

## Analyzing the health information needs of families with children suffering from cancer in the city of Yazd

Khalil Kalavani<sup>1</sup>, Razieh Akhondzardaini<sup>2\*</sup>

1. Student Research Committee, Faculty of Management and Medical Information Sciences, Kerman University of Medical Sciences, Kerman, Iran. k.kalavani@kmu.ac.ir, ORCID ID: 0000-0002-7869-7931

2. Faculty of Management and Medical Information Sciences, Kerman University of Medical Sciences, Kerman, Iran

\*Corresponding author: Dr. Razieh Akhondzardaini, Faculty of Management and Medical Information Sciences, Kerman University of Medical Sciences, Kerman, Iran. Email: akhondzardaini@gmail.com. ORCID ID: 0000-0001-8411-6956.

Received: 31 December 2023

Accepted: 21 February 2024

### Abstract

**Background:** It is of paramount significance to address the needs of parents who have children with cancer. This research aims to analyze the health information needs of families with children suffering from cancer in Yazd city.

**Materials and Methods:** This descriptive-analytical study was conducted on a total of 248 individuals from families whose children underwent cancer treatment at Shahid Sadoughi Hospital in Yazd. The participants were selected through a non-random, purposeful, and voluntary sampling method. The data were collected using a comprehensive questionnaire consisting of 48 items. The data analysis was performed with the SPSS software version 25 and through t-tests, chi-square, ANOVA, and correlation analyses.

**Result:** Through a meticulous comparison of the scores obtained with a predetermined threshold of 3, all levels of information needs were satisfactorily met. However, it became evident that the parents needed more information to be given by the treatment staff regarding cancer and called for social, economic and spiritual support ( $p \leq 0.5$ ). Moreover, the study identified and prioritized the information needs based on the average scores across the four examined factors. The highest-priority need was identified as "the information about cancer provided by the treatment staff" ( $2.99 \pm 0.7$ ). The second most important need was found to be "social, economic and spiritual support" ( $2.98 \pm 0.7$ ). The third priority was assigned to "the accessibility and exchange of relevant health information" ( $2.77 \pm 0.62$ ). Lastly, the fourth priority pertained to "health facilities, services and counseling" ( $2.61 \pm 0.63$ ). Furthermore, the independent t-test revealed that the average score on the total health information needs of the families with cancer-affected children was significantly higher for the women ( $140.5 \pm 20.4$ ) than for the men ( $117.7 \pm 11.55$ ).

**Conclusion:** When handling children with cancer, it is crucial for the treatment staff to provide information about cancer and give social, economic and spiritual support in order to fully meet the information requirements of the families involved.

**Keywords:** Cancer, Family, Health, Information.

### Introduction

Childhood cancer, a distressing condition resulting from abnormal cellular changes, is one of the primary causes of disease in children (1, 2). This deadly illness is of various types, such as blood malignancies, central nervous system tumors, and kidney tumors (3, 4). High-income countries have made remarkable advancements in pediatric oncology, leveraging technological breakthroughs that have led to improved treatments and increased life expectancy for affected children (5).

The global annual incidence of childhood cancer exceeds 200,000 cases, with over 80% occurring in developing nations (6-8). Notably, South and Southeast Asia bear the highest burden of childhood cancers (4, 9). In Iran, cancer ranks as the third leading cause of death, following cardiovascular diseases and accidents (10). In the west of Asia, including Iran, the reported rates of childhood cancer are 140.9 per million for the age group of 0-14 and 150.7 per million for the age group of 0-19 (11).

The impact of childhood cancer goes beyond the affected children, permeating multiple aspects of their life as well as that of their families (12). The diagnosis of a child's cancer causes numerous problems, such as psychological and social concerns, strains on parental relationships, financial hardships, social isolation, and adjustments in job and family responsibilities (13, 14). In such circumstances, parents of children with cancer express a strong yearning for information to comprehend and manage the disease and make wise decisions. Access to essential and easily understandable information can significantly enhance the quality of life for children and help their parents provide optimal support for them (3).

Regrettably, many parents feel that medical teams avoid providing them with comprehensive information regarding their children's condition and treatment (15). Consequently, their need for health information is often overlooked by medical professionals. What parents need is to have additional knowledge and profound understanding of their children's disease (16). Given that children themselves are unable to meet their own information needs, it becomes very important to identify and address the information needs of parents who care for these young patients (17).

Familiarizing oneself with the intricacies of childhood cancer constitutes an essential aspect of parental care. Information serves as a powerful tool that gives parents a deep understanding of the situation at hand (18). When parents possess limited knowledge about the disease, they often experience feelings of helplessness, anxiety and stress. Therefore, acquiring information pertaining to the diagnosis, treatment and potential complications of cancer as well as appropriate long-term care plans becomes

important for parents. Equipped with this knowledge, they can actively engage in caring for their children by ensuring their well-being and providing the necessary support (19, 20).

Recent studies shed light on the unmet needs experienced by the parents of children diagnosed with cancer, with a particular emphasis on psychosocial aspects. According to these studies, approximately 97% of the parents of children with cancer report some level of perceived need, and a significant proportion of them experience moderate to high levels of needs across various domains (21). It is evident that addressing these unmet needs and providing comprehensive support to parents are crucial elements in offering holistic care to both the child and his or her family.

