# **Knowledge of Turkish Mothers with Children in the 0-13 Age Group about Cancer Symptoms**

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# Abstract

Background: There have been few studies in Turkey on the incidence of childhood cancers. A mother's knowledge about signs and symptoms of cancer is important for early diagnosis, effective treatment, and improvement of life expectancy. This study was conducted with a group of mothers of children, aged 0-13, at a Family Health Center (FHC) in Turkey's Eastern Black Sea Region, to analyze their knowledge about cancer symptoms in childhood. <u>Materials and Methods</u>: The study group of this descriptive/cross-sectional research comprised 2,061 mothers, ages 19-49, at an FHC in the Eastern Black Sea Region in February 1, 2011 - June 1, 2011. Before the study, permission was obtained from the local ethics board and the institutions concerned. A value of p<0.05 was accepted as statistically significant. <u>Results</u>: Of the mothers, 34.9% were between the ages of 40-47, 40.5% had three children, 73.8% had no experience with children with cancer, 45.9% said they learned about cancer on television, 39.7% stated that the primary reason for childhood cancer was the mother's smoking during pregnancy, 68.8% said that early diagnosis would save a child, and 98% wanted to learn about childhood cancer. <u>Conclusion</u>: It was determined that the mothers' knowledge of cancer was deficient.

Keywords: Cancer symptoms - children - knowledge - mother

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# Introduction

Cancer is a potentially fatal disease with high incidence that threatens health and family in society, taking second place in terms of mortality in Turkey and in many other countries in the world after cardiovascular disease. (Bilge and Ünal, 2005; Peter and Bernard, 2008). According to a report published in Turkey titled "Cancer Burden 2006" (The Burden of Cancer, 2006), every year, 11 million people in the world and 150,000 in Turkey develop cancer (Bilge and Ünal, 2005; Peter and Bernard, 2008).

Of the cancers seen in a human being's lifetime, 1-2% are diagnosed in children. In Turkey, 2500-3000 children under the age of 15 are newly diagnosed with cancer each year. Due to better living conditions and new treatment methods and drugs, dramatic improvements have been observed in life expectancy rates in the last 10-20 years. While survival rates were in the range of 10-20% in the 1960s, in 2010, one out of every 600 people over the age of 25 who had been diagnosed with cancer were cured (Emir, 2009).

Today, medicine has understood the nature of cancer and significant advances have been made in treatment methods. With developing technologies and methods of treatment, cancer patients can now live longer lives. On the other hand, caring for a child with cancer and the onset of illness in a family disrupts the daily routine and life experiences of all family members (Rivero-Vergne et al., 2006). Childhood cancers (CCAs) five-year survival now exceeds 70-80% (Vegian et al., 2012). The incidence of cancer in children under 15 years of age is 110-150 in a million; cancer in children is rare compared to adults and only 0.5% of all cancers are diagnosed in children younger than 15. Cancer is second in the leading causes of children's deaths in the United States and in many other developed countries; though not second in Turkey, child deaths from cancer are among the first four major causes of death (Ünal and Tuncer, 2004; Kutluk, 2007). There is no study in Turkey on the incidence of childhood cancers. As with other cancers, the development of childhood cancer takes a certain period of time (Esin et al., 2004). In this period, a mother's knowledge of the signs and symptoms of cancer is very important for early diagnosis, effective treatment, and in terms of life expectancy. As cancer and its effects spread and produce an impact over the whole of society, it is unfortunate that there has not been an adequate number of studies in Turkey that have explored the general level of knowledge, sensitivity and awareness about this disease. A look into studies of cancer incidence in Turkey shows that cancer in the Black Sea

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Region is no different than in other parts of the country (Peter and Bernard, 2008). It is however a fact that since the Chernobyl accident of 1986, the Black Sea Region continues to draw attention because of the potentially dangerous hazards it still presents in terms of cancer. After the Chernobyl incident, all of the surrounding countries recorded a heightened risk of thyroid cancer and leukemia (Emir, 2009). The area in which the present study was conducted was also exposed to the Chernobyl risk.

This study was conducted with mothers of children in the 0-13 age group who had come to the Family Health Center of a province in Turkey's Eastern Black Sea Region, for the purpose of analyzing the level of knowledge mothers displayed in the context of identifying cancer symptoms in their children.

## **Materials and Methods**

## Design and setting

The universe of this descriptive/cross-sectional study was derived from the Family Health Center (FHC) in a province in the Eastern Black Sea Region during the period February 1, 2011 - June 1, 2011.

