate, many parents of children with cancer don't want to be, and should not be, considered the exclusive and final decision-makers in such difficult situations.

Cultural misinterpretations and reference to fortune-tellers were other barriers to providing ethical care for children with cancer from the nurses' perspective. Banerjee *et al*.[25] conducted a qualitative study and evaluated the cultural beliefs and coping strategies of Asian immigrant parents of children with cancer in Canada. Participants in this study reported four fundamental cultural beliefs related to childhood cancer: childhood cancer is rare, cancer is incurable, cancer is unspeakable, and cancer is understood through religion. Some participants in this study questioned whether their child's cancer was a consequence of their own or their child's mistakes in the past or present. Some other parents felt that God was not happy with them or that cancer was a form of punishment or a message from God. Cultural factors affecting treatment and care processes in childhood cancer were evaluated in a study by Walubita *et al*.[26] in Zambia. Results of that study showed that some cultural beliefs, such as "childhood cancer is a result of witchcraft," affected treatment seeking by parents of children with cancer. Due to these beliefs, some parents were not willing to place their children on chemotherapy and preferred various forms of traditional medicine systems, such as indigenous herbalism. Another cultural issue was the belief that performing a series of healing prayers would cure the disease completely. In another qualitative study by Yeh *et al*.,[27] parents of children with cancer reported that they had related their child's cancer to their past sins and had consulted with fortune-tellers about the possible explanation of illness causes. These participants also reported that fortune-tellers and diviners had related the child's cancer to flaws in the parents' character or the day and time of the child's birth. Naidoo *et al*.[28] conducted a qualitative study and evaluated African mothers' perspectives about having a child with cancer. Participants in this study stated that it is believed in their community that children's cancer is due to the ill will or the curse of an ancestor. These participants had consulted with traditional healers before seeking appropriate medical care and treatments because of their traditional belief systems.

The above results show that various and particular cultural attitudes and beliefs in different countries can affect treatment-seeking behaviors in parents of children with cancer. Thus, nurses and other healthcare professionals need to evaluate and be aware of cultural beliefs or misunderstandings of families with a child who has cancer.

Participants in our study stated two important facilitators of providing ethical care for children with cancer: family hopefulness and parents' religious background. Hope is a fundamental resource for humans. It can affect health and well-being in different life situations. Being hopeful and having trust in God have been identified as essential coping strategies used by parents of children with cancer.[29] On the other hand, religion is an essential factor for many people, especially when confronting severe diseases. Religion can also act as a positive coping mechanism.[30] However, it is important to note that the influences of religious attitudes are mainly culture-specific and may be various in different cultures.[31]

The role of parental hope and religious background in caring for children with cancer has been evaluated in some studies. For example, Conway *et al*.[29] evaluated parents' experience of hope when their child has cancer. Participants in that study defined hope as "being optimistic regarding a child's health," "knowing that everything will be ok," and the "belief that God has a plan." About 90% of these parents considered hope as an important or very important factor in coping with their child's disease. In another qualitative study, Moridi *et al*.[32] evaluated parents' experiences regarding pediatric cancer in Iran. One of the main themes that emerged in this study was horror and hope, with subthemes of hope for God's mercy and trust and faith in absolute divine power. These participants also stated that parental hope could strengthen the child's morale to continue treatments. In their cross-sectional study in Iran, Fathollah Zade *et al*.[33] reported that the total score of hope was positively correlated with spirituality among mothers of children with cancer. In the qualitative study conducted by Stewart *et al*.,[34] one of the strategies that parents of children with cancer used for making the right decisions was relying on their faith. Participants in this study stated that they had used strategies such as praying for guidance and putting their child's life into God's hands to be relieved of some of the burdens of decision-making. Bozkurt *et al*.[35] evaluated the relationship between coping strategies, religious attitudes, and optimism among mothers of children with cancer in Turkey. The results of this cross-sectional study revealed that mothers with higher religious attitudes had better social support and were more optimistic about their children's treatments and health status. Results of a qualitative research by Abdoljabbari *et al*.[36] in Iran showed that parents of children with cancer believed performing religious activities is a helpful means for achieving composure, being hopeful in the future, and tolerating hardships and critical conditions related to their child's cancer.

It can be said that family hopefulness and family religious background are two essential and interrelated factors that can help children with cancer and their families cope efficiently with challenges and difficulties related to the disease and its treatments. Healthcare professionals can improve the hopefulness of parents of children with cancer with measures such as providing information regarding treatment and disease prognosis, collaborative decision-making, providing emotional and social support, establishing good communication with children and their families, etc.

Participants in our study introduced two approaches for improving ethical care for children with cancer. The first approach was the necessity of conducting research in the field of cultural backgrounds. As mentioned before, cultural beliefs and misunderstandings have considerable effects on the process of treatment and care provided for children with cancer. Future research can be conducted to evaluate different cultural backgrounds and their influences on pediatric cancer care, and develop relevant guidelines to improve clinical practices in the field of pediatric oncology.

The second introduced approach was the establishment of ethical-religious committees. In this regard, Bartholdson *et al*.[37] conducted a cross-sectional study to evaluate healthcare professionals' opinions regarding participation in ethics discussions in pediatric oncology settings. Nurses and physicians who participated in their study reported that participation in ethics discussion is related to perceptions of greater involvement, the possibility to influence decisions, and greater responsibility for making ethical decisions regarding patient care. These participants viewed interdisciplinary ethics discussions as very helpful when confronting ethical issues in the care of children with cancer. Based on these results, it can be proposed that healthcare centers hold decision-making committees on a regular basis and with the participation of physicians, nurses, patient, and their family members, as well as experts in the fields of bioethics and religious doctrines. Such committees can guide healthcare professionals and parents of children with cancer in making the best possible decisions regarding treatment and the process of care.

One limitation of this study is the limited generalizability of the results. We evaluated Iranian nurses' experiences and perceptions of ethical care for children with cancer; thus, our results are highly relevant to the cultural and religious background of Iranian society. Therefore, these results may not be generalized to various cultural and religious institutions worldwide. In addition, we only explored the experiences of nurses who care for children with cancer, and the experiences of other stakeholders such as physicians, parents of children, and other healthcare professionals were not evaluated in this study. However, exploring the experiences of all these stakeholders in a single study may be associated with methodological issues and diverse results that may not be conclusive.

Conclusion

Three categories and seven subcategories emerged after analyzing nurses' statements regarding ethical care for children with cancer. These three categories included barriers to providing ethical care, facilitators of providing ethical care, and approaches for providing ethical care. Since nurses and all other healthcare professionals, as well as family members, experience various challenges in caring for children with cancer, our results can guide them in the process of decision-making for their patients. Furthermore, each of these categories and even subcategories can be evaluated in separate studies to attain a better understanding of them and develop evidence-based guidelines to improve clinical practices and the quality of nursing care.

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Conflicts of interest

Nothing to declare.

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