Recognizing the importance of addressing the information needs of the parents of children with cancer is as crucial as meeting the needs of the children themselves (16, 17). Conducting regular assessments of these information needs, as well as the factors that influence them, can significantly enhance the quality of the care provided to these children (22). Additionally, gaining an understanding of parental preferences regarding the gathering of health information can help to improve and refine the existing methods of disseminating such vital information (16). Given the limited number of the studies conducted on this topic in Iran, the present research can contribute to the field by shedding light on the specific information requirements of these families (12). It is expected that the findings of this study will enhance the dissemination of health information for child patients with cancer and their families in Iran. Therefore, the primary objective of the study is to investigate the health information needs of parents who care for children with cancer.

## Materials and Methods

This descriptive-analytical study aims to examine the health information needs of families with children diagnosed with cancer in Shahid Sadoughi Hospital of Yazd. The study duration spanned from September to March of 2022. The statistical population consisted of all the families referring to the hospital during this period.

According to the number of the hospitalized patients in the same period of six months before the study, the research population was 600 people. Also, based on the Morgan table, 234 people and, according to a 10% decrease, 256 people were considered as the sample size. The sampling was non-random, purposeful and voluntary based on the inclusion criteria. According to these criteria, the participants in the study were the families who had at least one child having suffered from cancer for one year after the diagnosis. The relatives or other people who took care of the children due to the absence of their parents were not included in the study. Also, those who left the study and refused to cooperate were not included.

The research tool used in this study is the "Questionnaire of Information Needs of Families of Children with Cancer". It was developed by Koohkan et al. (12) and evaluated for its face validity, qualitative content validity, structural validity, and reliability (Cronbach's alpha = 0.96). The questionnaire consists of two sections. The first one gathers demographic data about gender, marital status, level of education, income, place of residence, type of the child's cancer, gender of the child, and insurance status. The second section includes four sub-sections. Sub-section A focuses on accessibility, provision and exchange of health-related information (19 items), Sub-section B examines the provision of cancer-related information by healthcare agents (15 items), Sub-section C evaluates healthcare facilities, services

and counseling (7 items), and Sub-section D assesses social, economic and spiritual support (7 items). In total, the questionnaire comprises 48 items rated on a 5-point Likert scale ranging from "very low" (1) to "very high" (5). The maximum score of this questionnaire is 48, and its maximum is 240. It was distributed to the participants in person at the hospital, and the data collection was done accordingly. This study received approval from the ethics committee with the ethics code of IR.KMU.REC.1402.059. Verbal informed consent was also obtained from each participant, ensuring the confidentiality of the collected data. The data analysis was done using independent t-test, chi-square, analysis of variance, correlation analysis and one-sample test. The analyses were performed with the SPSS software version 25.

## Results

Table I showed the frequency distribution of the demographic data for the studied respondents in the families of children with cancer. A total of 248 parents of children with cancer were examined in this study. The mean age of the cancer-affected children was 7.05 years with a standard deviation of 4.7 years. The minimum age was 1 year, and the maximum age was 11 years. The age range of the parents was from 18 to 60 years, with a mean of 36.6 years and a standard deviation of 9.7 years (Table I).

Table II showed the comparison of the average scores on the family health information needs of children with cancer and the threshold value. Using a one-sample test, the scores obtained for each level of information needs were compared with the threshold value of 3. The results revealed that all the levels of information needs were met, as the average needs were lower than the established threshold. However, in the case of the two specific factors, namely "providing information

about cancer by the treatment staff" and "social, economic and spiritual support", further analysis indicated that there was no significant difference between the average scores and the threshold. Consequently, it can be inferred that parents require additional information in relation to these two factors. The results highlight the importance of meeting specific information needs to ensure comprehensive support for parents in these areas.

Based on the findings and the average scores on the four examined factors, the highest priority need is "the provision of information about cancer by the treatment staff". The second most important need is "social, economic and spiritual support". The third priority is "the accessibility, provision and exchange of relevant health information". Lastly, the fourth priority pertains to "health facilities, services and counseling" (Table II).

The comparison of the mean scores on the health information needs of the families of children with cancer in terms of the gender of the respondents and the sick children was shown in Table III. The results of the Kolmogorov-Smirnov test demonstrated that the scores in both gender groups followed a normal distribution, as the p-values were greater than 0.05. Furthermore, the independent t-test revealed that the average score on the total health information needs of the families with cancer-affected children was significantly higher for the women than for the men. This suggests that women tend to have a greater need for information regarding their children's cancer diagnosis, treatment, and the related topics. However, no significant difference was observed between the men and women regarding the social, economic and spiritual support. This implies that both men and women have similar levels of need for support in these particular areas.

Furthermore, as the analysis indicated, there was no significant relationship between the mean score on health information needs and the gender of the cancer-suffering children, as well as the total score and their gender. This suggests that the information needs of a families caring for a child with cancer are not influenced by the gender of the child. However, there was a significant difference in terms of health care facilities, services and counseling. This finding implies that parents have a greater need for information in this specific area, particularly for their male children (0.05) (Table III).

