Original Article

Assessing Parental Awareness of Childhood Cancer in the Pediatric Oncology Unit at Tikur Anbessa Specialized Hospital, Ethiopia: A Descriptive Cross-Sectional Study

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Abstract

Background: Awareness of childhood cancer among parents improves childcare, facilitating early diagnosis and adherence to treatment. However, many parents often lack adequate awareness about cancer, including its definition, causes, treatment methods, and side effects. This study assesses childhood cancer awareness among parents visiting the pediatric oncology unit of Tikur Anbessa Specialized Hospital (TASH) in Ethiopia.

Method: A descriptive cross-sectional study was conducted from June to December 2022 involving 386 parents of children with cancer. Parents were selected consecutively and interviewed using interviewer-administered structured questionnaires. The data were analyzed using SPSS version 26. Descriptive statistics, including numerical values and proportions, were used to present the data in tables and graphs. Chi-square tests were employed to assess variations in parental awareness based on demographic variables.

Result: Only 57 parents (15%) had heard of childhood cancer before their child's diagnosis. The primary sources of information included TV (39; 67.2%), radio (35; 60.3%), and neighbors/relatives (21; 36.2%). Cancer was defined as a fatal, worrisome, and uncomfortable illness by 55.2%, 69.4%, and 62.2% of parents, respectively. The majority (328; 85.3%) of parents was unaware of its causes. and approximately 41.7% were not aware of possible side effects of cancer treatment. Nearly all (98.2%) parents reported that they believe cancer is curable with treatment. The most common reactions among parents upon first hearing their child's diagnosis were shock (330; 85.5%) followed by fear (194; 50.3%). Awareness of the causes of childhood cancer, treatment side effects and prior knowledge of cancer before their child's diagnosis were associated with factors such as place of residence, educational level, and household income.

Conclusion: Parents' awareness of childhood cancer, its treatment side effects, and its causes was found to be low. Most parents perceive cancer as a fatal, fearful, uncomfortable, and painful condition. The study recommends increasing media awareness about childhood cancer and implementing structured education and counseling programs for parents regarding its causes, treatment options, side effects, and prognosis. [*Ethiop. J. Health Dev.* 2024; 38(4): 00-00]

Keywords: Childhood cancer; awareness; parent; Ethiopia

Introduction

Child mortality and morbidity due to cancer have received less attention compared to adult cancer. However, a significant number of children are affected by cancer (1,2). More than 300,000 children are diagnosed with cancer worldwide, with approximately 90% of these cases occurring in low- and middleincome countries (1). Even though there is a scarcity of data on childhood cancer in Ethiopia, the Addis Ababa City population-based Cancer Registry reported an incidence rate of 84.6 cases per million from 2012 to 2017. Leukemia, lymphoma, and renal tumors are the most common types of childhood cancer in Ethiopia (3).

The decisions made by parents directly influence the care that a child receives. Therefore, the behavior and characteristics of parents play an essential role in determining child care (4). Parents' awareness of childhood cancer contributes to improve child care, early diagnosis, and adherence to child treatment (5). Additionally, parents' knowledge about childhood cancer has been found to decrease parental stress (6,7). Despite this awareness, parents' understanding

of the definition of cancer, its possible causes, treatment methods, and side effects remains inadequate (8,9).

Terms like "suffering" and "chemotherapy" were reported as the first thoughts of parents when they hear the term "cancer" (5). Satisfactory knowledge about childhood cancer was reported by only 14% to 22% of parents (10,11). Parents have described cancer as a worrisome, painful, dangerous disease, , a source of fear, and a fatal illness (5,8,12). Even though not all parents knew the cause of cancer (9), both correct and incorrect causes were identified in previous studies. Some reported causes include inadequate nutrition, radiation exposure, smoking during pregnancy, unhealthy eating habits, poor hygiene, and fate (5,8,11,12). Additionally, parents generally had limited knowledge about the treatment side effects and their management (9,10). Midea sources, such as radio and television, were found to be an essential sources of information, alongside healthcare providers, friends, and relatives (12,13). Most parents expressed optimism about the likelihood of a cure and

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preferred not to disclose the diagnosis to their child (11,13,14).

