

Causal Perceptions in Turkish Parents of Children with Cancer

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OBJECTIVE

To more fully explore how the parents of childhood cancer patients perceive the causes of their disease.

METHODS

This cross-sectional study included 229 parents of children with cancer who were admitted at one of the largest children's hematology and oncology clinics in Ankara, Turkey. The parents completed the causal representations subscale of the Illness Perception Questionnaire. Analyses of variance and other descriptive tests were performed.

RESULTS

The most common causal attributions were a function of the Risk Factors Subscale (M=2.94) pertaining to diet and eating disorders. The answers to the open-ended questions indicated that the most significant issue in their children's disease was faith-based, the will of God, and the "evil eye" (43.9%). The mean scores on the subscale did not vary by parental, marital, educational status, region of residence, or time of diagnosis; there was only a significant difference based on income level and age.

CONCLUSION

Parents responding in a self-report on the causal representations subscale suggested that most risk factors involved more fatalistic views, which were due to societal differences. This is important for clinicians, who plan and implement education and treatment, to better understand parents' perceptions regarding cancer. Our findings highlight the need for more attention to these cultural matters in cancer care.

Keywords: Childhood cancer; cancer perception; parents. Copyright © 2018, Turkish Society for Radiation Oncology

Introduction

The International Agency for Research on Cancer report indicates that about 300,000 children aged <19 years worldwide were diagnosed with cancer between 2001 and 2010. It is estimated that childhood cancer causes 80,000 deaths worldwide every year.[1] According to the records of the Turkish Pediatric Oncology Group from 2002 to 2009, 11,898 children were affected with cancer in Turkey.[2] Childhood cancers used to have high mortality rates; however, today cancer has become a life-threatening chronic disease rather than a mortal disease thanks to advances in cancer treatment. [3] Despite this significant decrease in mortality, the perception of mortal disease lingers within the society. Cancer is a disease that arouses feelings of fear, uncertainty, guilt, helplessness, and death.[4,5,6,7] Therefore, the diagnosis of cancer in children negatively affects both the children and their parents emotionally, socially, mentally, and spiritually, apart from the physical effects of cancer.[3,8]

Although the causes of childhood cancer are not known with certainty, some structural and environmental risk factors that play a role in the development of cancer have been identified. These include congenital or genetic anomalies, immunodeficiency syndromes, virus infections, exposure to radiation or some chemicals [such as benzene or pesticides], and some medicines used during pregnancy.[9] Individuals may develop theories about the cause of cancer that may not be based on scientific knowledge. Such attempts to understand or make sense of the illness are described as causal attributions.[10] Causal attributions can be classified by locus [internal or external], controllability, and modifiability.[11]

Previous studies have shown that people's opinions on the causes of cancer are differs. For example, adult cancer patients have stated the causes of cancer to be mostly misfortune or bad luck.[12] Patients with lung cancer listed the causes of their disease to be smoking, bad luck, working hard, stress, genetic, or familial factors, nutritional habits, or work environment.[6] In a large study of American Cancer Society on cancer survivors, the 10 most common causes of cancer declared were lifestyle, biological, environmental, smoking, chance/luck, stress, existential, prior health condition, psychological.[11]

The level of knowledge regarding the causes of childhood cancer among parents remains uncertain. [5] The limited number of studies conducted on parents of children with cancer reported that the parents stated psychosocial problems [13], emotional stress and nutrition [14], and faith and their insufficiency in their maternal role.[15] In the studies conducted on parents of healthy children in Turkey, the participants stated that cancer is most frequently caused by smoking, foods (prepared food stuffs, food additives, barbecue, tea, etc.), alcohol, radiation, environmental pollution, stress, sorrow, genetic factors, sun, bacteria or viruses, or cell phones.[5] There is no study about causal perceptions in Turkish parents of children with cancer. As known, perceptions vary by cultural characteristics; hence, this study will contribute to the literature about these cultural differences.

Causal attributions may affect cancer survivors' quality of life, psychosocial adjustment, and distress levels [11,16], and they may increase one's perception

of control [17], which could affect overall adjustment to a cancer diagnosis. Nevertheless, parents understanding the causes of their children's disease could affect coping, reduction of negative beliefs, effective control of the treatment process, prevention of cancer, and adherence to postcancer treatment.[14,18] Positive compliance of parents with the treatment contributes to the children's adherence to the disease and treatment process along with their development. [8,13,14,19]

Determining the parents' causal attributions for their children's cancer could be guide pediatric nurses to plan family-oriented interventions and ensure the compliance of children and their parents with treatment. This study aims to determine parents' causal attributions for their children's illness and differences according to sociodemographic factors.