Comparison of the mean scores on the health information needs of the families of children with cancer according to the place of residence, marital status, and type of insurance was shown in Table IV. The Kolmogorov-Smirnov test results indicated a normal distribution of the variable scores across different places of residence, types of insurance, and marital status groups. Additionally, the independent t-test results showed no significant difference in the mean scores of health information needs between the families residing in urban and rural areas. It suggests that the information needs of families are comparable, regardless of their place of residence. This finding emphasizes the importance of ensuring equal access to health information for families, whether residing in urban or rural areas.

Unfortunately, due to the limited number of single individuals in the study population, it was not possible to compare the average scores of information needs based on the variable of parents' marital status. However, the independent t-test did show a significant difference in the average score of the factor "accessibility, presentation and exchange of health information" between the individuals who had a cancer patient in their second-degree

family and those who did not. Specifically, those with a second-degree family member affected by cancer had a higher average score in this particular factor. On the other hand, no significant difference was observed in the average scores of the other health information needs of the families with cancer-suffering children, including the total score. These findings highlight the importance of considering the impact of family cancer history when addressing the information needs of individuals. It suggests that individuals with a second-degree family member affected by cancer may have raised awareness and information-seeking tendencies regarding health-related matters. By recognizing this distinction, healthcare providers can tailor their information and support services to meet the specific needs of individuals with a family cancer history, while ensuring that comprehensive support is also provided to families without such a history (Table IV).

The relationship between the health information needs of the families of children with cancer and the levels of education and income was shown in Table V. The results of Spearman's correlation coefficient analysis revealed a direct relationship between the level of education and the score on "accessibility, provision and exchange of relevant health information". This suggests that individuals with a higher level of education tend to have a greater score on this variable, indicating a stronger desire and ability for it. However, no significant relationship was observed between the level of education and the other areas, as well as the total score of health information needs in families with cancer children. It indicates that the level of education does not significantly impact the overall health information needs in these families, except for the variable "accessibility, provision and exchange of relevant health information". These

findings imply that, while education level may play a role in certain aspects of health information needs, it does not significantly influence the overall information requirements of families caring for children with cancer. Spearman's correlation test found no significant relationship between the respondents' income level and their score on the information needs, but there was a significant relationship between the age of the sick children and the scores on "accessibility, provision and exchange of relevant health information", "providing information about cancer by the treatment staff", and the overall score of the health information needs in families with cancer-diagnosed children. Additionally, the duration of the disease after diagnosis was associated with the score on "provision of cancer information by the treatment staff" and the overall score, but no significant relationship was found with the other aspects of health information needs. Similarly, no relationship was there between the four dimensions of health information needs in families of cancer-diagnosed children and the presence or absence of a cancer patient in the first or second-degree family (Table V).

Table VI shows the relationship between the health information needs of the families of cancer children and the respondents' age, the number of household members, the age of the sick child, and the duration of the disease since diagnosis. Based on Pearson's correlation coefficients, a significant relationship existed between the age of the respondents and their scores on "accessibility, presentation and exchange of relevant health information". This indicates that aging is notably associated with higher scores in that specific aspect of health information needs. However, there was no significant relationship between the age of the respondents and their scores on the other areas of need for family health

information. This suggests that age does not significantly impact the overall health information needs in these families, apart from the specific domain of "accessibility, presentation and exchange of relevant health information". Moreover, the analysis demonstrated that the number of people in the household had no significant

relationship with the total scores of health information needs in families of children with cancer, nor was it correlated to any other area of need. One can imply that the size of the household does not play a significant role in determining the overall health information needs of families (Table VI).

*Table I: Frequency distribution of the demographic data for the studied respondents in the families of children with cancer*

Variable	Group	Percentage	Number
<b>Gender</b>	male	29.4	73
	female	70.6	175
<b>Marital status</b>	single	2.8	7
	married	97.2	241
<b>Level of education</b>	illiterate	6.0	15
	diploma	58.9	146
	postgraduate diploma	14.9	37
	bachelor	11.7	29
	master's degree	2.8	7
	Ph.D	5.6	14
<b>Monthly income (Tomans)</b>	less than 8 million	58.9	146
	8-15 million	35.1	87
	more than 15 million	6.0	15
<b>place of residence</b>	city	73.4	182
	village	26.6	66
<b>Type of child cancer</b>	sarcoma	6.0	15
	lymphoma	24.6	61
	ALL	53.2	132
	tuberculosis germ tumor	8.9	22
	blastoma	7.3	18
<b>Gender of the child</b>	girl	44.0	109
	boy	56.0	139
<b>Insurance status</b>	social security	64.9	161
	public health	8.5	21
	armed forces	8.1	20
	other	18.5	46
<b>The presence of another cancer patient in the first-degree family</b>		7.6	19
<b>The presence of another cancer patient in the second-degree family</b>		15.3	38

**Table II: Comparison of the average scores on the family health information needs of children with cancer and the threshold value**

