

Research Article

Perspectives of Pediatric Patients, Parents, and Healthcare Providers on the Disclosure of a Leukemia Diagnosis and the Investigation of Internalizing Symptoms in Children with Leukemia

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Introduction

A recent comprehensive review and numerous systematic studies focused on cancer-specific information and communication for patients, but there is still no consensus on the appropriate person, time, and place to inform patients and their relatives of a cancer diagnosis and prognosis [1-3]. Most information to date has been obtained from adult studies [4-14]. These have indicated that, for adult patients, good communication between patient and physician enhances the quality of life and reduces anxiety levels during cancer diagnosis and treatment. The

Abstract

Background: The purpose of this study was to examine study participants' knowledge, attitudes, anxiety, and coping strategies following a leukemia diagnosis.

Study Design: The 350 participants included 100 pediatric patients, 100 parents, and 150 healthcare providers. The survey was filled out by all participants. Patients' and Parents' perceptions of their children's anxiety levels were also evaluated using the Revised Child Anxiety and Depression Scale.

Results: In total, 84 pediatric patients were aware of their leukemia diagnosis, but the remaining 16 were not at the time of the survey. Thirteen (82%) of the 16 patients were under the age of seven at the time of diagnosis. Parents and health care providers strongly agreed that leukemia diagnosis should be disclosed directly to children. Compared with healthcare providers, parents were significantly more likely to opt for disclosure after starting chemotherapy by the parents in the doctor's office ($p < 0.05$). Parent's perceptions of their children's anxiety levels were significantly higher than patients' ($p < 0.05$). Healthcare providers responded to the survey that 32% of the pediatrician, 16% of nurses, and 86% of interns received training on delivering bad news.

Conclusions: Our research shows that there is no agreement among healthcare providers and patients' parents about who, when, and where to inform children of a leukemia diagnosis. The findings also highlight the importance of reinforcing children diagnosed at less than 7 years when they are older. Additionally, delivering bad news training to healthcare providers and providing psychological support to parents and adolescents have a positive impact.

Keywords: Leukemia diagnosis; Anxiety; Children; Health care provider; Parents

cornerstone of this communication is, to tell the truth about the patient's diagnosis and prognosis [4,15]. Regardless, delivering bad news about diagnosis and prognosis to cancer patients is challenging for many reasons. The most important of these are pediatric age, knowledge levels, attitudes of the patient's relatives, cultural and religious differences, and concern that the psychological devastation caused by the news may delay treatment. However, data on issues such as informing children, com-

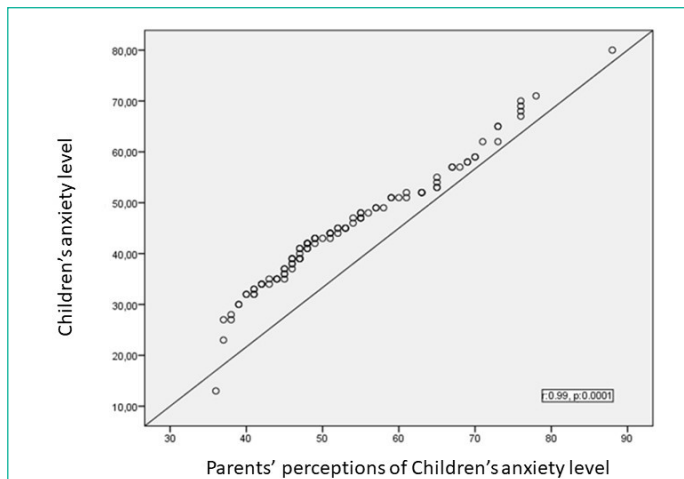


Figure 1: The relationship between the parent’s perceptions of their children’s anxiety levels and patients’ anxiety levels.

municating with parents, and delivering bad news to healthcare providers about a leukemia diagnosis are scarce.

The aim of this study was to evaluate the impact of leukemia diagnosis on Turkish pediatric patients, their parents, and healthcare providers.

Materials and Methods

This cross-sectional study was carried out in our leukemia center. The Institutional Review Board approved the investigation, and patients or their parents gave informed consent.

Study Population

Three groups of participants were enrolled: pediatric leukemia patients (n=100), patients' parents (n=100), and healthcare providers (n=50). A total of 100 consecutive pediatric acute leukemia patients were enrolled. At the time of diagnosis, hematology specialists obtained routine institutional consent and assent forms from older patients (>12 years old) and parents of all pediatric patients. Only one parent (mothers; n=70, fathers; n=30) who accompanied their children during the chemotherapy period completed the survey. The healthcare providers were divided into three subgroups: pediatricians (n=50), interns (n=50), and nurses (n=50). Patients with lymphoma or solid tumors, or those over the age of 18, were excluded from the study.