Materials and Methods

Sample and Setting

This study had a cross-sectional design. The sample consisted of the parents of the patients hospitalized between February 2014 and January 2015 in the Pediatric Hematology and Oncology Unit of Ankara University Cebeci Children's Hospital (n=229) who agreed to participate in the study with consecutive sampling. This hospital accepts patients from all over Turkey because it has one of the largest children's hematology and oncology clinics in the capital city of Turkey.

Inclusion criteria were being a parent of a cancer patient hospitalized in the Pediatric Hematology and Oncology Unit of Ankara University Cebeci Children's Hospital. Parents who have cognitive/neurological problems and who refuse to participate in the study were excluded from the study.

Measures

The data were collected using an Introductory Information Form and the Causal Representations subscale of the Illness Perception Questionnaire (IPQ). The scales were administered by the researchers to the parents who met the inclusion criteria and agreed to participate in the study. Questionnaires fulfilled with face-to-face interviews in the parent's resting area. The Introductory Information Form. This was prepared by the researchers and consisted of eight questions on the age, gender, marital status, educational status, socioeconomic status, region of residence, children's diagnosis, and the time passed after the children had been diagnosed.

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Socio-demographics	n	%
Parental Status		
Mother	212	92.6
Father	17	7.4
Parental age (years)		
19-24	12	5.2
25-30	41	17.9
31-35	61	26.6
36-40	61	26.6
41-45	36	15.7
46+	18	7.9
Marital Status		
Married	221	96.5
Single/Divorced	8	3.5
Income Level		
Medium	135	59.0
Low	83	36.2
High	11	4.8
Education Status		
Illiterate	11	4.8
Primary school	95	41.5
Secondar school	31	13.5
High school	65	28.4
Graduate/Postgraduate	27	11.9
Region of Residence		
Ankara	102	44.5
Outside of Ankara	127	55.5
Time of diagnosis		
0-6 mth	66	28.82
7-12 mth	75	32.75
13-60 mth	78	34.06
Over 60 mth	10	4.36
Diagnoses		
Leukemia	103	45.0
Lymphoma	19	8.3
Central Nervous System tumours	22	9.6
Neuroblastoma	6	2.6
Retinablastoma	8	3.5
Nephroblastoma	1	0.4
Hepatoblastoma	4	1.7
Bone Tumours	48	21.0
Soft Tissue and Extraosseal Tumours	8	3.5
Malignant Epithelial Carcinomas	1	0.4
Others	9	3.9

The Causal Representation Subscale of the IPQ. This was used to determine the causes of cancer perceived by parents of children diagnosed with cancer. Question-naire was developed by Weinman (1996) [10], revised by Moss-Morris et al. (2002) [21] and adapted in Turk-ish by Armay et al. in 2007.[4] The Causal Representa-

tion Scale, a five-point (from 1 representing "strongly disagree" to 5 representing "strongly agree") Likert type, consists of four subdimensions and a total of 18 items. The subdimensions are Psychological Attributions, Risk Factors, Immunity, and Accidental, or Chance. The scale, developed to determine the causes of disease in adult patients, was re-organized for adaptation to childhood cancers. The item "My mental attitude" was excluded from the possible causes, and the item "aging" was changed to "growing." A pilot administration was performed with parents of 10 children with cancer using the final subscale with 17 items. In addition, the parents were asked to indicate the three most significant causes of their children's disease (they could either make choices from the table in the subscale or write what they thought to cause cancer) to allow qualitative assessment. The aim was to learn the parents' own thoughts beyond subscale limitations. Causal representations subscales were reported high internal reliability and Cronbach's alpha value ranging from 0.41 to 0.78.[4] In the present study, the Cronbach's alpha coefficient of the Causal Representations subscale was found to range between 0.42 and 0.66 [Table 2].

Data Analyses

The sociodemographic data were analyzed using descriptive statistical analysis (frequency, mean, and percentage) methods. The multiple analysis of variance (MANOVA) test was used to analyze the total scores of the Causal Representation subscales according to independent variables (sociodemographics as age, parental status, marital status, education status, income level, region of residence, and time of diagnosis variables). Post hoc (Schefe) tests were used to find out, which variable is the source of the difference. All analyses were performed using the SPSS 21 package.

