



# Unmet Needs of Palliative Care Among Iranian Children with Cancer and Their Families: A Qualitative Study

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## Abstract

**Background:** Palliative care is one of the primary rights of children with cancer and their families. Identifying the unmet needs of palliative care for these children is important in providing high-quality care.

**Objectives:** The present study aimed to explore the perception of formal and informal caregivers about the unmet palliative care needs of children with cancer and their families.

**Methods:** This qualitative study was conducted from October 1, 2020, to May 15, 2021, in one of the children's hospitals in Rasht (Northern Iran). This study enrolled 25 caregivers (nurses, doctors, grandmothers, sisters, aunts, neighbors, and parents of children with cancer) and 5 children with cancer, who met the inclusion criteria by purposeful sampling to participate in in-depth and semi-structured interviews. The interviews continued until data saturation. A directed content analysis was performed according to the Elo and Kyngas proposed approach and based on the National Consensus Project (NCP) framework. The findings were managed by MAXQDA2020 software. Guba and Lincoln criteria were used to ensure the trustworthiness of the data.

**Results:** The average age of the participants was  $32.40 \pm 1.4$  years, and 1,450 codes were extracted. The extracted theme was "the need for holistic care", which included 7 main categories such as "the structure and process of care", "physical aspects of care", "psychological aspects of care", "social aspects of care", "cultural aspects of care", "care of the patient nearing the end of life", and "spiritual, religious, and existential aspects of care", and 23 subcategories.

**Conclusions:** Children with cancer and their families have many physical, psychological, spiritual, and social needs. To meet these needs, it is suggested to provide the necessary infrastructure for palliative care, strive for justice in access to palliative care services for children with cancer and their families, empower caregivers, form an interdisciplinary team, and promote cultural awareness regarding cancer and end-of-life care.

**Keywords:** Unmet Need, Palliative Care, Cancer, Children, Caregiver, Iran

## 1. Background

Cancer is a debilitating and life-threatening disease that affects children and their families (1). Although the prevalence of cancer is lower in children than in adults, it is the second leading cause of death in children under 14 years of age in Iran. Considering the growing trend of the young population and the high mortality caused by cancer in children in Iran, it is crucial to prioritize the needs of this group within the Iranian healthcare system (2).

As cancer is a chronic condition, affected children and their families have extensive needs such as physical support, psychological support, communication, empathy, knowledge improvement, self-care promotion, and financial support (3, 4). Since cancer has a long-lasting impact on the lives of both the child and their family, it is crucial to provide them with comprehensive and long-term care. This care should include palliative and supportive care services (4). Palliative care is a service that can improve the quality of life of children with

cancer and their families by providing support in physical, psychological, spiritual, cultural, and social dimensions (5).

Despite the high importance of providing palliative care, many children with cancer and their families do not have access to it. According to the World Health Organization (WHO) statistics, 40 million children in the world need palliative care every year, of whom 86% are deprived of access to these important services (6). Due to the increased rate of life-threatening diseases such as cancer in children, they need palliative care services (7).

According to the statistics, about 8,000,000 children with life-threatening diseases such as cancer need palliative care services (8). There is little evidence in Iran regarding the consistent provision of palliative care for children with cancer and their families. Based on the study by Khanali Mojen et al., many of the palliative care needs of these children and their families are unmet or insufficiently met (4). The life-limiting nature of disease events for children with life-threatening diseases leads to situations in their health that make their management difficult. This means that providing such services for these children is challenging (9). This issue leads to a lack of proper access to services for these children and their families, resulting in unmet palliative care needs (10).

Also, most of the time, parents are the primary caregivers of children during a child's disease, and their care responsibilities lead to changes in performance, roles, and emotions and expose them to unknown needs (11). The care needs of parents are very diverse and related to receiving information and psychological, emotional, spiritual, and physical support, all of which are provided through supportive and palliative care (12). In Iran, most parents complain about the heavy burden of caring and need supportive and palliative care (13). Such unmet needs affect not only their communication and contribution to the healthcare team during the child's hospitalization but also the ability of families to provide psychological and spiritual support for patients in different stages of the disease (14).