Study Design

A survey was designed based on similar studies in the literature [7-14] as well as feedback from patients, parents, and healthcare providers. The survey's primary outcomes focused on how healthcare providers, children, and their parents perceived a leukemia diagnosis. The secondary outcomes assessed the anxiety and coping strategies of children, and their parents following a leukemia diagnosis. The importance of training for healthcare professionals on delivering bad news was the third outcome.

Study participants were invited to respond, and each completed this survey in written form for approximately 15-20 minutes in a quiet room. All pediatric patients were over the age of seven at the time of the survey. Of them, eighty-one percent had completed the leukemia protocol, while the remaining 19% were still receiving chemotherapy. Parents assisted children under the age of 12 in completing the survey. Most question items were designed as short answers (Yes or No), and some required detailed explanations (Table 1). The questions were composed

Table 1: Survey to evaluate the knowledge and attitudes of study participants about leukemia diagnosis.

General Questions	
1-	Age:
2-	Gender:
3-	Diagnosis:
4-	Chemotherapy: <input type="radio"/> Ongoing <input type="radio"/> Completed
Questions for Healthcare Providers and Parents	
1-	Should the diagnosis of leukemia be disclosed to the pediatric patient? <input type="radio"/> Yes <input type="radio"/> No
2-	Who should tell the patient of the diagnosis and prognosis? <input type="radio"/> Doctors <input type="radio"/> Parents <input type="radio"/> Others
3-	When should the information be given? <input type="radio"/> Before starting chemotherapy <input type="radio"/> After starting chemotherapy
4-	Where should the information be given? <input type="radio"/> In the doctor's office <input type="radio"/> Outside the doctor's office
5-	Who should be informed? <input type="radio"/> Patient <input type="radio"/> Parents
6-	Do you inform if a patient doesn't know diagnosis? <input type="radio"/> Yes <input type="radio"/> No
7-	If no, to whom would you direct it? <input type="radio"/> Doctor <input type="radio"/> Parents <input type="radio"/> Others
8-	Do you want to know the leukemia diagnosis and prognosis if you are the patient? <input type="radio"/> Yes <input type="radio"/> No
Questions For Healthcare Providers	
1-	Have you received any training in delivering bad news to cancer patients? <input type="radio"/> Yes <input type="radio"/> No
2-	What is your attitude to inform your patients about the leukemia diagnosis and prognosis? <input type="radio"/> I always inform <input type="radio"/> I usually inform <input type="radio"/> I rarely inform
3-	Do you think there is a need for such studies? <input type="radio"/> Yes <input type="radio"/> No
Questions for Patients	
1-	Do you know the name of your disease? <input type="radio"/> Yes <input type="radio"/> No
2-	If no, do you want to know the diagnosis? <input type="radio"/> Yes <input type="radio"/> No
3-	If yes, from whom did you learn the diagnosis? <input type="radio"/> Doctor <input type="radio"/> Parents <input type="radio"/> Other
4-	If yes, when did you learn? <input type="radio"/> Before starting chemotherapy <input type="radio"/> After starting chemotherapy
5-	If yes, where did you learn it? <input type="radio"/> In the doctor's office <input type="radio"/> Outside the doctor's office
6-	How did you feel when you learned the diagnosis? <input type="radio"/> Anxiety <input type="radio"/> Fear <input type="radio"/> Shock <input type="radio"/> Other
7-	Have you received any psychiatric support? <input type="radio"/> Yes <input type="radio"/> No
8-	Have you taken any psychiatric medication? <input type="radio"/> Yes <input type="radio"/> No

so as to assess the knowledge level, attitudes, anxiety, and coping strategies of the Turkish participant groups after a leukemia diagnosis. Patients’ and Parents’ anxiety levels were also evaluated using the Revised Child Anxiety and Depression Scale. This scale was an internationally validated, standardized, and reliable anxiety and depression assessment tool [16]. The parents’ version was completed by parents, while the self-reported version was administered to patients (7-18 years of age). This survey contains 47 questions grouped under six items: Separation Anxiety, Social Phobia, Obsessive-Compulsive Disorder, Panic Disorder, Generalized Anxiety Disorder, and Major Depressive Disorder. A total score of more than 65 indicates that the individuals suffer from significant anxiety and depression. The Parents’ version evaluates parent reports of their child's anxiety and depression symptoms across the same contexts.