Ethical Consideration

The study was conducted according to the precepts of the Helsinki Declaration. The approval of the Ethics Committee of Ankara University Rectorate (Decision no: 1288, Dated: 10.1.2014) and the permission of the Head of Ankara University Cebeci Children's Hospital were obtained to conduct the study. The aim of the study was explained to the parents and their informed consents were obtained.

Results

The study included 229 parents staying with their hospitalized children. A majority (92.6%) of the primary

caregivers of the children were their mothers. The average age was 35.8 ± 7.00 years for mothers, 38 ± 9.88 years for fathers, and 8.24 ± 5.52 years for children. Of the parents, 41.5% had graduated from primary school, and 55.5% came from outside Ankara. The time of disease diagnosis was mostly 1–5 years (34%).

The children in this study were mostly diagnosed with leukemia (45%) and osseous tumors (21%). This distribution was similar to the distribution of childhood cancers in Turkey.[20] Although the prevalence of childhood cancers differs by country, leukemia is the most frequently observed childhood cancer type around the world, with a rate of 35%.[1] Table 1 shows the sociodemographic information of the parents and children. Table 2 shows the mean scores of the subdimensions. It was 2.94 for risk factors, 2.39 for immunity, 1.76 for accident or chance, and 1.69 for the Psychological Attributions subdimension.

The MANOVA test showed that the total scores of the Causal Representation subscale did not vary by parental status, marital status, education status, region of residence, and time of diagnosis (p>0.05). Mean score of the parents on the Psychological Attributions subdimension was found to show a statistically significant difference according to their income level (F=4.410; p=0.013). The parents with a low income level obtained higher scores on the Psychological Attributions subdimension than those with a medium income level.

The mean score of the parents on the Psychological Attributions and Risk Factors subdimensions were found to show a statistically significant difference according to their age. The older parents obtained higher scores on the Psychological Attributions (F=2.558; p=0.028) and Risk Factors (F=2.356; p=0.041) subdimension than younger ones (Table 3).

They also indicated in the open-ended question the most significant causes of their children's disease to be faith, the will of God, and the evil eye (43.9%); stress, sorrow, and worry (20.0%); and nutrition (medicines, genetically modified foods, junk foods, etc.; 12.6%). Other answers of the parents were infections, germs, viruses, radiation, technology, environmental pollution, genetic factors, and physical weakness or immunodeficiency (Table 4).

Discussion

In this study, the majority of parents identified specific causal attributions for their children's illness. Overall, the most common causal attribution were risk factors (internal control), indicating most of parents identified causal attributions in their control. However, when they were asked their opinion with open ended, they believe their children's illness occurred out of their control (because of faith, will of God, and evil eyes). We observed variation in causal attributions by parental age and income level.

The literature reports that the most frequently observed causes of childhood cancers are genetic factors, ionizing radiation, and behavioral factors; and that the

Table 2 The Mean Scores of Causal Representations							
Sub-Dimensions	Items	Mean of Item	Min	Max	Mean	SD	Cronbach's Alpha (α)
Psychological Attribu	tions Stress or worry	2.02					
	Family Problems	1.36					
	Overwork	1.72	5	20	1.69	3.70	0.62
	My emotional state	1.52					
	My personality	1.82					
Risk Factors	Genetic factors	1.98					
	Diet or eating habits	2.25					
	Poor medical care in her/his pas	t 1.73					
	My own behavior	1.60	7	28	2.94	3.60	0.66
	Growing	1.59					
	Drink alcohol during pregnancy	/ 1.09					
	Smoking	1.51					
Immunity	A germ or virus	2.31					
	Pollution of enviroment	2.31	3	14	2.39	3.02	0.48
	Altered immunity	2.54					
Accident/ Chance	Chance or bad luck	2.14	2	10	1.76	1.75	0.42
	Accident or injury	1.37					

