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# Health information needs of families at childhood cancer: A qualitative study

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## Abstract:

**INTRODUCTION:** Cancer is the second cause of mortality among children. The aim of this study is to identify the health information needs of families in childhood cancer as main source of support and care for these children.

**MATERIALS AND METHODS:** The qualitative content analysis approach was used in this study. The study population comprised parents of childhood cancer patients visiting Omid Hospital among which 35 were selected using purposive sampling until data saturation was achieved. The study tool was semi-structured interview.

**RESULTS:** A total of 9 main themes and 24 subthemes were identified. The main themes included: (1) information about cancer, (2) disease management and self-care, (3) communication and information interaction of medical team, (4) consultation services, (5) information sharing and exchange, (6) access to health services, (7) hospital's facilities and equipment, (8) access to social and financial support, and (9) access to health information sources.

**CONCLUSION:** Health information needs of families in Isfahan are consistent in information needs of families identified in other studies. Meeting this information needs through plans of health-care system can help these families in better control and treatment of their children's condition.

## Keywords:

Childhood cancer, family, health information needs

## Introduction

Cancer is a debilitating and common condition and one of the main causes of mortality in children in developed and developing countries.<sup>[1]</sup> Today, there is an increase in the number of children diagnosed with cancer, turning cancer to the second most common cause of mortality among children with age from 5–14.<sup>[2]</sup> Childhood cancer usually occurs among two age groups, including early childhood and during adolescence.<sup>[3]</sup> According to the reports by the World Health Organization, it is expected for the total number of children annually diagnosed with cancer to rise from 10 million in the year 2000 to 2015 million in 2020, 60% of whom live in less developed countries.<sup>[1]</sup>

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The crisis caused by sickness and hospitalization of children is one of the main sources of tension and anxiety for families because families are the main and primary source of support for sick children.<sup>[4]</sup> Family cares for the sick child and can be counted on for offering health and medical care, prevention, and general support.<sup>[5]</sup> However, families require access to suitable information regarding their children's conditions in order to participate in health-care activities.

Recognition, awareness, and gathering of information about their condition and health care for cancer patients can help them adapt to their condition, while access to timely, relevant, and comprehensible information can improve the quality of life for patients while also helping their

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families in offering support.<sup>[6]</sup> However, parents of cancer patients often complain about incomplete information given by the medical team about their children's condition and treatment. They need to have access to transparent and comprehensible information so that they can make the best decisions regarding care of their children.<sup>[7]</sup> Evaluating and answering the families' needs at the start of this crisis is of utmost important. In other words, it is necessary to quickly identify and answer the information needs of families in order to minimize negative stressor effects on families, medical team, and patient, enabling the families to concentrate on caring for their patient.<sup>[8]</sup> In family-centered care, parents are in direct interaction with sick children and have to deal with related problems and challenges. Families along with health-care institutes play a decisive role during caring for the patient which becomes even more important given the direct dependence of children to their families.<sup>[9]</sup> The first principle of health information process is health need assessment and precise identification of health information needs.<sup>[6]</sup> Information needs are information needs of people faced with problems and challenges which results in need and desire for better awareness and more knowledge.<sup>[10]</sup> These problems can include diseases such as cancer and its relevant information needs. Children are among the group of patients who are unable to meet their own information needs and thus are dependent on their families. Therefore, we need to know what information needs are important to families and parents of these patients.<sup>[11]</sup> Attention to information needs of parents is as important as attention toward the needs of the children.<sup>[11,12]</sup> Therefore, knowledge of parents' preferences in gathering health information can help improve and modify existing health information dissemination methods while providing them with suitable survives.<sup>[11]</sup> Since only a small number of studies have investigated health information needs of families with childhood cancer patients in Iran, the current study aimed to identify health information needs of these families in order to help improve health information dissemination process for these patients.

## Materials and Methods

The current study is a qualitative study carried out in order to discover the experiences of participants using qualitative content analysis approach. The study population comprised 35 parents of children diagnosed with cancer visiting Isfahan Seyed-Al-Shohada (Omid) Hospital selected using purposeful sampling. Inclusion criteria included parents of children diagnosed with cancer hospitalized in the hospital, desire for participation, signing an informed consent form, and having suitable psychological conditions for participating in the study. To have maximum variety in the sample, we attempted to select the sample among