Health information needs	Mean	Standard deviation	Mean Difference	P-value
<b>Accessibility, provision and exchange of relevant health information</b>	2.77	.62	-.22	.000
<b>Providing information about cancer by the treatment staff</b>	2.99	.70	-.009	.886
<b>Health facilities, services and counseling</b>	2.61	.63	-.38	.000
<b>Social, economic and spiritual support</b>	2.98	.70	-.009	.886
<b>Total score</b>	2.91	.68	-.08	.223

One-sample test: statistically significant at  $p \leq 0.05$

**Table III: Comparison of the mean scores on the health information needs of the families of children with cancer in terms of the gender of the respondents and the sick children.**

Health information	Gender variable	Male		Female		P-value
		Mean	Standard deviation	Mean	Standard deviation	
<b>Accessibility, provision and exchange of relevant health information</b>	Respondents	38.3	8.3	45.9	9.5	0.001
	The gender of the sick child	42.46	11.39	44.68	8.41	0.08
<b>Providing information about cancer by the treatment staff</b>	Respondents	44.8	3.7	54	9.8	0.001
	The gender of the sick child	52.13	12.60	50.63	6.37	0.257
<b>Health facilities, services and counseling</b>	Respondents	15	1.6	18.9	4.8	0.001
	The gender of the sick child	19.53	5.46	16.42	3.16	0.001
<b>Social, economic and spiritual support</b>	Respondents	20.6	2.7	21.6	4	0.06
	The gender of the sick child	20.20	4.64	20.15	2.71	0.9
<b>Total score</b>	Respondents	117.7	11.55	140.5	20.4	0.003
	The gender of the sick child	136.33	27.04	131.89	15.47	0.12

t: Student t-test, \*: Statistically significant at  $p \leq 0.05$

**Table IV. Comparison of the mean scores on the health information needs of the families of children with cancer according to the place of residence, marital status, and type of insurance.**

Children's family health information needs	Variable	Mean	Standard deviation	P-value
<b>Accessibility, provision and exchange of relevant health information</b>	Residence	city	44.2	10.61
		village	42.1	7.02
	Marital status	single	41.0	0.0
		married	43.7	9.8
	Type of insurance	social security	45.0	10.9
		public health	44.0	5.0
		other	40.4	7.4
<b>Providing information about cancer by the treatment staff</b>	Residence	city	51.6	9.9
		village	50.2	8.6
	Marital status	single	45.0	0.0
		married	51.4	9.5
	Type of insurance	social security	53.0	10.1
		public health	49.3	6.4
		other	47.5	8.0
<b>Health facilities, services and counseling</b>	Residence	city	17.5	4.2
		village	18.5	5.5
	Marital status	single	17.0	0.0
		married	17.8	4.6
	Type of insurance	social security	18.2	4.9
		public health	16.0	2.0
		other	17.2	4.1
<b>Social, economic and spiritual support</b>	Residence	city	21.2	3.7
		village	20.5	4.0
	Marital status	single	20.0	0.0
		married	21.0	3.8
	Type of insurance	social security	21.8	3.4
		public health	19.6	6.1
		other	19.5	3.6
<b>Total score</b>	Residence	city	134.7	24.0
		village	131.4	9.9
	Marital status	Single	123.0	0.0
		married	134.1	21.3
	Type of insurance	social security	138.2	22.8
		public health	129.0	4.58
		other	124.7	17.6

t: Student t-test and ANOVA test, \*: Statistically significant at  $p \leq 0.05$

Table V: The relationship between the health information needs of the families of children with cancer and the levels of education and income

Health information needs	Level of Education		Level of Income	
	R	P-value	R	P-value
<b>Accessibility, provision and exchange of relevant health information</b>	0.345	0.04	.107	.548
<b>Providing information about cancer by the treatment staff</b>	0.02	.869	-.065	.713
<b>Health facilities, services and counseling</b>	.122	.493	.324	.062
<b>Social, economic and spiritual support</b>	.131	.461	.128	.472
<b>Total score</b>	.163	.357	.138	.435

Spearman's correlation statistically significant at  $p \leq 0.05$

Table VI. The relationship between the health information needs of the families of cancer children and the respondents' age, the number of household members, the age of the sick child, and the duration of the disease since diagnosis

Health information needs of families of children with cancer	Respondent's age		Number of household members		The age of the sick child		The duration of the disease since diagnosis	
	R	P-value	R	P-value	R	P-value	R	P-value
<b>Accessibility, provision and exchange of relevant health information</b>	0.383	0.02	-.295	.090	0.383	0.025	-.174	.32
<b>Providing information about cancer by the treatment staff</b>	.029	.87	-.079	.65	0.409	0.01	-.489	.00
<b>Health facilities, services and counseling</b>	.174	.32	-.263	.13	0.298	0.07	-.120	.50
<b>Social, economic and spiritual support</b>	.066	.71	-.272	.11	.061	.73	-.089	.61
<b>Total score</b>	.061	.73	-.277	.11	0.782	0.001	-.341	.04