Unmet needs can lead to adverse consequences such as reduced quality of life, decreased satisfaction, depression, anxiety, and worsening physical and psychological symptoms (4, 15). Therefore, to provide quality care, it is very important to identify the unmet needs of these children and families as a prerequisite for the healthcare team to provide quality palliative care (16).

Identifying the needs of children with various diseases and their caregivers has been introduced as one of the 70 global research priorities (17). Also, based on a review study, the available evidence regarding the unmet needs of children with incurable disorders such as cancer and

their caregivers is very limited, and there is a need for more research (7).

## 2. Objectives

As the palliative care needs of children with cancer and their families are not well known in Iran, the present study aimed to exploring the perception of formal and informal caregivers about the unmet needs of palliative care of children with cancer and their families.

## 3. Methods

### 3.1. Study Design

The present study was conducted to explore the perception of caregivers about the unmet needs of palliative care of children with cancer and their families using the qualitative study using a directed content analysis approach. The directed content analysis aimed at developing and expanding a theoretical framework because the knowledge of the intended phenomenon was not comprehensive and needed further clarification (18).

### 3.2. Study Setting and Participants

The participants in this study included 11 informal caregivers of children with cancer (parents, sisters, aunts, grandmothers, and neighbors), 14 formal caregivers (nurses and doctors), and 5 children with cancer, who were selected by purposeful sampling. The inclusion criteria for informal caregivers were people responsible for caring for a child with cancer since at least 6 months ago, not suffering from mental problems, having the ability to speak Persian, and being interested in sharing their experiences in caring for a child with cancer. The inclusion criteria for children included those hospitalized in Rasht Children's Hospital regardless of the type of cancer and declared their willingness to participate in the study. There were no restrictions on the type of cancer and the stage of the disease. Formal caregivers (nurses and doctors), who had at least 1 year of experience providing care to children with cancer in the oncology department, were included in the study. Informal caregivers, who had the main responsibility for caring for a child with cancer and were willing to participate in the research, were included in the study. The exclusion criteria for formal and informal caregivers included a history of mental disorders, according to their statements, which prevented them from participating in the study. The exclusion criteria for children included instability in their clinical conditions based on the statements of the attending physician and nurse.

### 3.3. Data Collection

All the interviews were conducted in one of the children's hospitals in Rasht (north of Iran). Data were collected through semi-structured and in-depth interviews until data saturation from September 20, 2021, to March 20, 2022. The interviews lasted 45 to 60 minutes. After explaining the objectives of the research, the time and place of the interviews were coordinated with the participants. The tools used included a demographic information form and a semi-structured interview guide. All the interviews were conducted in a room in the hospital with a quiet atmosphere, and the participant's privacy was fully respected. Interviews with informal caregivers began with the following questions: "What experiences and challenges have you had in caring for your child since the diagnosis of the disease?", "What are the needs of your child and you as a caregiver that should be paying attention?". Interviews with formal caregivers began with the following questions: "What services do children with cancer and their families need?" and "Which needs of children with cancer and their families are not met by this hospital?". The interview with the children began with the following questions: "What needs have you had since you were admitted to this hospital?" and "What would you like to be done for you while you are hospitalized?". In the following, probing questions were used for further investigation, such as "Can you explain more?" or "Can you give an example?".

### 3.4. Research Framework

The conceptual framework of the current study was based on the National Consensus Project (NCP). In this project, palliative care is defined as a set of services that focus on managing pain and other symptoms, assessing and meeting the needs of caregivers, and coordinating care that leads to the improvement of the physical, practical, functional, psychological, and spiritual dimensions of a patient with a life-threatening illness. Palliative care can be provided for all patients with life-threatening illnesses regardless of age, environment, and type of disease. Also, palliative care has an individual and family-oriented approach to care; it relieves the pain and suffering of patients with life-threatening diseases and ultimately improves the quality of life and satisfaction of patients and families. The NCP includes 8 dimensions of care for patients with life-threatening illnesses: The structure and process of care, physical aspects of care, psychological aspects of care, social aspects of care, spiritual, religious, and existential aspects of care, cultural aspects of care, taking care of a dying patient, and ethical and legal aspects of care (19, 20).