Parents' higher need for the information, as reported in previous studies, underscores the importance of educating parents about cancer, its treatment, and its outcome (5,12,15,16). To equip parents with the required level of knowledge, it is essential to assess their awareness in the study area. This study defines awareness as "the state or ability to perceive, feel, or be conscious of events, objects, or sensory patterns." We assessed the level awareness regarding childhood cancer and its treatment among parents of children with cancer (17). This study, therefore, sought to determine the level of childhood cancer awareness among parents visiting the pediatric oncology unit at Tikur Anbessa Specialized Hospital (TASH). Specifically, it sought to investigate parents' awareness of cancer prior to their child's diagnosis and their perceptions of possible causes.

Methods

Study design, area and period

A cross-sectional descriptive study was conducted as part of the planning to design a family-centered care intervention program from June to December 2022. The study took place at the pediatric oncology unit of TASH, which serves as the primary referral center for childhood cancer treatment for children from all parts of the country. The unit provides care for an estimated 600 children per year and is the main referral center for childhood cancer treatment in a country with more than 120 million people. Care is provided by a team of hemato-oncologists, hemato-pathologists, general practitioners, and nurses.

Study population

A total of 339 parents of children with cancer were consecutively approached. The inclusion criteria were as follows: the child must have a diagnosis of cancer, be visiting either the inpatient or outpatient department of the pediatric oncology unit, be referred to or transferred from other facilities, and identify themselves as a parent/caregiver, defined as someone responsible for day-to-day decision-making regarding the child's care. Parents of critically ill emotionally unstable children were excluded from the study.

Data collection instrument and procedure

Structured questionnaires were administered by interviewers to collect data. The questionnaire was developed based on previous research (12,18) and experts opinions. Initially designed in English, the questionnaire was translated into Amharic and subsequently back-translated into English to ensure consistency. The principal investigator monitored and facilitated the overall data collection process. Six multilingual data collectors with MSc/MPH degrees and two MSc nurses with previous experience in data collection, served as data collectors and supervisors. Training was provided for both data collectors and supervisors before data collection. The training focused on the objectives and importance of the study, the methods for obtaining relevant information, data collection techniques, methods for acquiring informed consent, and the inclusion and exclusion criteria. The issues of confidentiality and privacy were emphasized during the training session. Pretests were conducted at St. Paul Millennium Medical College, leading to necessary modifications based on feedback from the pretest.

Data processing and analysis

The data were collected using an Android app, the Kobo data collection tool, after preparing the data collection template on <u>https://www.kobotoolbox.org/.</u> <u>The date was then</u> exported to SPSS version 26. Prior to further analysis, the data were cleaned. Descriptive statistics were calculated, and the results were presented with tables and graphs. Chi-square was used to assess the association between parent awareness and demographic variables. Statistical significance was declared at a p-value of less than .05.

Ethical Consideration

Ethical approval was obtained by the Institutional Review Board at Addis Ababa University College of Health Sciences, bearing the protocol number 022/22/SPH. Concurrently, consent was obtained from the Pediatric Oncology Unit at TASH. Each study participant provided written informed consent for the interview. A designated location was used to ensure the respondents' physical privacy. Participants were explicitly informed of their right to withdraw from the interview at any point, and their decision to participate or refuse would not affect their access to health services or any other services. No names or other personal information was collected or documented, and all data were treated with confidentiality. We linked the parents who needed further explanation about childhood cancer with a healthcare provider at the center.

Results

Socio-demographic characteristics of the study families

As this study is part of a larger project aimed at designing family-centered comprehensive education and counseling services for parents of children with cancer, the socio-demographic characteristics of parents and children may be shared in a study published elsewhere (19). During the study period, 393 families of children with cancer were approached, and 386 provided complete responses (response rate 98.2%). The respondents ranged in age from 18 to 75 years, with a mean age of 35.24 (SD=9.06). The higher percentage of parents was fathers 184 (47.6%), employed 234 (60.4%), from urban settings 235 (60.9%), and had completed secondary school 136 (35.5%). Ninety-one percent of the families were married or cohabiting. Fifty-three parents (13.6%) said they could make financial savings (Table 1).