Pearson's correlation statistically significant at  $p \leq 0.05$

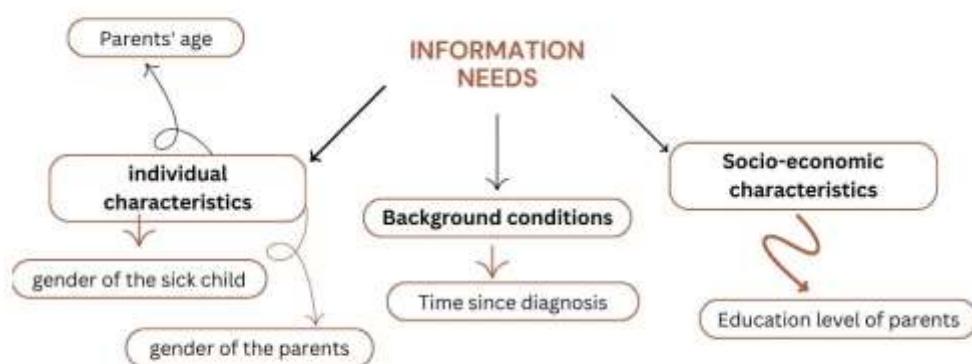


Figure 1. The relationship between the demographic characteristics and information needs of the families with children fighting cancer.

## Discussion

Caring for a child with cancer is an incredibly challenging responsibility that comes with numerous additional obligations. In order to cope with these new demands, parents must assume new roles and responsibilities. The experience of having a sick child gives rise to new needs that can impact all the aspects of life. It is important to note that parents of ill children often do not receive adequate support; they are left to confront their problems largely on their own (23-25). The objective of this study is to analyze and examine the information needs of parents who have children diagnosed with cancer.

In this study, a one-sample test was used to examine the information needs of parents with children diagnosed with cancer. The scores obtained for each level of information needs were compared with a threshold value of 3, which was considered as the cutoff point. The results indicated that, on average, all the levels of information needs were addressed, as the average scores were lower than the threshold number.

The studies conducted by Qingying et al. (21) and Adamsi et al. (26) revealed that parents of children with cancer have average levels of information needs regarding their child's illness, which is in line with the results of this study.

Based on the findings and the average scores of the four factors examined, the highest-priority need identified was "provision of information about cancer by the treatment staff". This underscores the importance of healthcare professionals' responsibility to provide accurate and comprehensive information about cancer to parents. It is essential for healthcare providers to ensure effective communication and information sharing with parents, as this can alleviate their concerns and help them make informed

decisions regarding their child's treatment process. This is due to parents' strong desire for detailed and accurate information about their child's medical condition, including the diagnosis, treatment options, potential side effects, and prognosis. Understanding their information needs in these areas is crucial for healthcare professionals to provide tailored support and empower parents in making informed decisions regarding their child's healthcare.

In this context, Bourjellil et al. (27) focused on identifying parents' health information needs and found four main topics of interest including medicine, physical health, health care, and family lifestyle information. Among them, the primary need was the acquisition of medical information. The second most important need was "social, economic, and spiritual support". This highlights the holistic nature of support that parents require when their child is diagnosed with cancer. Providing emotional support, addressing financial concerns, and meeting spiritual needs can significantly contribute to the well-being of both the parents and the sick children. Lewandowska (28) indicated that parents of children with cancer have moderate to high levels of psychological and emotional needs. This suggests that psychological and emotional support ranks second among the areas requiring assistance, which aligns with the findings of our study. The recognition of these needs emphasizes the importance of addressing the emotional well-being of parents alongside their informational requirements. Moreover, parents of children suffering from cancer have more psychological difficulties than parents in the general population do; thus, they also have higher psychological and emotional needs (25, 29).

The third identified priority was "accessibility, provision and exchange of

relevant health information". This emphasizes the importance of accessible and reliable sources of information for parents. Healthcare providers should take proactive measures to ensure that parents have access to accurate and up-to-date information about their child's conditions, treatment options, and available support services. As research indicates, one of the primary needs of parents is information. Indeed, it is crucial for families to have access to accurate and comprehensive information regarding their children's condition. Parents of children with cancer frequently express dissatisfaction with the quality and quantity of the information provided by medical teams regarding their children's condition and treatment (12).

Lastly, the fourth priority belongs to "health facilities, services and counseling". This points to the need for improved healthcare facilities and supportive counseling services for parents and children. Investing in the development of comprehensive healthcare facilities and providing counseling support can greatly alleviate the stress experienced by parents during their child's cancer journey. In fact, medical treatments combined with counseling services can help parents cope with the emotional and psychological challenges associated with their child's sickness. The research by Inman (30) showed the specific needs of these parents for information about how to address behavioral problems, facilitate education, manage sleep disorders, solve eating issues, and foster effective communication with others.

In such studies, understanding the characteristics of the participants is crucial as it provides a contextual framework for interpreting the findings. Accordingly, this study partly focused on the relationship between demographic information and parents' information needs.

The results showed a noteworthy disparity in the mean scores of health information

needs between the families of children with cancer. In this regard, the women scored significantly higher than the men. This suggests that mothers often assume primary responsibility for the patient care, thereby needing better information than the other family members. Interestingly, the results of a study by Koohkan et al. (12) on the information needs of hip cancer patients corroborates our findings; they reported that women tend to require more information than men in similar circumstances.