### 3.5. Data Analysis

Data analysis was done simultaneously with data collection. Data management was done by MAXQDA software (21), and data analysis was done based on Elo and Kyngas' directed content analysis method, which included 3 stages of preparation, organization, and reporting (Table 1) (18, 22). For this purpose, the text of each interview was read several times to get an overall understanding. Then, the meaning units were selected and primary codes were extracted. Then, similar primary codes were placed in larger categories, and the main categories were extracted. Finally, the results of content analysis abstracted in all stages were reported. Table 2 presents an example of data analysis.

### 3.6. Rigor and Trustworthiness

For data trustworthiness, the proposed criteria by Lincoln and Guba were used (23). Data credibility was ensured through long-term engagement with participants (12 months), continuous observation, peer review, and allocation of sufficient time for data collection and analysis. Data dependability was ensured through triangulation in data collection (observation, field notes, and interviews), maximum variation, and external audits. Data confirmability was ensured through the review and approval of the research steps by the research team and the review of interview transcripts by the participants. Data transferability was ensured by accurate quotes from the participants. To ensure data authenticity, the researchers tried to portray the events and experiences of the participants honestly so that the readers could imagine that they had experienced these events themselves.

### 3.7. Ethical Considerations

This study was approved by the Ethics Committee of Guilan University of Medical Sciences (IR.GUMS.REC.1400.267). Ethical considerations include voluntary participation in the study, obtaining written informed consent, explaining the research objectives, anonymity, the possibility of withdrawal of the participants, and trustworthiness in reporting the results.

## 4. Results

Thirty participants with an average age of  $32.40 \pm 1.4$  years participated in this study. Their demographic characteristics are presented in Table 3. After analyzing the data, 1,450 codes were extracted, all of which represented a theme under the title "Need for holistic care", which was in line with the NCP guideline and included 7 main

**Table 1.** Data Analysis Based on the Elo Kyngas Method

Stages	Processes
<b>Preparation stage</b>	-Determine the unit of analysis; -Try to make sense of the whole subject -After transcribing verbatim, the text of interviews was analyzed and semantic units emerged; -We read the text many times to prolonged engagement with data
<b>Organizing stage</b>	-Formed analytical matrix; -Data extraction from content based on categories; -Grouping; -Classification; -Abstraction -We used “the structure and process of care”, “physical aspects of care”, “psychological aspects of care”, “social aspects of care”, “cultural aspects of care”, “care of the patient nearing the end of life”, and “spiritual, religious, and existential aspects of care” as main categories in the matrix; -We reviewed all data and semantic units and coded for correspondence with or exemplification of the identified main categories; The main categories were formed according to logical relationships between sub-categories; -We classified the formed groups according to their differences and similarities. -The revealed categories (sub-category or generic category) based on abstraction were placed in the analytical matrix
<b>Reporting stage</b>	- All the processes including data collection, data analysis, characteristics of participants, and the resulting main categories, sub-classes, and quotations are presented in detail in the results section.

**Table 2.** Example of Data Analysis Process

Main Category	Generic Category	Subcategories	Primary Codes	Quotation
<b>Psychological aspects of care</b>	Need for psycho-cognitive supports	-Need for a comprehensive plan for psycho-cognitive symptom management; -Need for the education of families regarding psycho-cognitive symptom management	-Lack of training for parents regarding communication with sick child; - Lack of training regarding coping strategies for families; -Inappropriate adjustment of children and families during treatment; -Lack of psychological support after breaking bad news	- “...Parents need to be supported psychologically during their children’s disease ...” (A nurse); - “...Many parents suffering from depression. They really need to train about coping strategies, hopefulness...” (An oncologist)

categories under the titles of “the structure and process of care”, “physical aspects of care”, “psychological aspects of care”, “social aspects of care”, “cultural aspects of care”, “taking care of a dying patient”, and “spiritual, religious, and existential aspects of care” (Table 4).