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Variables	Category	egory Frequency			
Relationship with child	Mother	153 39.6			
-	Father	184	47.7		
	Brother/sister	20	5.2		
	Others*	29	7.5		
Sex	Male	207	53.6		
	Female	179	46.4		
Age of the parent/guardian	<=29 Years	107	27.7		
	30-39 years	161	41.7		
	>=40 years	119	30.6		
Place of residence	Urban	235	60.9		
	Rural	39.1			
Employment status	Housewife's	90	23.3		
	Currently not employed	62	16.1		
	Currently Employed	234	60.6		
Parent/guardian educational	Illiterate/Read and write	62	16.1		
level	Primary education	88	22.8		
	Secondary education	136	35.2		
	College and above	100	25.9		
Marital status	Currently Married/cohabiting	352	91.2		
	Not Married/not cohabiting	34	8.8		
Income and household expenses	Your household can save money 53 13.				
	Your household spends what it earns	217	56.2		
	Your household eats into its assets and savings	68	17.6		
	Your household gets into debt	12.3			

Table 1: Socio-demographic characteristics of parents/guardians of children with cancer at TASH

*Grandparent, uncle, aunt

General awareness about childhood cancer

Parents of children with cancer were asked about their knowledge of cancer prior to their child's diagnosis. Only 57 (15%) reported having heard about cancer before their child's diagnosis. Most of these

respondents received this information from TV 39 (67.2%), radio 35 (60.3%), and neighbors/relatives 21 (36.2%). Before the child's diagnosis, healthcare providers were identified as a source of information for 17.2% of parents. See Figure 1.



* Others include Peers, internet, working partners, and social media

Figure 1: Source of child cancer-related information before a child's diagnosis among parents of children with cancer at TASH pediatric oncology unit, from June to December 2022 (n=57).

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The majority of parents defined cancer as a fatal disease 213 (55.2%), a worrisome or uncomfortable illness 268 (69.4%), and a painful illness 240 (62.2%). A smaller proportion of parents characterized cancer as a very difficult disease 18 (4.7%), as something that can be cured if treated 7 (1.8%), and as an evil spirit 4 (1.0%). When asked about their knowledge of the causes of childhood cancer, the vast majority, 328 (85.3%) of parents, indicated that they did not know its cause. Among the 57 parents who reported possible causes of cancer, the most frequently stated were processed and packaged foods and drinks, 26 (45.6%),

followed by exposure to radiation, 19 (33.3%). See Table 2.

Regarding parents' awareness of treatment side effects, a significant proportion, and 161 (41.7%), reported having no knowledge of the possible side effects of cancer treatment. The top four side effects mentioned by parents were Vomiting 191 (84.9%), nausea 184 (81.8%), hair loss 179 (79.6%), and infection 149 (66.2%). In addition, these side effects were the most frequently experienced by their children. See Table 2.

Table 2: Child cancer-related awareness among parents of children with cancer at TASH pediatric oncology unit from June to December 2022 (n=386).

Variables	Category	Frequency	Percentage		
How would you define cancer?	A fatal disease	218 56.5			
(n= 386)	A worrisome/uncomfortable illness	271	70.2		
(Multiple answers were	A painful illness	240	62.2		
accepted)	Very difficult disease	18	4.7		
	Can be cured if treated	7	1.8		
	Evil spirit	4	1.0		
	Others (Disease of reach of people, it affects the economy)	2	0.5		
Awareness of causes of	Yes	57	14.7		
childhood cancer(n=365)	No	328	85.3		
Causes of childhood cancer	Packaged Foods	26	45.6		
(n=57)	Radiation	19	33.3		
(Multiple answers were	Smoking during pregnancy	15	26.3		
accepted)	Unhealthy eating style	15	26.3		
	Injury, wound, or infection	10	17.5		
	Unhealthy hygiene	5	8.8		
	Fate	5	8.8		
	Chemical	8	14.0		
	Hereditary	5	8.8		
	Factory disposal	3	5.3		
	Others (Food shortage, From sun, 5 8.8				
	Idiopathic, evil spirits)				
Awareness of treatment side	Yes	225	58.3		
effects (n= 386)	No	161	41.7		
Reported possible child cancer	Vomiting	191	84.9		
treatment side effects ($n=225$)	Nausea	184	81.8		
(Multiple engruence more	Hair loss	179	79.6		
(Multiple answers were	Infection	149	66.2		
accepted)	Loss of appetite	37	16.4		
	Major organ dysfunction	33	12.9		
	Bleeding	3	1.2		
	Behavioral changes	9	3.5		
	Weight loss	9	3.5		
	Fatigue	7	2.7		
	Diarrhea	7	2.7		
	Rush	6	2.4		
	Others (allergies and infertility at a later 2 0.8 age)				
Commonly encountered side	Vomiting	159 72.9			
effects by the child (n=218)	Hair loss	145	66.5		
(Multiple answers were	Nausea	131	60.1		
accepted)	Infection	92	41.3		
	Loss of appetite	52	23.9		
	Major organ dysfunction	5	23		