The research findings revealed a significant difference in the scores of "health services, treatment facilities, and counseling" based on children's gender. This suggests that parents have a greater need for information in these specific domains, particularly when it comes to their sons. This finding is in agreement with the results of Shamsi et al. (31), who observed a relationship between the gender of cancer patient and the psychosocial risks experienced by their parents. It emphasizes the impact that patients' attributes, such as gender, can have on the informational needs of their families when going through medical hardships.

In the present study, the assessment of information needs found no significant difference between the residents of urban and rural areas. However, the study conducted by Koohkan et al. (12) yielded contrasting results. It indicated that caregivers residing in rural communities have significantly higher health data needs than those living in urban areas. These divergent findings highlight the complexity of information needs and the potential variations that can exist in different populations and contexts.

In our analysis, considering the children's insurance type, no significant differences were found in the average scores across the four dimensions of family information needs. This finding aligns with the study conducted by Koohkan et al. (12), which

similarly found no significant variations related to insurance coverage distinctions. While the methods of securing healthcare costs understandably impact certain patient and family experiences, our analysis suggests that these variables may not significantly shape the relationships with healthcare-related awareness and learning desires.

A correlation was found between the parents' education level and the factor of "accessibility, provision and exchange of health-related information". As the parents' education level increased, their need for information increased too. This finding was supported by Kennynenbur et al. (32), who studied children with cancer, survivors, and their families. They showed that individuals with higher levels of education were generally more receptive of insights and information compared to those with lower levels of education.

The present research did not find any significant difference in the information needs of individuals across different income levels. However, independent investigations conducted by Koohkan et al. (12) and Mohaddesi et al. (33) showed a correlation between parents' financial status and their educational and information needs. Although the present study did not confirm this relationship, some other studies have shown the effects of income and economic status on information needs, particularly in terms of access to health resources, services, and financial support systems. These findings suggest the need for further exploration of this topic in future studies.

This study revealed a significant association between the respondents' age and their need for "accessibility, presentation and exchange of health-related data". These results are in line with the independent research conducted by Jenkins et al. (34), which highlighted a connection between age and the quantity

of information followed by cancer patients. By and large, these analyses suggest that older parents may place a higher value on accessing guidance compared to younger ones. They may seek insights to effectively manage their children's health, particularly as the treatment goes on. In this case, the results of the present study contradict the findings of Koohkan et al. (12), who identified a negative correlation between age and health information needs. This discrepancy may be attributed to the relative lack of experience among younger parents, leading to a greater need for health information in caregiving. Further research is needed to explore the complexities of age-related differences in health information needs among parents.

There was no discernible correlation between the number of individuals in the household and the overall score of health information needs among families with cancer-affected children, nor in any specific areas of information needs. This finding diverges from the findings of Kohkan et al. (12), who reported a significant relationship between household size and information needs. However, it is worth noting that the research conducted by Mohaddesi et al. (33) and Shamsi et al. (31) demonstrated a significant association between the number of children and their families' need for information and education. This disparity can be attributed to the cultural and environmental differences between the present study conducted in Yazd City and the study by Shamsi et al. (31) conducted in Tehran. Additionally, the type of the disease affecting the children in the present study compared to that in the study by Mohaddesi et al. (33) may account for the observed differences.

The duration of the disease after diagnosis was significantly correlated to the score on the "provision of cancer information by the

treatment staff" as well as the overall score on the information needs. This finding aligns with the research conducted by Shamsi et al. (31), which identified a significant relationship between the duration of the child's cancer and the parents' psychosocial risks. Prolonged treatment processes and unfavorable conditions for the family were found as contributing factors in their study. Similarly, Koohkan et al. (12) observed a negative correlation, indicating that parents initially display a heightened eagerness to receive and exchange information at the onset of their child's diagnosis, which gradually diminishes over time. In contrast to these findings, our study showed that, as time passes after the disease diagnosis, parents' need for information actually increases. This may be attributed to factors such as the patient's lack of response to treatment in certain cases, the prolonged duration of the treatment process, or the decline in the family's psychological well-being. These results shed light on the evolving information needs of parents throughout the course of their child's illness and underscore the importance of continued support and information as the disease goes on.

In this study, a notable correlation was identified between the age of the afflicted children and various aspects of health information needs in their families. Specifically, there was a significant relationship between the children's age and the scores on "accessibility, presentation and exchange of health-related information", "presentation of cancer information by the treatment staff", and the overall score on health information needs. These findings are in agreement with the research conducted by Koohkan et al. (12), which similarly reported the significance of age in relation to health information needs among families with pediatric cancer.

Based on the investigation of the correlation between demographic characteristics and the information needs of families with children battling cancer, certain socio-economic factors are linked to the information needs across all the four dimensions. However, it is important to note that every socio-economic element does not exhibit this relationship. These factors can be categorized into three distinct groups including individual characteristics, background conditions, and socio-economic characteristics. Notable personal characteristics in this research include the gender and age of the parents and the sick children. The corresponding background conditions also include the time since diagnosis. Moreover, the socio-economic characteristics in this research pertain to the parents' level of education (Figure 1). The findings point to a complex interplay between demographic characteristics and the information needs of families with cancer-suffering children, emphasizing the significance of tailoring support and providing targeted information to deal with the unique needs of each family.