**4.1. Need for Holistic Care**

Based on the participants’ statements, it was determined that children with cancer and their families need comprehensive care to improve their quality of life and satisfaction. These findings align with the NCP guideline and include 7 categories and 23 subcategories.

**4.2. Structure and Process of Care**

This dimension includes assessing palliative care, providing palliative care services by trained and expert people, and the necessary structures and processes in providing palliative care. In the present study, this category includes 8 subcategories, including “need for access to palliative care through telehealth”, “need for standardization of oncology department”, “need for separation of outpatient and inpatient cancer care delivery”, “need for respite care”, “need for diagnostic and screening services”, “need for welfare services”, “need for bereavement services”, and “need for rehabilitation services”.

**4.2.1. Need for Access to Palliative Care Through Telehealth**

Many parents and children with cancer need telehealth to prevent unnecessary admissions. One of the physicians, who had long experience in the field of pediatric oncology says:

”We need to start telehealth. In many cases, we see that parents come from a distance due to chemotherapy complications...” (P4)

**4.2.2. Need for Standardization of the Oncology Department**

In the studied setting, lack of standard clean room, insufficient ventilation, improper cooling and heating facilities, and the high number of beds were the main problems. One of the mothers of a child with leukemia says:

”The number of beds in each room is high, and there is no proper ventilation for our child.” (P15)

Need for separation of outpatient and inpatient cancer care delivery

The separation of outpatient and inpatient care delivery was another need that could increase satisfaction and quality of care. One of the oncology nurses with a bachelor’s degree says:

”Nurses have to care for both outpatients and inpatients patients. This overload can result in our patients being neglected.” (P13)

**Table 3.** Demographic Characteristics of Participants

Number	Role	Age, y	Gender	Marital Status	Education	Job	Relationship with Sick Child	Cancer Type
1	Formal caregiver	42	Female	Married	Master of sciences	Nurse	Nurse	Leukemia
2	Formal caregiver	28	Female	Married	Bachelor	Nurse	Nurse	Lymphoma
3	Formal caregiver	36	Female	Married	Bachelor	Nurse	Nurse	Leukemia
4	Formal caregiver	55	Male	Married	Fellowship	Oncologist	Doctor	Leukemia
5	Formal caregiver	45	Male	Married	Fellowship	Oncologist	Doctor	Neuroblastoma
6	Formal caregiver	50	Female	Single	Bachelor	Nurse	Nurse	Leukemia
7	Formal caregiver	25	Female	Married	Bachelor	Nurse	Nurse	Lymphoma
8	Formal caregiver	33	Female	Married	Bachelor	Nurse	Nurse	Lymphoma
9	Formal caregiver	49	Female	Married	Master of sciences	Nurse	Nurse	Leukemia
10	Formal caregiver	43	Female	Married	Master of sciences	Nurse	Nurse	Leukemia
11	Formal caregiver	39	Female	Married	Bachelor	Nurse	Nurse	Leukemia
12	Formal caregiver	25	Female	Single	Bachelor	Nurse	Nurse	Neuroblastoma
13	Formal caregiver	28	Female	Single	Bachelor	Nurse	Nurse	Leukemia
14	Formal caregiver	29	Female	Single	Bachelor	Nurse	Nurse	Neuroblastoma
15	Informal caregiver	45	Female	Married	Diploma	Housewife	Mother	Leukemia
16	Informal caregiver	37	Female	Married	Diploma	Housewife	Mother	Leukemia
17	Informal caregiver	35	Female	Married	Diploma	Housewife	Mother	Wilms tumor
18	Informal caregiver	35	Female	Married	Bachelor	Teacher	Mother	Lymphoma
19	Informal caregiver	42	Male	Married	Bachelor	Computer engineer	Father	Leukemia
20	Informal caregiver	37	Male	Married	Diploma	Agriculture	Father	Wilms tumor
21	Informal caregiver	33	Male	Married	Bachelor	Bus driver	Father	Leukemia
22	Informal caregiver	36	Male	Married	Bachelor	Mechanics	Father	Leukemia
23	Informal caregiver	62	Female	Married	Diploma	Housewife	Grandmother	Leukemia
24	Informal caregiver	29	Female	Married	Bachelor	Teacher	Sister	Wilms tumor
25	Informal caregiver	41	Female	Married	Bachelor	Housewife	Aunt	Leukemia
26	Child with cancer	5	Female	Single	Kindergarten	–	–	Leukemia
27	Child with cancer	14	Female	Single	Junior high school	Student	–	Leukemia
28	Child with cancer	16	Male	Single	High school	Student	–	Leukemia
29	Child with cancer	8	Male	Single	Elementary school	Student	–	Leukemia
30	Child with cancer	6	Male	Single	Kindergarten	–	–	Leukemia