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Behavior change	5	2.3
Weight loss	6	2.8
Fatigue	5	2.3
Rush	8	3.7
Others (puffy face, diarrhea, abdominal	3	1.4
cramping)		

Parents aware of child cancer treatment

Parents of children with cancer were asked about their knowledge regarding their child's diagnosis and treatment. Three hundred-seventy-nine (98.2%) parents reported that they believe cancer is curable when treated, while 273 (70.7%) said cancer can re-

occur. Only 110 (28.5%) parents reported that they believe the diagnosis should be communicated to their child. The main reason for not disclosing the diagnosis child was the child's age, 145 (53.1%), followed by the concerns about the child becoming frightened 137 (50.2%). See table 3

Table 3: Parents' awareness about child cancer among parents of children with cancer at the TASH pediatric oncology unit from June to December 2022 (n=386).

Category Variables				
Awareness of the medical name	217(56.2)			
Awareness of names of medicines (at least some)				
Awareness of the duration of tre	196(50.8)			
Awareness of painful procedures	262(67.9)			
Awareness of curability with treat	379(98.2)			
Awareness that cancer can re-oc	273(70.7)			
Difficulty in understanding the i	76(19.7)			
Do you think that the child know	128(33.2)			
Should a child be told about their diagnosis?				
Reason for not informing the	They are a child (Developmental limitation)	145(53.1)		
child about their diagnosis	May get frightened	137(50.2)		
(n=273)	Cannot understand	75(27.5)		
	Fear of psychological effects	72(26.4)		
(Multiple answers were	May not cooperate with treatment	31(11.4)		
accepted)	It may become unmanageable	10(3.7)		
	Others (Fear of bullying at school, inability to take food,	3(1.1)		
	He forgets)			

Parents' perception of child cancer

Parents were asked to describe their feelings upon hearing their child's diagnosis for the first time. Accordingly, the most frequently mentioned reaction was shock 330 (85.5%), followed by fear 194 (50.3%). Seventy-one parents (18.4%) responded that they felt they were too late in seeking care for their child. . . For these parents, the reasons for the delay included at self-medication and paying less attention to early signs and symptoms of the disease. When asked why they thought their child had cancer, the majority of parents 279(72.3%) stated that they did not know the cause. One hundred three parents (26.7%) thought it was merely a matter of chance, while 20 (5.3%) and 15 (3.9%) associated it with a history of accidents and linked it to consuming packaged food, respectively. See Table 4.

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Table 4: Parents' perception of child cancer among parents of children with cancer at the TASH pediatric oncology unit from June to December 2022 (n=386).

Variables	Category	Frequency	Percentage	
	Shock	330	85.5	
	Fear	194	50.3	
Parent's first reaction upon	Disbelief	91	23.6	
hearing the diagnosis	Denial	46	11.9	
(n=386)	Helplessness	46	11.9	
(Multiple answers were accepted)	Numbness	40	10.4	
	Anger	37	9.6	
	Ambiguity	23	6.0	
	Sad	14	3.6	
	Other *	30	7.8	
Perceived delay in seeking	Yes	71	18.4	
treatment (386)	No	315	81.6	
	Tried self-medication	27	38.0	
	Giving less attention	17	23.9	
Main reasons for the delay:	Long referral system	12	16.9	
(n=71)	Family issues	6	8.5	
	Lack of transport	6	8.5	
	Others **	19	26.8	
	I do not know	279	72.3	
	It is a matter of chance	103	26.7	
	Accident	20	5.3	
Parent perception of the cause of	Packed food	15	3.9	
their child having cancer (386)	Pregnancy and birth-related ***	6		
(Multiple answers were accepted)	God's curse	5	1.3	
	Hereditary	5	1.3	
	Evil intervention	5	1.3	
	A family member has cancer	3	0.8	
	Spouse's fault	3	0.8	
	Nutrition-related (Malnutrition, food	food 3 0.8		
	shortage, loss of appetite)			
	Others ****	11	2.8	
Others in this table include:				

* Cry, Stress, Nothing, Disturbed, Chance, Pain, Hate Myself

** The hospital procedures and Lack of beds, though they will be cured by it, Lack of transport, Economic problems, Road insecurities, Cultural treatment, though it is another illness