Table 3 Causal representations subscales by sociodemographics						
Socio-demographics	Psychological Attributions	Risk Factors	Immunity	Accident or Chance		
Parental Status						
Mother	8.58±3.75	11.82±3.58	7.20±3.07	3.5±1.78		
Father	7.00±2.80	11.29±3.90	6.88±2.34	3.70±1.40		
p value	0.91	0.56	0.67	0.65		
Parental Age (years)						
19-24 (A)	6.83±2.65	10.91±2.90	7.83±3.78	2.66±1.23		
25-30 (B)*	7.17±2.79	10.78±2.51	7.29±3.05	3.31±1.55		
31-35 (C)	8.5±3.78	12.13±3.96	7.16±3.01	3.67±1.70		
36-40 (D)	8.68±3.64	11.52±4.17	7.1 9±3.00	3.70±1.99		
41-45 (E)*	9.77±3.97	13.3±3.17	6.88±2.94	3.77±1.75		
46+ (F)	8.94±4.64	11.33±2.7	7.05±3.05	2.94±1.62		
p value	0.028*	0.041*	0.965	0.203		
	Between B-E	Between B-E				
Marital Status						
Married	8.38±3.62	11.81±3.62	7.21±3.04	3.54±1.76		
Single/Divorced	8.33±4.93	8.66±2.88	5.33±2.51	3.00±1.73		
p value	0.981	0.136	0.287	0.597		
Income Level						
Medium (A)*	7.94±3.43	11.75±3.70	7.21±3.10	3.33±1.79		
Low (B)*	9.40±4.00	11.91±3.48	7.10±2.87	3.87±1.67		
High (C)	7.63±3.44	11.18±3.51	7.27±3.43	3.18±1.53		
p value	0.013*	0.810	0.964	0.066		
	Between A-B					
Education Status						
Illiterate	8.72±3.84	12.81±3.91	6.72±2.76	4.18±2.04		
Primary school	9.08±3.94	12.21±3.77	6.90±3.00	3.78±1.74		
Secondar school	7.38±2.91	11.48±3.99	7.12±3.12	3.22±1.64		
High school	7.98±3.22	11.67±3.43	7.80±3.02	3.24±1.84		
Graduate/Postgraduate	9.09±6.37	10.3±2.64	7.35±2.83	3.36±1.51		
p value	0.131	0.379	0.169	0.359		
Region of Residence						
Ankara	7.97±3.35	11.8±3.40	7.60±3.04	3.57±1.78		
Outside of Ankara	8.85±3.93	11.77±3.77	6.83±2.97	3.48±1.72		
p value	0.072	0.947	0.054	0.675		
Time of diagnosis						
0-6 mth	8.28±3.63	11.75±3.50	7.21±2.92	3.22±1.48		
7-12 mth	9.22±3.98	11.71±4.17	7.31±3.10	3.87±1.75		
13-60 mth	8.10±3.46	11.61±3.04	7.12±3.09	3.43±1.92		
Over 60 mth	7.00±3.43	14.1±3.57	6.50±2.99	3.4±1.83		
p value	0.195	0.297	0.936	0.209		
*p<0.05.						

factors such as environmental pollution and stress play a less important role.[22,23] The present study indicated that the causes of cancer stated by the parents were different compared to those reported in the medical literature.

In this study, the most common causal attributions were risk factors (M=2.94). The most common reasons cited within the Risk Factors subdimension were diet or eating habits (M=2.25). According to their open-ended answers, nutrition (medicines, genetically modified foods, junk foods, etc.; 12.6%) was the most cited reason. Nutrition/eating habits are well known as individuals have internal behaviors that they can control, and that the lack of adequate consumption of vegetables and fruit increases cancer incidence in the literature.[24] In a study with cancer survivors, eating and diet was also attributed as the most common cause.[11]

Attribution	Dout Ca	usai		
Why do you think your child got cancer?	n*	%**		
Faith, Will of God, Evil eye	91	43.9		
Stress, Sorrow, Worry	41	20.0		
Nutrition (medicines. genetically	26	12.6		
modified foods. etc.)				
Infection, Germs, Viruses	17	8.3		
Radiation, Technology,	12	5.8		
Environmental pollution				
Genetic factors	10	5.0		
Physical weakness/Immunodeficiency	9	4.4		

*Multiple answers were allowed

**The percentages were calculated on the total number of answers.

Similar to this study, previous studies have also indicated this risk factor among the possible causes of cancer.[5,6,25,26,27,28,29,30] However, in Hopman and Rijken's study (2015) [12], it was the third leading cause of the subscales. This situation is thought to arise because of cultural differences.

The second-highest scoring average of the Causal Representation subscale was the Immunity subdimension (M=2.39). In a study of adult cancer survivors in the United States, immunity (M=3) was the second-most common subscale [12]. Parents stated their child's altered immunity (M=2.54) as the most significant cause of cancer within the Immunity subdimension. Many studies reported immunity to be one of the most significant causes of cancer.[5,25,31,32,26] Immunity is especially listed among the risk factors of acute lymphoblastic leukemia (ALL) and non-Hodgkin lymphoma (NHL).[9,23,33] Because the majority of the children in this study were diagnosed with ALL, parents were aware of the risk factors in this type of cancer.