families from different demographic backgrounds (such as education, occupation, income level and source, and geographical location). After achieving saturation and repeat in the data, sampling was terminated. The study tool was semi-structured interviews with length of 20 min. All interviews were recorded and typed word for word at the end of the day in MS word software, version 2013 (U.S.A). After typing, interviews were divided into smaller meaning units (primary codes) after several reviews. Then, these meaning units were compared with each other and categorized based on their similarities and differences (subthemes). Next, these subthemes were categorized into the main themes through constant comparison and their similarities. To satisfy the ethical requirements, precision in transcription of interviews, lack of bias in analyses, confidentiality of information, and acquisition of written consent were all considered. To improve data validity, sample variety, precision in data gathering, long involvement with data and review of results by participants, research partners, and external observer/checker were used. Data transferability was satisfied with enriched data description. There were a total of 64 primary codes or themes which resulted in 9 main themes and 24 subthemes after open and axial coding.

## Results

Table 1 shows the demographic characteristics of the participants. Data analysis led to identification of 9 main themes and 24 subthemes [Table 2 and Figure 1].

## Discussion

The current study identified 9 main themes and 24 subthemes for health information needs of families with childhood cancer patients in Isfahan. The main themes include: (1) information about cancer, (2) disease management and self-care, (3) communication and information interaction of medical team, (4) consultation services, (5) information sharing and exchange, (6) access to health services, (7) hospital's facilities and equipment, (8) access to social and financial support, and (9) access to health information sources. In the study by Borjalilu *et al.*,<sup>[13]</sup> four main themes were identified for health information needs of parents including medical information, physical health care information, psychoeducational health-care information, and family lifestyle information. Adams *et al.*<sup>[14]</sup> identified the main information needs of families of cancer patients as treatment, diagnosis, coping with disease, self-care, types of cancer, support information, hospital care, special topics, and rehabilitation. Inman<sup>[15]</sup> also reported that health information of parents of children suffering from cancer include: (1) long-term effects of cancer treatment on survivors; (2) concerns about remaining physical

**Table 1: Demographic information**

Characteristic	Frequency (%)
Family relation	
Father	9 (25.8)
Mother	26 (74.28)
Education	
Illiterate	4 (11.42)
Middle school	6 (17.14)
High school and associate degree	20 (57.14)
Bachelor's degree	5 (14.28)
Parents' age	
20-30	6 (17.14)
30-40	22 (62.9)
40-50	7 (20)
Child's gender	
Female	24 (68.6)
Male	11 (31.42)
Cancer type	
ALL	15 (42.85)
Wilms' tumor (kidney)	2 (5.8)
Brain tumor	4 (11.42)
Lymphoid tumor	11 (31.42)
Osteosarcoma	3 (8.6)
Occupation	
Office worker	5 (14.28)
Self-employed	3 (8.6)
Laborer	4 (11.42)
Homemaker	23 (65.71)
Place of residence	
Urban	27 (77.14)
Rural	8 (22.85)

ALL=Acute lymphoma leukemia

and mental survivors; (3) performance of parents and family members; and (4) access to information about behavioral problems, schooling, sleep and eating disorders, psychology and emotional performance, and communication with others.

The main theme of information about cancer included the subthemes of general information about cancer, specialized information about cancer type, diagnosis information, treatment methods, and medicine information. These results are similar to the ones reported by Abedi *et al.*<sup>[16]</sup> who stated that information about patient's condition, treatment plan, and care is necessary for families of elderly patients. Ghazanfari *et al.*<sup>[12]</sup> also believed that identifying information needs of parents of children with thalassemia regarding nature of the condition, complications, prevention, and treatment are necessary for improving their performance. Furthermore, the study by Riahi *et al.*<sup>[6]</sup> showed that medication information and knowing the name and type of disease are among the important needs of cancer patients. Valizadeh *et al.*<sup>[17]</sup> also believed that information on the disease and treatment is essential for parents of children suffering from cancer. Rahimi