*** born preterm, radiation exposure during pregnancy, history of abortion, birth control, medical professionals' fault that happened during birth and putting the child into warming room without my consent, instability during pregnancy, Lack of breastfeeding, Injection during immunization

**** bad smell associated with animals, microorganisms from plant leaves, Heatstroke, Sweeting in the eye, Lack of cleanness and high temperature, traditional treatment, family curse, blood transfusion, Because of the diaper, Unknown cause, My fault

Association of child-related awareness and sociodemographic characteristics

A chi-square test was conducted to evaluate variations in parents' awareness of childhood cancer before their child's diagnosis, including awareness of the cause of childhood cancer, and the side effects of treatments, based on socio-demographic characteristics. Accordingly, significant variations were observed in parents' awareness of childhood cancer, the causes of treatment and side effects based on their residence and educational level. On the other hand, household income and expenses were associated with parents' awareness about childhood cancer before their child's diagnosis. See Table 5.

Table 5: Association of child-related awareness and socio-demographic characteristics among parents of children with cancer at the TASH pediatric oncology unit from June to December 2022 (n=386).

Category	Heard	about chi	ld cancer	Aware of the causes of child cancer			Aware of side effects		
	Yes	No	p-value	Yes	No	p-	Yes	No	p-value
Relationship with child						value			
Mother	22	136	.614	23	135	.575	89	69	.808
Father	30	148		25	152		106	72	
Others*	6	44		10	40		30	20	
Sex									
Male	32	175	.798	28	178	.386	124	83	.489
Female	26	153		30	149		101	78	
Parent Age									
<=29 Years	12	95	.305	17	90	.623	56	51	.236
30-39 years	29	132		21	140		101	60	
>=40 years	17	101		20	97		68	50	
Place of residence									
Urban	44	191	.011	43	192	.026	151	84	.003
Rural	14	137		15	135		74	77	
Employment status									
Housewife's	8	82	.066	11	79	.689	48	42	.473
Currently not employed	14	48		10	52		39	23	
Currently Employed	36	198		37	196		138	96	
Parent/guardian educational lev	/el								
Illiterate/Read and write	6	56	.004	3	58	.004	27	35	<.001
Primary education	9	79		16	72		40	48	
Secondary education	17	119		15	121		79	57	
College and above	26	74		24	76		79	21	
Marital status									
Currently	51	301	342	50	301	148	201	151	128
Married/cohabiting	51	201		50	501		201	101	.120
Not Married/not cohabiting	7	27		8	26		24	10	
Income and household expense	, S	2,		U	20		2.	10	
Con sava monay	12	40	004	14	30	000	22	20	117
Su an da sub at it a sura	15	40	.004	14	190	.099	120	20	.447
Spends what it earns	21	190		28	189		128	89	
Eats into its assets and savings	5	63		9	58		34	34	
Gets into debt	13	35		7	41		30	18	

*Grandparent, brother, sister, uncle, aunt

Discussion

The current study described parents' awareness of childhood cancer among those visiting tertiary-level hospitals in Ethiopia. Parents play a pivotal role and serve as a crucial factor throughout child care (20,21). Improving parents' understanding by integrating health education into established knowledge and belief systems is vital. This process emphasizes the significance of how individuals perceive health and illness in everyday terms. To this end, this study is unique in its attempt to quantitatively describe the awareness of Ethiopian parents regarding their children's cancer. Thus, the findings from this study will provide vital input to guide the design and delivery of parent education programs.

Our findings indicate that a small proportion of (15%) parents had heard about childhood cancer before their child's diagnosis. This finding is consistent with a qualitative study in a similar setting (7), where parents reported never having heard about cancer before their child's diagnosis and did not anticipate the

occurrence of cancer in the early stages. Parents reported that their child's diagnosis was a significant source of stress. Awareness of cancer has been shown to play an essential role in identifying early cancer symptoms and seeking care (22). Among several factors contributing to delays in parents' treatmentseeking behavior, a lack of awareness may also be a crucial factor. Therefore, interventions to enhance cancer awareness at the community level are essential.

This study also revealed that, among those who were aware of childhood cancer, the primary source of information was mass media (radio and TV); with only a small proportion (17.2%) obtaining information from healthcare providers. A similar study from Türkiye reported that TV and radio were the primary sources of information (12,23). This finding contradicts a previous study (22) that asserted healthcare providers were the most preferred source of information for parents. It underscores the importance of reinforcing awareness creation activities through mass media and considering it as a primary channel for information dissemination. The limited number of parents receiving information from healthcare providers in this study, coupled with the insufficient provision of cancer-related information by healthcare providers in a previous study (23), emphasizes the necessity of enhancing health workers' ability to provide cancer related information.