#### Participants

The FHC located in Trabzon accepted 3816 mothers with children of the ages 0-13. Of these mothers, 2061 agreed to participate in the study. Prior to the start of the study, permission was obtained from the ethics board and the institution concerned. All of the women were provided with information about the study and their verbal consent was obtained. Mothers not within the 19-49 age group, mothers whose children were not in the 0-13 age group, and mothers who had not been registered at the FHC where the study took place, were excluded from the research.

#### Data collection tools

The mothers were asked to fill out a questionnaire which had been drawn up by the researchers. The questionnaire contained questions about the individuals' socio-demographic characteristics and cancer symptoms. The form was filled out by the researchers in a face-to-face interview with the mothers; each interview was completed in 15 minutes. The questionnaire, which the researchers prepared and developed based on the literature, consisted of 20 questions on the mothers' socio-demographic characteristics and the distribution of the mothers' statements about children's cancer symptoms, as well as the statements of their first reactions to the word "cancer".

#### Data analysis

The statistical analysis of the collected data was performed over the electronic medium. Percentages and the Chi-square test were used for the evaluation of the data. The tests were assessed with p<0.05 being accepted as statistically significant.

#### Ethical approach

Permission was obtained for the implementation of the study from the local ethics board of the province. The cooperation of the doctors, nurses and other employees

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of the FHC was enlisted by explaining to the health professionals the goal of the study and the methods that were to be used. An explanation of the objective, plan and benefits of the study was provided to the mothers and they were requested to sign a patient information sheet. In the light of these explanations, the mothers agreeing to participate in the study were asked to sign a consent form.

## Results

Of the mothers in the study, 34.9% were between the ages 40-47, 46.5% were primary school graduates, 67.7% were unemployed, 40.5% had three children, 55.9% had no chronic disease, and 53.4% were non-smokers (Table 1).

As can be seen in Table 2, 73.8% of the mothers had experience with children with cancer, 68.8% had seen children with cancer at the hospital/on the street/on television, 45.9% stated they had learned about cancer on television, 39.7% stated that smoking during pregnancy was the foremost cause of childhood cancers, 49.9% said that lung X-rays/tomography/ultrasonography should be taken/performed as a precaution to achieve an early diagnosis in children, 49.6% stated that X-rays were important for early diagnosis, 68.8% asserted that early diagnosis could save a child's life, 51.3% spoke of cancer as a fatal disease and 98.1% expressed the desire to receive more education in the early diagnosis and treatment of childhood cancers (Table 2).

As can be seen in Table 3, in the responses given concerning the symptoms of children with cancer, the symptoms mentioned by the mothers were: purple bruising in various parts of the body (50.5%), weight loss (37.7%), nose-bleeds (30.8%), the inclination to sleep (29.4%), swelling in different parts of the body (27.3%), anemia (24.7%), lack of appetite (21.1%), vomiting (18.6%), fever (19.1%), enlarged abdomen (19%), night sweats (18.6%),

Table 1. Identifying Characteristics of Mothers

		n	%
Age	19-25	258	12.5
U	26-32	433	21
	33-39	410	19.9
	40-47	720	34.9
	≥48	240	11.6
Educational status	Literate	646	31.3
	Primary school	958	46.5
	High School	338	16.4
	University	119	5.8
Health insurance	Social Insurance Institut	ion 789	38.3
	Vinculación	925	44.9
	Retired	300	14.6
	Green card	47	2.3
Working Status	Employed	666	32.3
	Unemployed	1395	67.7
Number of children	≤4	1962	95.2
	≥5	99	4.8
Smoking experience	oking experience Smoking (all the time/once in a while		ile)
		960	39.3
	Non-smoking	1101	53.4
Chronic Illness Status	Yes	922	44.1
	No	1139	55.9