*et al.*<sup>[13]</sup> stated that it is important to formulate educational plans regarding the best treatment methods for children with cancer and Borjalilu *et al.*<sup>[13]</sup> mentioned the need for medical information (cause, treatment methods, and complications of treatment methods). In the study by Jenkins *et al.*,<sup>[18]</sup> cancer patients required specialized information about different aspects of their condition. Huber *et al.*<sup>[19]</sup> noted the need for medical information and specific information about the disease process for the parents of the child. The result of the study Mitchell *et al.*<sup>[20]</sup> showed that parents were satisfied with the medical information received from physicians and nurses during the diagnosis and during the treatment. Adams *et al.*<sup>[14]</sup> mentioned the information needs of parents are about treatment, diagnosis, types of cancers, and specific issues about the disease. Matsuyama *et al.*<sup>[21]</sup> also emphasized the information needs of cancer patients regarding diagnosis and disease changes during the treatment. In the study by van Weert *et al.*,<sup>[22]</sup> patients mostly needed information regarding treatment. Wakefield *et al.*<sup>[23]</sup> showed that patients require information about their chances of survival, possible consequences of cancer, different treatment stages, and possible treatments. The result of the study by Yi *et al.*<sup>[24]</sup> showed that patients mostly required information on their condition, chances of treatment, and treatment results. The results of the study conducted by Maree *et al.*<sup>[25]</sup> showed that in Africa, parents of children with cancer required information about disease, its causes, possible relevant studies, effect of treatment on children, different treatment methods, treatment length, surgery, and its results.

The main theme of disease management and self-care includes two subthemes of "self-care" and "home care by the family." This is similar to the results reported in the study by Mohaddesi *et al.*<sup>[26]</sup> about the need for parents for home care of children with hemophilia and Abedi *et al.*<sup>[16]</sup> about the need to understand care program and method of participation in caring for the patient in family members of elderly patients. Shamsaei *et al.*,<sup>[27]</sup> Riahi *et al.*,<sup>[6]</sup> and Yi *et al.*<sup>[24]</sup> also emphasized the need for information about care and self-care.

The main theme of "communication and information interaction of medical team included two subthemes of communication and information interaction with the patient and with patient's family. This is similar to the results of several studies. Loghmani *et al.*<sup>[28]</sup> emphasized the need for interactive care training (identifying the information needs of patients' families, meeting these needs, and training the patients). Rozmovits and Ziebland<sup>[29]</sup> stated the need for constant communication with health-care professionals and nurses and the ability to reach them for support and consultation. Mitchell *et al.*<sup>[20]</sup> emphasized the need of parents of children with cancer to receive relevant medical information from