In addition to care at the hospital, parents are primarily responsible for providing home care to their children, which exposes them to a high burden of childcare (24,25). Hence, to alleviate this burden on parents and enhance parental care, it is crucial for parents to possess sufficient information about the side effects of cancer treatment and their management. Nevertheless, the findings from this study indicate that a substantial proportion of (41.7%) parents are unaware of the side effects of their child's treatment. A similar observation was noted in a previous study (9,10). This absence of awareness may hinder parents' ability to differentiate between the signs and symptoms of the cancer disease and the effects of treatment. Due to this reason, parents may mistakenly associate treatment side effects with a deterioration in their child's health condition, leading to psychological distress (7) and, in the worst cases, the discontinuation of treatment.

A smaller percentage (14.7%) of parents in this study responded positively being aware of the causes of childhood cancer. While some parents identified potential causes such as packaged foods, radiation, and smoking during pregnancy, others mentioned less improbable factors such as fate and evil spirits. This finding is consistent with previous studies (5,12). The variance in how "ordinary" individuals perceive health and illness in their daily lives, as opposed to the "medical" approach, may account for this discrepancy. In alignment with this, some parents cited conditions like a history of accidents, God's/divine curse, and a spouse's fault as causes for their child's illness. Furthermore, parents attributed pregnancy-related factors such as preterm birth, a history of abortion, birth control practices, medical professionals' errors, instability during pregnancy, and injections during immunization= as responsible for their child's illness. These findings underscore the importance of appropriately emphasizing the education of parents regarding the causes of cancer.

In the present study, a substantial proportion of parents were found to lack awareness about the medical name of their child's cancer (43.8%) and the names of the medicines (at least some) their child is receiving (41.5%). Additionally, half of the (49.2%) parents are unaware of the duration required for their child's treatment. This discovery aligns with a qualitative study conducted among parents of children with cancer, in which one parent expressed the challenge of obtaining accurate information about her child's diagnosis (7). Similarly, previous studies have reported that a lower proportion of parents received information about their child's clinical condition (9,26). This is discordant with the parents' need for factual information about their child's health status (27). Therefore, it is important to prepare structured

educational materials and facilitate the delivery of information by healthcare providers to inform parents about their state child's cancer health status.

In addition, almost all (98.2%) parents believe that their child's cancer can be cured with treatment. This finding aligns with prior research indicating that parents of children with cancer frequently maintain optimism regarding their child's prognosis, often holding prognostic estimates that are higher than those provided by their physicians (13,14). This tendency of optimistic harboring overly and unrealistic expectations among parents may be associated with several factors including physicians having little confidence in the child's prognosis, misestimating of prognosis, physicians depending on excessively positive statements, avoiding challenging discussions about the prognosis, or parents' incorrect perceptions of the conveyed prognosis (13,14,28,29). How physicians convey prognostic information can significantly impact parents' perceptions of the severity of the clinical situation. Healthcare providers often bolster parental hopes and tend to omit discussions about the incurable nature of the disease (30). Moreover, 66.8% of parents stated that they do not believe a cancer diagnosis needs to be noted to their child. This finding is consistent with a previous study, which reported that 77.7% of mothers would not tell their child about the cancer diagnoses (11).

Regarding the primary reaction of parents upon first hearing about their child's diagnosis, they were found to be shocked and fearful. This response may be linked to the method of communication used to deliver the diagnosis and the healthcare providers' skills in conveying bad news. This is further supported by parent's definitions of cancer as a fatal disease, worrisome/uncomfortable illness, and a painful illness.

Limitations of the current study include the absence of a standardized tool for measuring parental awareness and knowledge, which makes it challenging to calculate an overall level of awareness and perform additional statistical analyses. The cross-sectional design and single institution nature of the study may also impede the generalization of findings to the broader population. Additionally, the study is susceptible to recall bias, as some responses relied on the parents' memory.