#### 4.2.3. Need for Respite Care

Diagnosis of cancer in a child can lead to mental burden and anxiety for families that need respite care services. One of the mothers of a child with lymphoma says:

”Since the diagnosis of cancer in my child, I have forgotten myself. I really need to rest, watch TV, and renew my physical and mental strengths.” (P18)

#### 4.2.4. Need for Diagnostic and Screening Services

The lack of diagnostic and screening services such as CT scan, MRI, and specialized laboratory kits were also expressed. One of the oncology nurses with a bachelor's degree says:

”The lack of equipment such as MRI makes us refer children to more equipped centers. This increases our workload and also confuses families.” (P11)

**Table 4.** Data Analysis of the Interviews

Themes	Main Categories	Sub-categories
<b>Need for holistic care</b>	Structure and process of care	Need for access to PC through telehealth; Need for standardization of the oncology department; Need for separation of outpatient and inpatient cancer care delivery; Need for respite care Need for diagnostic and screening services; Need for welfare services; Need for bereavement services; Need for rehabilitation services
	Psychological aspects of care	-Need for a comprehensive plan for psycho-cognitive symptom management; -Need for the education of families regarding psycho-cognitive symptom management
	Physical aspects of care	Need for a comprehensive plan for symptom assessment; Need for a comprehensive plan for symptom management; Need for empowerment of families regarding symptom management
	Taking care of a dying patient	Need for end-of-life support for child and family; Need for decision-making regarding the child's place of death; Need for interdisciplinary collaboration
	Social aspects of care	Need for peer relationships of cancer children; Need for continuity of education for school-aged children; Need for sibling's support
	Cultural aspects of care	Need for cultural awareness regarding PC; Need for destigmatization of cancer
	Spiritual, religious, and existential aspects of care	Need for spiritual care; Need for empowerment of interdisciplinary team regarding spiritual care

4.2.5. *Need for Welfare Services*

In the studied setting, there are no welfare services such as a restroom for parents or entertainment toys suitable for the child's age. One of the caregivers, who was the aunt of a child with leukemia, says:

"My niece has cancer and I always have to make fresh food for him, while here there is not enough toaster or kitchen devices for cooking." (P25)

4.2.6. *Need for Bereavement Services*

Counseling families during bereavement has been recognized as one of their unmet needs. One of the physicians, who had long experience in pediatric oncology says:

"After the child dies, we no longer have anything to do with the families, and our communication with them is cut off." (P4)

4.2.7. *Need for Rehabilitation Services*

Many children with cancer need rehabilitation services, which are not adequately provided. A 28-year-old oncology nurse with a bachelor's degree says:

"Most children with cancer suffer from chronic fatigue or walking disorders and need support." (P13)

4.3. *Physical Aspects of Care*

4.3.1. *Need for a Comprehensive Plan for Symptom Management*

Many of these children suffer from problems such as pain, nausea and vomiting, neuropathy, mucositis, and

fatigue. A 25-year-old oncology nurse with a bachelor's degree says:

"We need to have a comprehensive program and evaluate and manage the physical symptoms of these children." (P12)

4.3.2. *Need for Empowerment of Families Regarding Symptom Management*

Many families need to be empowered about the symptoms and physical problems related to cancer in children. A 25-year-old oncology nurse with a bachelor's degree says:

"Cancer in children affects the family for a long time, and families need to have the necessary knowledge." (P7)