 Table 2. Identifying Characteristics of Mothers with

 Children Diagnosed with Cancer

0			
	n	%	
Experience with children with cancer			_
Yes	1520	73.8	
No	541	26.2	
Relation of the child with cancer			
Relative	287	13.9	
Friend/neighbor	187	9.1	
I've seen children with cancer in the hos	pital/on		
the street/on TV	1046	68.8	1(
Source of information about cancer			
TV	947	45.9	
School	416	20.2	
Health professionals	484	23.5	7
Neighbor/relative	201	9.8	
Newspaper/magazine	13	0.6	
What kinds of childhood cancers are there?			_
Leukemia	1020	49.4	5
Lymph cancer	880	42.6	
Lung cancer	161	7.8	
Causes of cancer in children			_
Smoking during pregnancy	819	39.7	4
Unhealthy eating style	317	15.3	
Unhealthy hygiene	105	5.2	
Radiation	682	33.2	
Fate	138	6.6	
I pay attention to cleanliness	248	12.1	
How would you define cancer?			
A fatal disease	1066	51.3	
A worrisome/uncomfortable illness	881	42.7	
A painful illness	185	6	
Asking for education on the subject of prote	cting child	ren fro	m
and treating childhood cancers	0		
Yes	2020	98.1	
No	41	1.9	

 Table 3. Distribution of Mothers' Statements about

 Childhood Cancer Symptoms

	n	%
Purple spots	1041	50.5
Weight loss	778	37.7
Nose-bleeds	635	30.8
Inclination for sleep	605	29.4
Swelling in the body	563	27.3
Anemia	509	24.7
Loss of Appetite	435	21.1
Fever	393	19.1
Swollen Abdomen	391	19
Vomiting	383	18.6
Night sweats	384	18.6
Headaches	373	18.1
Speech Disorders	320	15.5
Motor Disorders	280	13.6

Table 4. Distribution of Mothers' First Reactions tothe Word "Cancer"

Statements	n	%
Very bad pains	1266	61.4
Loss of hair	411	19.9
Chemotherapy/Radiotherapy	226	11
Faces with masks	158	7.7
Total	2061	100

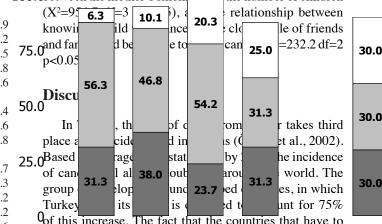
headaches (18.1%), speech disorders (15.5%), and motor disorders (13.6%) (Table 3).

An analysis of the mothers' first association when the word "cancer" was mentioned showed that 61.4% mentioned very bad pains, 19.9% loss of hair, 11% chemotherapy, and 7.7% said faces with masks (Table 4).

The following relationships were found to be statistically significant: the relationship between the mother's education and the manner in which she learned about cancer ( $X^2$ =779.3 df=3 p<0.05), the relationship **00.0** between the mother's smoking and the number of children

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None



Of this increase. The fact that the countries that have to face carrying this heavy load are the pages of the world that have access to only 5% of the world audget that will be allotted to this gause makes it impedative for these countries to focus on cancer control programs and early diagnosis Tuncer, 2009).

Activities in Turkey conducted within the scope of the national cancer control program fall into four main headings Prevention, screening and early diagnosis, treatment and palliative care (Tuncer, 2009). In our study, the mother had a low level of education, they had between 4-6 children, and all of them showed the desire to receive education in this subject. This finding indicates that cancer control programs in our country are still inadequate.

As cancer and its effects spread and produce an impact over the whole of society, it is unfortunate that there has not been an adequate number of studies in Turkey that have explored the general level of knowledge, sensitivity and awareness about this disease. There is deficiency in Turkey in the level of information doctors pass on to patients and the public on certain subjects (Acikgöz et al., 2011). The public needs to be informed to visit the places or the persons when they have complaints or early cancer semptoms (Ali et al., 2006). It has been reported in one study that knowledge about cancer is mostly gleaned from TV and that the percentage of people who have not received any information from health professionals is high (Gültekin et al., 2011). In particular, it would be expected that family doctors would inform mothers about cancer since it is the mother who is the more effective figure in child care. The finding of the present study that indicates that mothers get most of their information about cancer from television and express their thoughts that health professionals are deficient in educating mothers is consistent with the literature.

A study conducted in Turkey found from the responses given to questions about early diagnosis that a general

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check-up was seen to be the first useful method, and that having X-rays taken was second (Gültekin et al., 2011). In the mothers' responses to the question on "What should be done to achieve early diagnosis and protect the child?" most of the mothers in the present study believed that X-rays would be the most useful method, a finding that openly suggests a lack of knowledge. The results point to a low level of education in Turkey concerning early diagnosis and treatment. That almost all the mothers in the study showed a desire for more education in this context is another indication of this deficiency.