The identification of the factors associated with the health information needs of families helps to develop tailored policies and programs to effectively comply with these needs. Meeting information needs optimally not only enhances the well-being of patients but also reduces the financial burden on families and the healthcare system as a whole. By identifying the corresponding features, caregivers can implement targeted initiatives aimed at alleviating information-related challenges for all stakeholders, while ensuring evidence-based practices. Undoubtedly, this proportionate approach will be of benefits for all the parties involved, fostering improved outcomes and enhanced efficiency (35, 36).

## Conclusion

In agreement with previous research findings, this study highlights the average information needs of parents with children diagnosed with cancer. The highest priority was identified for the need of accurate and comprehensive information about cancer provided by the treatment staff. This emphasizes the crucial role of healthcare professionals in effectively communicating with parents and addressing their information needs. The second priority is social, economic and spiritual support, i.e., the holistic support required by parents. The third priority is the access to relevant health information, highlighting the importance of accessible and reliable sources of information. Lastly, the fourth priority is the availability of quality health facilities, services, and counseling to alleviate the burden on parents. Overall, meeting the information needs of parents can empower them and enhance their ability to navigate their child's cancer journey effectively.

## Acknowledgments

The authors would like to express their gratitude to the Student Research Committee of Kerman University of Medical Sciences for their financial support. Additionally, the authors would like to thank all the reviewers who contributed to improving the paper. During the preparation of this work, the authors used "poe.com" in order to edit the English of the manuscript. After using this service, the authors reviewed and revised the content as needed.

## Authors' contributions

The authors would like to express their gratitude to the Student Research Committee of Kerman University of Medical Sciences for their financial support. Additionally, the authors would like to thank all the reviewers who

contributed to improving the paper. During the preparation of this work, the authors used "poe.com" in order to edit the English of the manuscript. After using this service, the authors reviewed and revised the content as needed.

## Ethical approval

This study was approved by the ethics committee of Kerman University of Medical Sciences. The ethics code is IR.KMU.REC.1402.059 (<https://ethics.research.ac.ir/IR.KMU.REC.1402.059>).

## Funding

None

## Conflict of interests

There is no conflict of interests.

## References

1. Tan C-E, Lau SCD, Latiff ZA, Lee CC, Teh KH, Sidik SM. Information needs of malaysian parents of children with cancer: A qualitative study. *Asia Pac J Oncol Nurs* 2022; 9(3): 143-152.
2. Fallahzadeh H, Momayyezi M, Akhundzardeini R, Zarezardeini S. Five year survival of women with breast cancer in Yazd. *Asian Pac J Cancer Prev* 2014; 15(16): 6597-6601.
3. Riahi A, Hariri N, Nooshinfard F. Health information needs of immigrant patients with cancer in iran. *JMIS* 2016; 2(1): 21-30.
4. Force LM, Abdollahpour I, Advani SM, Agius D, Ahmadian E, Alahdab F, et al. The global burden of childhood and adolescent cancer in 2017: An analysis of the global burden of disease study 2017. *Lancet Oncol* 2019; 20(9): 1211-1225.
5. Baig N. Assessing and implementing nursing standards in pediatric oncology units in a low-to middle-income country. *Clin J Oncol Nurs* 2022; 26(6): 673-678.
6. Khazaei S, Ayubi E, Soheylizad M, Manosri K. Incidence rate and distribution

of common cancers among iranian children. *Middle East J Cancer* 2017; 8(1): 39-42.

7. Poulalhon C, Goujon S, Marquant F, Faure L, Guissou S, Bonaventure A, et al. Factors associated with 5-and 10-year survival among a recent cohort of childhood cancer survivors (france, 2000–2015). *Cancer Epidemiol* 2021; 73: 101950.

8. Laura Botta GG, Riccardo Capocaccia, Charles Stiller, Adela Cañete, Luigino Dal Maso, Kaire Innos, Ana Mihor, Friederike Erdmann, Claudia Spix, Brigitte Lacour, Rafael Marcos-Gragera, Deirdre Murray, Silvia Rossi; EUROCARE-6 Working Group. Long-term survival and cure fraction estimates for childhood cancer in europe (eurocare-6): Results from a population-based study. *Lancet Oncol* 2022; 23(12): 1525-1536.

9. Azizah A, Hashimah B, Nirmal K, Siti Zubaidah A, Puteri N, Nabihah A, et al. Malaysia national cancer registry report (mnccr). National Cancer Institute, Ministry of Health: Putrajaya, Malaysia. 2019.

10. Mousavi SM, Pourfeizi A, Dastgiri S. Childhood cancer in iran. *J Pediatr Hematol Oncol* 2010; 32(5): 376-382.

11. Steliarova-Foucher E, Colombet M, Ries LA, Moreno F, Dolya A, Bray F, et al. International incidence of childhood cancer, 2001–10: A population-based registry study. *Lancet Oncol* 2017; 18(6): 719-731.