4.4. *Psychological Aspects of Care*

4.4.1. *Need for a Comprehensive Plan for Psycho-cognitive Symptom Management*

According to many participants' statements, it is necessary to provide psychological support for families and children. A 28-year-old oncology nurse with a bachelor's degree says:

"One of the important needs of children is psychological counseling according to their age during their hospitalization." (P2)

4.4.2. *Need for the Education of Families Regarding Psycho-cognitive Symptom Management*

Many children with cancer and their parents suffer from problems such as depression, anxiety, aggression,

fatigue, exhaustion, and behavioral disorders, but they do not know how to cope. A 55-year-old physician, who had long experience in pediatric oncology says:

“...Many parents suffer from depression. They really need to train about coping strategies and hopefulness...” (P4)

#### 4.5. Social Aspects of Care

##### 4.5.1. Need for Peer Relationships of Cancer Children

Children with cancer are often hospitalized for a long time, making them stay away from interactions with their peers and society; it can adversely affect them. A 45-year-old physician, who had long experience in pediatric oncology says:

“The children who are admitted here need to be connected with their peers.” (P5)

Need for continuity of education for school-age children

According to the participants’ statements, many children with cancer drop out of school and education due to long-term hospitalization. One of the physicians, who had long experience in pediatric oncology says:

“Unfortunately, we don’t have any education services for school-age children.” (P4)

##### 4.5.2. Need for Sibling’s Support

Parents are heavily involved in providing care after a child in the family is diagnosed with cancer. This results in other children being abandoned. One of the mothers of a child with lymphoma aged 35 years old with a bachelor’s degree says:

“I have come to this center from a distant city, and I haven’t seen two of my daughters for exactly two months.” (P18)

#### 4.6. Cultural Aspects of Care

##### 4.6.1. Need for Cultural Awareness Regarding PC

Many families do not have the necessary knowledge of palliative care, such as having a natural right to relieve pain or speak about their child’s death, and consider it taboo to talk about these issues. A 25-year-old oncology nurse with a bachelor’s degree says:

“I am taking care of a sick child, who is in severe pain, but his family considered the pain a sign of God’s anger.” (P7)

##### 4.6.2. Need for Destigmatization of Cancer

Many families think cancer is a completely incurable disease or stigma, so they try hiding it from other family members. A 49-year-old oncology nurse with a master of sciences degree says:

“Many parents hide their child’s cancer, and they consider cancer a shame.” (P9)

#### 4.7. Taking Care of a Dying Patient

This dimension refers to the clinical symptoms and conditions experienced by a child with cancer and his family in the last days and weeks of life and includes two subcategories: “Need for end-of-life support for child and family” and “need for bereavement support”.

##### 4.7.1. Need for End-of-life Support for Child and Family

Family of children during the end-of-life stage need special support. For example, they need to be supported spiritually or get to know the process of the child’s death or psychological counseling. A 25-year-old oncology nurse with a bachelor’s degree says:

“Children during end-of-life period will be transferred to the ICU ...in this situation, the families are very bewildered and need support.” (P7)

Need for decision-making regarding the child’s place of death

##### 4.7.2. Need for Interdisciplinary Collaboration

Many children, especially adolescents at the end-of-life stages, need to talk with a spiritual counselor psychologist or have appropriate pain relief provided by a pain specialist. A 55-year-old physician, who had long experience in pediatric oncology says:

“Many of our sick children ask questions about death or life after death. Many parents suffer from severe depression, and we really need a team to support these children and families.” (P4)

#### 4.8. Spiritual, Religious, and Existential Aspects of Care

This dimension includes assessing spiritual needs, addressing spiritual distress, and providing spiritual care for the child and their family. This dimension includes two subcategories: “Need for spiritual care” and “need for empowerment of interdisciplinary team regarding spiritual care”.