Conclusion and recommendation

In summary, the overall awareness of parents regarding childhood cancer, treatment side effects, and the causes of cancer was observed to be low. The majority of parents defined cancer as a fatal disease, a source of fear, an uncomfortable illness, and a painful condition. Only one in seven parents claimed to know the cause of childhood cancer, and approximately two in five parents lacked awareness about treatment side effects. Shocked and fear were the most common initial reactions to a child's diagnosis. Nearly all parents harbored overly optimistic and unrealistic expectations about the outcome of their child's treatment. Awareness before diagnosis, understanding of the causes of childhood cancer, and awareness of treatment side effects were associated with parental place of residence, educational level, and household savings.

Based on the findings of this study, we recommend enhancing the involvement of healthcare workers and reinforcing the delivery of child cancer-related awareness through mass media channels (radio and TV) to reach a larger segment of the community. For parents of children with cancer, it is advisable to design and implement structured education and counseling programs focusing on the causes of childhood cancer, its treatment, treatment side effects, and prognosis.

Availability of data and materials

All data sets analyzed during the current study are available within the manuscript.

Conflict of interests

The authors declare that they have no conflicting interest in the performance and publication of this review.

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Reference

- Bhakta N, Force LM, Allemani C, Atun R, Bray F, Coleman MP, et al. Childhood cancer burden: a review of global estimates. The Lancet Oncology. Elsevier Ltd; 2019. pp. e42–e53. doi:10.1016/S1470-2045(18)30761-7
- Pritchard-Jones K, Pieters R, Reaman GH, Hjorth L, Downie P, Calaminus G, et al. Sustaining innovation and improvement in the treatment of childhood cancer: Lessons from high-income countries. Lancet Oncol. 2013;14: e95–e103. doi:10.1016/S1470-2045(13)70010-X
- Belay A, Ali A, Ayele W, Assefa M, Jemal A, Kantelhardt EJ. Incidence and pattern of childhood cancer in Addis Ababa, Ethiopia (2012–2017). BMC Cancer. 2023;23: 1–7. doi:10.1186/s12885-023-11765-7
- Dang-Tan T, Franco EL. Diagnosis Delays in Childhood Cancer A Review. Am Cancer Soc. 2007;110. doi:DOI 10.1002/cncr.22849
- 5. Uribe-Ortiz L V., Garza-Ornelas BM, Vázquez-Fernández AC, Castorena-Torres F, Rodríguez-De-Ita J. Exploring knowledge of parents and caregivers on cancer symptoms in children: an observational study regarding the need for educational tools and health promotion in low- and middle-income countries. BMC Pediatr. 2022;22: 1–12.

doi:10.1186/s12887-022-03686-4

- Othman A, Mohamad N, Hussin ZA, Blunden S. Psychological Distress and Associated Factors in Parents of Children with Cancer. 2011;1. doi:10.7763/IJSSH.2011.V1.7
- Deribe L, Addissie A, Girma E, Abraha A, Adam H, Berbyuk Lindström N. Stress and coping strategies among parents of children with cancer at Tikur Anbessa Specialized Hospital paediatric oncology unit, Ethiopia: a phenomenological study. BMJ Open. 2023;13: e065090. doi:10.1136/bmjopen-2022-065090
- Muktar AM, Salifu A, Deme-Der, Ayiwor. Childhood Cancer Knowledge Among Parents Whose Children Are on Admission At the Paediatric Ward of Tamale Teaching Hospital (Tth). 2023;10: 117–128. Available: https://doi.org/10.47740/782.UDSIJD6i
- Shaima E, Hasan G, Mohamed SA, Ahmed SM, Fathy K, Sayed R, et al. Knowledge and Performance of Mothers Having Children with Cancer Undergoing Chemotherapy. Minia Sci Nurs J. 2020;8. doi:10.21608/MSNJ.2020.188042
- Bahig D, Akl A, Hassan N, Abdella A, Ahmed A, Morsy K. Assessment of Knowledge and Reported Practice of Mothers Having Children with Cancer and Undergoing Chemotherapy. 2016;3: 102–112. doi:10.21608/pssjn.2016.32515
- Hizel S, Toprak S, Albayrak M, Sanli C, Koçak Ü. Mothers' knowledge, attitudes, and behaviour concerning childhood cancer in a rural Anatolian province. Gazi Med J. 2009;20: 3–6. Available: https://hdl.handle.net/20.500.12587/2097
- Demirbağ BC, Kürtüncü M, Güven H. Knowledge of Turkish Mothers with Children in the 0-13 Age Group about Cancer Symptoms. Asian Pacific J Cancer Prev. 2013;14: 1031–1035. doi:10.7314/apjcp.2013.14.2.1031
- Levine DR, Cuviello A, Nelson C, Lu Z, Mandrell BN. Hope-Colored Glasses : Perceptions of Prognosis Among Pediatric Oncology Patients and Their Parents original contributions Hope-Colored Glasses : Perceptions of Prognosis Among Pediatric Oncology Patients and Their Parents. 17. doi:10.1200/OP.20.00762
- 14. Mack JW, Cook EF, Wolfe J, Grier HE, Cleary PD, Weeks JC. J OURNAL OF C LINICAL O NCOLOGY Understanding of Prognosis Among Parents of Children With Cancer : Parental Optimism and the Parent-Physician Interaction. 2007;25: 1357–1362. doi:10.1200/JCO.2006.08.3170
- 15. Arabiat DH, Altamimi A. Unmet care needs of parents of children with cancer in Jordan: implications for bed-side practice. 2012; 531–539. doi:10.1111/jocn.12122
- 16. Mack JW, Wolfe J, Grier HE, Cleary PD, Weeks JC. Communication about prognosis between parents and physicians of children with cancer: Parent preferences and the impact