12. Koohkan Aliabadi E, Rajabi G, Yousofian S, Zare-Farashbandi F. Factors related to health information needs of families who had children with cancer. *Payesh (Health Monitor)* 2019; 18(2): 161-171.

13. Maree JE, Parker S, Kaplan L, Oosthuizen J. The information needs of south african parents of children with cancer. *J Pediatr Oncol Nurs* 2016; 33(1): 9-17.

14. Koohkan E, Rajabi G, Yousofian S, Zare Farashbandi F. Development and validation of the health information needs questionnaire for families of children with cancer. *JMIS* 2019; 5(1): 50-59.

15. Kahouei M, Samadi F, Gazerani M, Mozafari Z. Investigation of information needs related to women's health under surgery in hospitals affiliated to semnan university of medical sciences in 2012-2013. *IJOGI* 2013; 16(63): 8-15.

16. Kahouei M, Najarioon O, Ebrahimi N, Ahmadi-Takhorani F, Haidari S. A study on the preferences of parents of patients with thalassemia major in obtaining health information. *HIM* 2016; 13(2): 78-83.

17. Ghazanfari Z, Arab M, Forouzi M. Knowledge level and education needs of thalassemic childern's parents of kerman city. *J Crit Care Nurs* 2010; 3(3): 99-103.

18. Ringnér A, Jansson L, Graneheim UH. Parental experiences of information within pediatric oncology. *J Pediatr Oncol Nurs* 2011; 28(4): 244-251.

19. Wong MYF, Chan SWC. The qualitative experience of chinese parents with children diagnosed of cancer. *J Clin Nurs* 2006; 15(6): 710-717.

20. Earle E, Clarke SA, Eiser C, Sheppard L. 'Building a new normality': Mothers' experiences of caring for a child with acute lymphoblastic leukaemia. *Child care, health dev* 2007; 33(2): 155-160.

21. Qingying J, Currin-McCulloch JA, Zhang A, Streeter CL, Jones BL, Chen Y. Assessing the needs of parents of children diagnosed with cancer in china: A psychometric study developing a needs assessment tool. *J Pediatr Oncol Nurs* 2018; 35(1): 6-15.

22. Shorofi SA, Jannati Y, Roohi Moghaddam H. The psychosocial needs of the families of the patients admitted to intensive care units: A review of literature. *JCE* 2014; 3(1): 46-57.

23. Stenka KEI, P. Parents facing their child's struggle with cancer. *Psychiatr Psychol Klin* 2018; 18: 306–614.

24. Olagunju ATS, Olagunju F, Habeebu T, Aina M. Hild's symptom burden and

depressive symptoms among caregivers of children with cancers: An argument for early integration of pediatric palliative care. *Ann Palliat Med* 2016; 5: 157–165.

25. Wiener LB, Zadeh H, Pelletier S, Arruda-Colli W, Muriel M. He perceived influence of childhood cancer on the parents' relationship. *Psychooncology* 2017; 26: 2109–2117.

26. Adams EB, Watson E. The information needs of partners and family members of cancer patients: A systematic literature review. *Patient Educ Couns* 2009; 77: 179–186.

27. Borjalilu SS, Azad Z, Afzali M.S, Koochakzadeh M , Afzali L. The information needs of parents of children with cancer: A qualitative study. *J Qual Res Health Sci* 2017; 6: 228–237.

28. Lewandowska A. The needs of parents of children suffering from cancer continuation of research. *Children* 2022; 9(2): 144-148.

29. Stenka KEI, P. Parents facing their child's struggle with cancer. *Psychiatr Psychol Klin* 2018; 18: 306–314.

30. Inman K. Examining Parent Information Needs in Pediatric Cancer. *EMU* 2017;1-9.

31. Shamsi A AFM, Iranmanesh S. Psychosocial risks among parents of children with cancer. *JPN* 2016; 2: 44-55.

32. Knijnenburg S, KLC L, Bos C, Braam K, Jaspers M. Health information needs of childhood cancer survivors and their family. *Pediatr Blood Cancer* 2010; 54: 123-127.

33. Mohaddesi H MZ, Moghaddam Tabrizi F. Study of eucationadl needs of parents in caring from eemophilic children in west azarbajian in 1381. *J. Urmia Nurs Midwifery Fac* 2014; 2: 1-8.

34. Jenkins V FL, Saul J. Information needs of patients with cancer: Results from a large study in uk cancer centres. *Br J Cancer* 2001; 84: 48–51.

35. Farbod Ebadifard Azar, Aziz Rezapour, Haleh Mousavi Isfahani, Saber Azami-Aghdash, Khalil Kalavani, Mahmoudi F. Evidence-based medicine performance among health care providers in iranian hospitals: A nationwide survey. *Med J Islam Repub Iran* 2017; 31: 77-87.

36. Khalil Kalavani, Rafat Mohebbifar, Rafiei S. Evidence based practice among healthcare providers: A cross-sectional study. *Int J Health Care Qual Assur* 2019; 32(5): 867-878.