##### 4.8.1. Need for Spiritual Care

A cancer diagnosis is one of the family’s crises that can lead to great spiritual distress. A 33-year-old oncology nurse with a bachelor’s degree says:

“After breaking bad news, families doubt the existence of God and lose their hope. In this situation, it is really necessary to give them hope.” (P8)



#### 4.8.2. *Need for Empowerment of Interdisciplinary Team Regarding Spiritual Care*

It is necessary for healthcare workers, especially nurses and doctors, to have appropriate knowledge and be empowered to provide spiritual care. In this regard, a 36-year-old oncology nurse with a bachelor's degree says:

"We don't have any information in the field of spiritual care." (P3)

### 5. Discussion

In this study, the unmet needs of palliative care of children with cancer and their families were identified from the point of view of caregivers (formal and informal). One of the dimensions of unmet needs identified in this study was the structure and process of care. This dimension focuses on providing diagnostic equipment, standardization of the oncology department, separation of the outpatient department from the inpatient department, welfare services, rehabilitation, bereavement, and respite care services. Bereavement support is one of the needs of families after the child dies in many countries (24) and Iran (25).

Another dimension of unmet needs identified in this study was respite care services. Cancer diagnosis in a child leads to much anxiety and worry for families. Studies recommend respite care services for families of children with special needs such as cancer (26). In Iran, there is no evidence regarding the provision of respite care services.

Another dimension of unmet needs identified in this study was "psychological and psychiatric aspects of care" and "physical aspects of care". To provide integrated services for children with cancer and their families, it is necessary to manage the physical and psychological complications of children with cancer that can decrease the quality of life and satisfaction in children with cancer and their families, which are the ultimate goals of palliative care (27). In Iran, no guidelines exist for managing physical and psychological symptoms for children with cancer (5).

Another dimension of unmet needs was the care for the patient nearing the end of life. Children with cancer in the final stage of life suffer from many physical and mental problems (28). So, providing care for these complex problems and meeting their needs requires an interdisciplinary team's cooperation (27, 29). Considering that cancer in children is the second cause of death in Iran, the establishment of a palliative care system is necessary to provide end-of-life care in the country (30), and the training of oncologists, pain specialists, and nurses is one of the priorities of the Middle East Cancer Consortium (MECC) (31).

Another dimension was the social aspects of care. One of the extracted subcategories was the need for sibling support. When a child in the family is diagnosed with cancer, all care providers and family focus on the sick child, and parents abandon siblings, which can result in a high level of anxiety (32). Palliative care is one of the primary rights of children with cancer, and family-centered care is one of the main principles of palliative care for children (27, 33). Therefore, it is necessary to care for the whole family, including siblings. In Iran, there is no comprehensive plan for the palliative care of children and all family members (5, 30).

Another dimension of unmet needs identified in this study was cultural aspects of care. Iranian people believe that death is under God's control and that deciding to stop treatment is against God's ability and will result in God's grace. Also, the diagnosis of cancer in a child is considered a stigma, taboo, and a divine test (34, 35). Therefore, managing this disease is impossible without considering families' cultural beliefs.

The last dimension of unmet needs was the spiritual, religious, and existential aspects of care. Palliative care is an interdisciplinary service provided in many parts of the world by a team. Nevertheless, instead of using an interdisciplinary team in Iran, only a few disciplines are responsible for providing palliative care services, mostly nurses and doctors (36).

#### 5.1. *Study Limitations*

One limitation of the current research was that it was conducted during the COVID-19 pandemic, making it difficult to access the participants. Also, even though qualitative studies are not conducted with the aim of generalizability, it is important to consider that cultural factors may influence the family's needs. Therefore, it is suggested to conduct quantitative studies with a large sample size in different populations.

#### 5.2. *Conclusions*

This study showed that children with cancer and their families have many needs. In this regard, providing the necessary infrastructure to provide palliative care, striving for justice in the access of children with cancer and their families to palliative care services in different centers of Iran, empowering caregivers, formation of interdisciplinary teams, and promoting the culture of people in the field of cancer and death are suggested.

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## Footnotes

**Authors' Contribution:** Conceptualization: SP, MR, ZTE, NZP, BD; data collection: SP, MR, ZTE, NZP, BD; data analysis: SP, MR, ZTE, NZP, BD; supervision: MR, ZTE, NZP, BD.

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**Data Reproducibility:** The dataset presented in the study is available on request from the corresponding author during submission or after publication.

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**Informed Consent:** Written informed consent was obtained.

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