**Table 2: Main themes and subthemes of health information needs of families with childhood cancer patients**

Main theme	Subthemes	Primary (interview) codes
Information about cancer	General information about cancer (symptoms, risk factors, etc.)	I wanted to know what caused my child's condition so that I could know if I had made a mistake or he just got sick <sup>[12]</sup>
	Specialized information about cancer type	Information about bone marrow and its problem and that infected cells shouldn't enter bone marrow <sup>[4]</sup>
	Diagnosis information (cancer type, diagnosis methods, and malpractice)	They gave us some information about cancer type. <sup>[8,13]</sup> They suggested sonography, found the tumor, and then suggested CT-scan; <sup>[14]</sup> they did bone marrow tests; <sup>[1]</sup> before diagnosis, they injected a lot of drugs for aches in the foot and keens; <sup>[9,13]</sup> if they had diagnosed it already, the tumor wouldn't have gotten this large <sup>[15]</sup>
	Treatment methods (different methods and their complications, treatment chance)	They first did sampling and then chemotherapy, <sup>[16]</sup> there is an improving trend, <sup>[6,16-21]</sup> they don't explain treatment process, <sup>[8]</sup> first they did chemotherapy and then 28 sessions of radiotherapy <sup>[22]</sup>
	Medicine information (side effects, effectiveness, etc.)	They explained some information about side effects of drugs, <sup>[3,23]</sup> I don't know the side effects or when each one is injected, <sup>[8]</sup> I want to know about the disease and effective medicines <sup>[24]</sup>
Disease management and self-care	Self-care	They have to take care not to get a cold; <sup>[1,19]</sup> they shouldn't get close to someone who has a cold <sup>[24]</sup>
	Home care by the family	Following doctors' instructions, <sup>[20,25]</sup> not taking them to crowded places like places of worship, <sup>[1,5,8,21]</sup> having clean and sterilized environment, <sup>[4]</sup> not using detergents <sup>[4]</sup>
Communication and information interaction of medical team	With patient's family	The medical team have good behavior, <sup>[1]</sup> medical staff in both wards are good and do their best, <sup>[11]</sup> doctor and medical staff give us information about the disease, <sup>[2]</sup> I do n't understand anything about it <sup>[5]</sup>
	With the patient	Medical staff, doctors, and nurses have good interactions with children, <sup>[14]</sup> he doesn't know what exactly is his condition; <sup>[4]</sup> she knows everything about her disease <sup>[16]</sup>
Consultation services	Providing consultation and psychological support (managing emotions, stress, anxiety, depression, coping with cancer)	We need psychologists and consolers; <sup>[8,6]</sup> psychologist talked to all family members; <sup>[9]</sup> there is a consoler in the hospital who helps and provides information; <sup>[14]</sup> hospital's consoler helped us cope with these conditions; <sup>[20]</sup> his friends mocked him because of hair loss but he's coping with his condition and is flexible; <sup>[4]</sup> it's hard to cope with this, and I still can't believe it <sup>[14]</sup>
	Providing dietary consultation (correct diet, useful supplements, etc.)	Not using preserved and processed foods; <sup>[1,4]</sup> not using salt; <sup>[4]</sup> I don't know what she should eat to help with her condition; <sup>[8]</sup> home cooked meals are better. They have to use peeled fruits such as apples, oranges, kiwi, lemons, and banana. They should n't use lettuce and vegetables <sup>[11]</sup>
Information sharing and exchange	With survivors	One nursing PhD student would bring cancer survivors to the hospital to give us and our children more hope; <sup>[9]</sup> Dr. Moghadasi invited cancer survivors to the hospital to increase our hopes <sup>[26]</sup>
	With families of other patients	I'm interacting with families of other patients; <sup>[8]</sup> when we talk to other mothers, we gather information <sup>[12]</sup>
Access to health services	Information about health service accessibility (traveling, doctors' experience level, insurance, drug acquisition centers)	This is the only hospital for children with cancer in this city, and I'm satisfied with its services; <sup>[3]</sup> there is a long distance to the hospital and a lot of transportation problems; <sup>[7]</sup> Some of the drugs aren't available in Isfahan, and we have to get them from Mashhad or Shiraz <sup>[13]</sup>
	Hospital support services after discharge	We have to again come to the hospital for treatment and observation; <sup>[27]</sup> it's possible to have complications 10 years after radiotherapy <sup>[15]</sup>
Hospital's facilities and equipment	Hospital facilities for family members (residence area, food, parking, etc.)	The hospital has good facilities; <sup>[5,28,29]</sup> hospital food doesn't have good quality; <sup>[10]</sup> the hospital, unfortunately, has problem with parking and greenery. There are places for staying. Only mothers can stay the night with children. I need to look for parking space <sup>[30]</sup>
	Hospital facilities for children (welfare and entertainment, privacy)	They need a play room; <sup>[6]</sup> there is not enough privacy in the hospital because each room has two patients which are hard for parents and visitors <sup>[30]</sup>
Access to social and financial support	Financial (treatment costs, loans, effect of disease on parents' work)	Costs are high and only some of it is covered by banks if they confirm it; <sup>[4-6]</sup> treatment costs are high and we have financial problems; <sup>[7,12,20-22,27,31,32]</sup> my husband is self-employed and costs are high, we had to take a load <sup>[12,14]</sup>
	Charities and associations	MAHAK and KASA charities help a lot; <sup>[5,7,19,22,29,32]</sup> MAHAK charity helps children under 12 years old <sup>[30]</sup>

Contd...



**Table 2: Contd..**

Main theme	Subthemes	Primary (interview) codes
Access to health information sources	Friends and family	We get help from our associates <sup>[24]</sup>
	Spiritual	Our only hope is God; <sup>[25]</sup> I pray a lot so I can calm down; <sup>[14]</sup> we shouldn't despair, and we have to trust in God <sup>[17]</sup>
	Children's education and learning	He can't go to school, so we had to hire provide tutors; <sup>[10]</sup> she's under treatment for sampling and can't go to school for 1 month; <sup>[33]</sup> she hadn't gone to school for now <sup>[12,23,34]</sup>
	Printed sources	We need a library <sup>[6]</sup>
	Electronic resources (websites, social networks, etc.)	At first, I gathered information from the internet; <sup>[2]</sup> I get most of the information from the net; <sup>[3]</sup> my 11-year-old son does the search; <sup>[35]</sup> I use the Telegram <sup>©</sup> channel of one of nursing PhD students who studies cancer <sup>[2,6,20,24]</sup>

CT=Computerized tomography

doctors and nurses during diagnosis and treatment. Jackson *et al.*<sup>[30]</sup> believed in necessity of effective communication between health-care workers and family members during diagnosis and hospitalization of children. Kästel *et al.*<sup>[31]</sup> emphasized the need for nurses to answer parents' questions, while Wakefield *et al.*<sup>[32]</sup> investigated parents' needs for receiving medical information and Maree *et al.*<sup>[25]</sup> stated the need to receive medical information orally from the medical team.