Among all cancers in the U.S., the annual cancer rate in children under the age of 14 is around 1/7000 (Gültekin et al., 2011). Childhood cancers have various characteristics that differentiate them from adult versions. Furthermore, types of childhood cancers differ from adult cancers in terms of their biological nature, the prognosis and responses to treatment. In some developing countries, leukemia is the most prevalent, while in others lymphomas take the lead (Stiller, 2004). In Turkey too, leukemia is the leading type of childhood cancer (Çavdar et al., 2012). In particular, acute lymphoblastic leukemia, although more rare in children under the age of 15, has been found to peak at ages 2-5 (Lanzkowsky, 2005). In our study, most of the mothers defined childhood cancer as leukemia.

A study with pediatric oncology patients reported that mothers were primarily responsible for the homecare of their children (Yılmaz et al., 2005). Another work of research stated that mothers were the persons who were effectively responsible for their children's care and that they spent 60% of their time at home caring for their children (Clarke et al., 2005). Studies both in Turkey and abroad have shown that, despite cultural differences, the roles and responsibilities of parents are similar and it is mostly women who take on the task of child care (Özdemir et al., 2009). These results clearly show that mothers must be the bridge that connects symptoms in the child to early diagnosis. The women in the study expressed their belief that they did not have adequate information and also showed the desire to receive education.

The habit of smoking does not only affect mothers themselves in pregnancy but also puts the baby's life at risk. Smoking in pregnancy is a major but preventable risk in terms of mortality and morbidity (Valanis et al., 2001; Dede and Çınar, 2010; Karatay et al., 2010). It has been reported that exposure of children to cigarette smoke during childhood leads to behavioral disorders and learning difficulties, hyperactivity and low IQ (Valanis et al., 2001; Dede and Çınar, 2010; Karatay et al., 2010; Rebholdz et al., 2012). It has been asserted that in the U.S., 15 million children and adolescents are exposed to their parents' cigarette smoke in their own homes (American Legacy Foundation, 2012). According to the data of the World Health Organization, more than half the children in the world are exposed to environmental cigarette smoke (World Health Organization, 2008). In Turkey, despite the fact that no data could be found about the country in general, it has been observed through small samplings that the extent of children's smoke exposure is quite pronounced (Boyacı et al., 2004; Bernstein et al., 2005). It was seen that the response of most of the mothers in the study to the question, "What do you think causes cancer?" was "Smoking during pregnancy." At the same time, however, the low rate of smoking among the mothers is a heartening result to consider.

Studies show that it is important in terms of the treatment of cancer that persons (especially mothers for childhood cancers) are aware of the signs and symptoms and can contribute to the process of early diagnosis and treatment (Öztürk et al., 2006; Hızel et al., 2009). The literature stresses that the more common symptoms of childhood cancer are paleness, loss of appetite, weight loss, and fever that does not disappear with antibiotics (Lanzkowsky et al., 2005). In a study conducted with 3096 people in Turkey, the most common responses to the question posed about cancer symptoms were fatigue, loss of appetite, and weight loss (Gültekin et al., 2011). The most common response in the present study was the presence of purple spots on the body.

The cancer phenomenon is as much an issue with mental and social components as it is a physical condition. Beyond its being a serious and chronic illness, it is perceived as a disease that harbors within it uncertainty, death associations, feelings of guilt, the fear of abandonment, panic, hostility, anger and anxiety (Hızel et al., 2009). An analysis of what mothers thought of first when they were asked what they associated the word "cancer" with showed that the more common associations were very bad pains, loss of hair, and chemotherapy.

In conclusion and recommendations, the results of the study indicated that the mothers: 1) referred to purple spots on the body as the first identifying symptom of cancer; 2) pointed to smoking in pregnancy as the primary cause of cancer; 3) had had experience with children with cancer; 4) had gotten most of their information about childhood cancer on TV; 5) wished to be informed about childhood cancers; 6) knew mostly about leukemia among the childhood cancer as a fatal illness; 8) referred to very bad pains as their first association when hearing the word "cancer".

The results indicate to all of us in the healthcare sector that care must be taken to inform mothers about cancer at every opportunity. In terms of the facility that the services of the healthcare sector in Turkey provide, it is clear that individuals, especially mothers, are easily able to access and communicate with the Family Health Centers that provide primary care to the public. Institutions engaged in primary care should have planned programs in which mothers are educated about cancer at regular intervals. In particular, mothers must be provided with the awareness of how important early diagnosis and the identification of cancer symptoms are in the treatment of cancer.

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