of prognostic information. J Clin Oncol. 2006;24: 5265–5270. doi:10.1200/JCO.2006.06.5326

- 17. Gafoor K. Considerations in measurement of awareness. 2012. doi:10.13140/2.1.2109.2643
- Nair M, Paul LT, Latha PT, Parukkutty K. Parents' knowledge and attitude regarding their child's cancer and effectiveness of initial disease counseling in pediatric oncology patients. Indian J Palliat Care. 2017;23: 393– 398. doi:10.4103/IJPC.IJPC_83_17
- Deribe L, Addissie A, Girma E, Gidey A, Teferra S, Lindström NB. Level of Family centered care and associated factors among parents of children with cancer at tertiary level hospital, Ethiopia. J Pediatr Nurs. 2024;0. doi:10.1016/j.pedn.2024.01.020
- Lor M, Crooks N, Tluczek A. A proposed model of person-, family-, and culturecentered nursing care. Nurs Outlook. 2016;64: 352–366. doi:10.1016/j.outlook.2016.02.006
- Committee on hospital care and institute for patient- and family-centered care, Eichner JM, Johnson BH, Betts JM, Chitkara MB, Jewell JA, et al. Patient- and Family-Centered Care and the Pediatrician's Role. Pediatrics. 2012;129: 394–404. doi:10.1542/peds.2011-3084
- 22. Szamreta EA, Wayser GR, Prabhu VS, Mulvihill E, Aguinaga K, Salani R. Information needs during cancer care: qualitative research with advanced cervical cancer patients in Brazil, China, Germany, and the United States. Gynecol Oncol Reports. 2022;101131. doi:10.1016/j.gore.2022.101131
- Gultekin M, Ozgul N, Olcayto E, Tuncer M. Level of knowledge among Turkish people for cancer and cancer risk factors. Clin Investig (Araflt>rma. 2011;8: 57–61. doi:10.5505/tjod.2011.93446
- Clarke JN, Fletcher PC, Schneider MA. Mothers' home health care work when their children have cancer. J Pediatr Oncol Nurs. 2005;22: 365–373. doi:10.1177/1043454205281834
- Elcigil A, Conk Z. Determining the Burden of Mothers with Children Who Have Cancer. 2010;3: 175–181.
- Pule Q, Mulilo E, Lushinga L, Miti J, Katowamukwato P. Caregivers satisfaction with care received by paediatric oncology patients admitted at the University Teaching Hospital-Lusaka Zambia. 2018;8: 22–29. doi:10.5430/jnep.v8n6p22
- Iconomou G, Vagenakis AG, Kalofonos HP. The informational needs, satisfaction with communication, and psychological status of primary caregivers of cancer patients receiving chemotherapy. 2001; 591–596. doi:10.1007/s005200100259
- Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. BMJ. 2000;320: 469–473. doi:10.1136/bmj.320.7233.469

- 29. Christakis NA, Iwashyna TJ. Attitude and self-reported practice regarding prognostication in a national sample of internists. Arch Intern Med. 1998;158: 2389– 2395. doi:10.1001/archinte.158.21.2389
- Miller VA, Cousino M, Leek AC, Kodish ED. Hope and Persuasion by Physicians During Informed Consent. 2014;32: 3229–3236. doi:10.1200/JCO.2014.55.2588