In the main theme of "consultation services," there were two subthemes of "psychological consultation" and "dietary consultation." This was in agreement with the results of several studies such as studies by Abedi *et al.*<sup>[25]</sup> on the need for empathy and emotional support for patients, Shamsaei *et al.*<sup>[27]</sup> about offering consultation services to patients, Seyedamini<sup>[4]</sup> about the need of mothers for guidance and consultation, Loghmani *et al.*<sup>[28]</sup> on the need for emotional reaction (emotional support, empathy, mutual understanding, inducing calmness and trust) and consultation and guidance for patients' families, Riahi *et al.*<sup>[6]</sup> on the nutrition information needs of cancer patients, and Rozmovits and Ziebland<sup>[29]</sup> on the need for constant access of patients to consultation and support.

The main theme of "information sharing and exchange" included the subthemes of information exchange with cancer survivors and with families of other patients. In the study by Rozmovits and Ziebland,<sup>[29]</sup> the need for access to experiences of other patients and "patients as specialists" (patients trained to talk to other patients) was also stated. Furthermore, the study by Mitchell *et al.*<sup>[20]</sup> emphasized the important of talking about disease with peers for sick children.

The main theme of "access to health services" included the subthemes of information about health service accessibility and hospital support services after discharge. These results were not similar to the results presented in other studies. It appears that this difference can be due to different mechanisms for accessing health

services in other countries, making it so that these types of services, especially support services are often vague in Iran.

The main theme of "hospital facilities and equipment" consisted of subthemes "secondary hospital facilities for families" and "hospital facilities for children." This is similar to the results reported by Abedi *et al.*<sup>[16]</sup> who emphasized the need for hospital welfare facilities. Furthermore, Sadeghi *et al.*<sup>[33]</sup> also mentioned physical needs (need for a suitable location and welfare facilities) of patients' families. However, these results contradicted the results mentioned by Seyedamini<sup>[4]</sup> which indicated that physical needs were the least important needs for mothers.

The main theme of "access to social and financial support" included the subthemes of financial support, charities and associations, friends and family, spiritual support, and children's education and learning. The study by Shamsaei *et al.*<sup>[27]</sup> mentioned the financial needs related to care and treatment of diseases. Seyedamini<sup>[4]</sup> believed that support-related needs are the most important needs for mothers. Loghmani *et al.*<sup>[28]</sup> cited spiritual needs (hope, attention to god, and use of religious practices) and emotional reaction (psychological support, empathy, and mutual understanding) among the needs of patients' families. Borjalilu *et al.*<sup>[9]</sup> implied the need for belief, hope, and social support for children suffering from cancer. Studies by Huber *et al.*<sup>[19]</sup> and Inman<sup>[15]</sup> also mentioned the need for educational services for children diagnosed with cancer.

The main theme of "access to health information sources" included two subthemes of printed and electronic sources. In a study by Riahi *et al.*,<sup>[34]</sup> the most important information sources and methods of access for the medical and health information included human resources (such as family, friends, acquaintances, and other immigrants) and the internet. Rozmovits and Ziebland<sup>[29]</sup> also mentioned written information, as well as educational clips about possible side effects, treatment,