It was also found that environmental pollution (M=2.31) was perceived as among the most significant causes of childhood cancer within the Immunity subdimension. A previous study has also reported that one in four cancer survivors have stated environmental pollution as the cause of the disease.[11] Environmental pollution is external factor and out of an individual's control. However, there is no scientific evidence that environmental pollution is an important cause of cancer.

The Accidental or Chance subscale of the Causal Representation scale had the third highest average score (M=1.76) even though when asked open-ended, it was 43.9% parents responded fatalistic answers such as the "will of God, faith, evil eye." In both the international and the national literature, patients with [6,12,18,25,28,29,34] and without [31,32] cancer consider misfortune and bad luck to be among the causes of cancer. Considering that the Turkish society culturally has a fatalistic approach [35], it can be said that misfortune, bad luck, faith, evil eye, etc. are commonly considered as causes of a serious disease such as cancer. The main reason for this may be the cultural structure and the important position of religious beliefs in people's perception of health and disease.[36,37] Abaan (1992) [38] also indicated that the will of God is perceived as a cause of disease.[38] Considering the current study's findings, Turkish people continue to attribute the diseases to external supernatural powers or factors two decades later.

The Psychological Factors subdimensions had the lowest score among the subdimensions (M=1.69). Likewise, the Psychological Factors subdimension (M=1.94) had the least score in the study on adult cancer survivors in the USA [12]. Within this subdimension, stress (M=2.02) was perceived by the parents as one of the most significant causes of cancer; according to parents' qualitative answers 20% parents believed stress was their children's illness reason. Although stress is considered a trigger of the carcinogenic process by suppressing the immune system and creating oxidative DNA damage [39,40], a scientific consensus does not exist on the fact that stress is a cause of cancer. Comparing our results to those of other studies, stress has been a common attribution in multiple populations.[5,18,25,31,32,26,27,29,38] The negative effects of stress on health are widely known; therefore, stress is associated with cancer.

Limitations

The major limitation associated with studies with a cross-sectional design is that direction of causation cannot be established. Although the study sample seems to be limited with only one hospital, it can be generalized to the Turkish population. This is because our hospital caters to patients from all over Turkey because it has one of the largest children's hematology and oncology clinics in the capital city of Turkey.

Because most primary caregivers were mothers, study sample was heterogeneous with regard to parents' sex. This study analyzed only the thoughts of parents of children affected with cancer regarding causes of their children's disease. It was not possible to make causal conclusions regarding the relationship between parents' thoughts on the causes of disease and sociodemographic variables. It is known that time of diagnosis is positively related to families' compliance with the disease treatment, coping with the disease, and treatment management. Therefore, determination of the relationship between the variables and the perception of the causes of disease could have strengthened our study findings. Another limitation of the study is that parents and children were not evaluated simultaneously. Addressing the parents' and children's perceptions about the causes of disease together will enable comparisons to be made. This will help determine the effects of parents' perceptions on the causes of disease on coping strategies. Comparisons according to age and diagnostic groups of children were considered to affect the evaluation of parents. For this reason, handling of these variables could have made the study stronger.

Implications for Nursing Practice

It is important for clinicians planning health education on preventing cancer to devote greater attention to cultural assessment and to include cultural beliefs in cancer care for Turkish pediatric cancer patients and their parents. The cultural beliefs should be included in the planning and evaluation of the case of each affected child. Adopting this approach would provide an opportunity to improve the cultural competency of pediatric nursing. Given the cultural context of illness representations, researchers and health providers must carefully consider how they construct models of parent's ideas about childhood cancer and how they create health interventions. Our results indicate that public health and healthcare efforts should be improved in both general healthcare as well as cancer care.

Conclusion

Our study results showed that parents of children affected with cancer have similar perceptions regarding cancer to those reported in the literature, but have more fatalistic views because of cultural differences. Education regarding the causes of diseases may help positively change parents' and children's perceptions of the disease. Further studies are needed to analyze the relationship between the perception of both the affected children and their parents on the causes of disease, compliance with treatment, and coping with the disease. The results of this study will guide pediatric nurses within the scope of individualized holistic healthcare. Determining the parents' causal representation of cancer may help healthcare providers plan initiatives to support the development of risk-decreasing health behaviors.

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