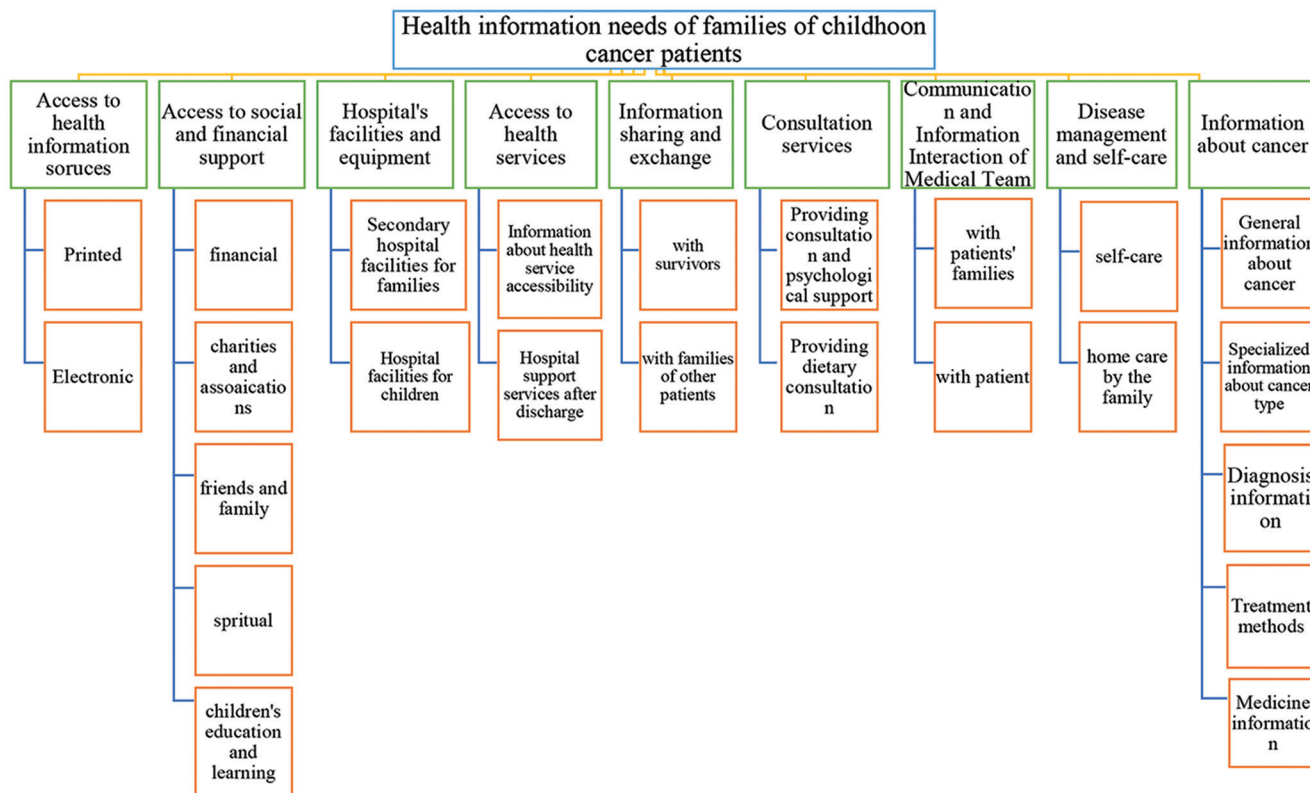


Figure 1: Main themes and subthemes of health information needs of families of childhood cancer patients

hospitalization length, and emotional factors. Mitchell *et al.*<sup>[20]</sup> stated that existence of a hospital library with books related to cancer, as well as audio information, facilitating access to information through internet and a list of credible and relevant websites on cancer and an internet search services are necessary for cancer patients and their families. Knijnenburg *et al.*<sup>[35]</sup> stated that patients use internet to answer their questions about late effects of their conditions. Furthermore, the study by Wakefield *et al.*<sup>[32]</sup> showed that parents required printed information (booklets) although they also used the internet as the best source of information to answer their questions. In another study, Wakefield *et al.*<sup>[23]</sup> showed that families of children suffering from cancer asked for a specialized guidebook for cancer in children. Maree *et al.*<sup>[25]</sup> also showed that patients need to receive printed information through booklets, brochures, and guidebooks.

### Conclusion

The current study managed to identify nine main themes as the most important health information needs of families with children suffering from cancer in Isfahan. Since family is the main source of support for sick children, attention to health information needs of family can facilitate family's role and participation in improvement, controlling, and treatment of cancer

in children. Furthermore, identification of these health information needs can be used for planning and policy-making of health-care system in order to train families and medical teams and reduce medical and financial costs of cancer. On the other hand, the results of this study can help determine a minimum data set for design of health-care systems.

Since some of the identified health information needs related to facilities, equipment, and health services, health-care managers in Isfahan can use these results to plan for answering health information needs of parents of children suffering from cancer. Furthermore, it is necessary to provide strategies for communication and interaction between medical staff and parents and patients in order to share the necessary information. Psychological and dietary consultation services and social and financial support are also among the needs of parents which should be considered by relevant authorities of the province.

In general, health information needs of families of childhood cancer patients are comparable to health information needs of families of cancer patients in other countries. Only three main themes of "access to health services," "access to hospital facilities and equipment," and "access to social and financial support" (except subtheme of education and training for children) have

not been mentioned in other studies which is probably due to lack of defined procedures for these types of services in Iran's health-care system. Furthermore, spiritual and social support often receives more attention in Iran.

The limitations of this study include the small number of participants, while qualitative nature of the study means that care should be taken in generalizing the results. Furthermore, lack of similar studies on this topic in Iran limited our ability to compare the results to results obtained in the same context.

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### Conflicts of interest

There are no conflicts of interest.

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