Statistical Analysis

Data were analyzed using the SPSS version 22.0 (SPSS Inc., Chicago, IL, USA). Differences were compared using the Mann-Whitney U test and Chi-square test. Odds Ratios (ORs) were calculated with a 95% confidence interval (95% CI). Pearson correlation coefficient was used. P values <0.05 indicated statistical significance.

Results

Table 2: Demographic data of the study participants.

Study Participants	
Pediatric patients (n, %)	100(29%)
Median-IQR* age (years)	13(7-17)
Gender	
Male/Female	60(60%)/40(40%)
Diagnosis	
ALL*/AML*	86(86%)/14(14%)
Chemotherapy status	
Completed/Ongoing	81(81%)/19(19%)
Patients' parents (n, %)	100(29%)
Median-IQR age (years)	39(18-78)
Gender	
Male/Female	30(30%)/70(70%)
Healthcare providers (n, %)	150(42%)
Pediatricians (n, %)	50(14%)
Median-IQR* age (years)	28(24-40)
Gender	
Male/Female	10(20%)/40(80%)
Nurses (n, %)	50(14%)
Median-IQR* age (years)	31(22-55)
Gender	
Male/Female	4(4%)/46(96%)
Interns (n, %)	50(14%)
Median-IQR* age (years)	23(22-29)
Gender	
Male/Female	26(52%)/24(48%)

*IQR: Interquartile Range; ALL: Acute Lymphoblastic Leukaemia; AML: Acute Myeloblastic Leukaemia.

All participants completed the survey. Participants' demographic data are presented in Table 2.

Patients' Parents and Healthcare Providers-Specific Questionnaire

The survey results of healthcare providers and patients' parents are summarized in Table 3. The patient's parents (n=90; 90%) and health care providers (n=144; 96%) strongly agreed that a leukemia diagnosis should be disclosed directly to a pediatric patient. Of the 150 healthcare providers, 90% (n=136) stated this should be done by the attending physician, and 10% (n=14) by the patient's parents. For the 100 parents, the corresponding proportions for these answers were 81% (n=81) and 19% (n=19). Compared with healthcare providers, parents were significantly more likely to opt for disclosure by the patient's parents (p<0.05). The rate of parents' disclosure was 2.65 times higher than healthcare providers' disclosure.

Of the 150 healthcare providers, 95% (n=143) stated that the appropriate time to inform the patient about their diagnosis was before the start of chemotherapy, and 5% (n=7) after the start of chemotherapy. The corresponding proportion results for 100 parents were 85% (n=85) and 15% (n=15). Compared with healthcare providers, parents were significantly more likely to opt for disclosure after starting chemotherapy by the patient's parents (p<0.05). The rate of parents' disclosure after starting chemotherapy was 3.6 times higher than in healthcare providers' disclosure after chemotherapy.

Table 3: The comparison of survey results of healthcare providers and patients' parents.

	Healthcare Providers	Patients' Parents	p	OR [95CI%]
	n=150	n=100		
Should the patient be informed of the diagnosis and prognosis?				
Yes				
No	144(96%)	90(90%)	0.102	0.37(0.13-1.06)
	6(4%)	10(10%)		
Who should inform				
Doctor	136(90%)	81(81%)	0.02	2.65(1.22-5.76)
Patients' parents	14(10%)	19(19%)		
When to inform				
Before starting treatment	143(95%)	85(85%)	0.01	3.60(1.41-9.19)
After starting treatment	7(5%)	15(15%)		
Where to inform?				
In the doctor's office	44(29%)	54(54%)	0	2.82(1.69-4.79)
Outside the doctor's office	106(71%)	46(46%)		
Whom to inform				
Patient	36(24%)	3(3%)	0	10.21(3.0-34.10)
Patients' parents	114(76%)	97(97%)		
Do you inform if a patient does not know the diagnosis,				
I inform				
I do not inform	49(32%)	36(36%)	0.586	1.15(0.68-1.97)
	101(68%)	64(64%)		

OR: Odds Ratio, 95CI%: Confidence Interval

Of the 150 healthcare providers, 29% (n=44) answered that the appropriate place for pediatric patients to be informed of their leukemia diagnosis is the doctor's office, whereas 71% (n=106) answered outside the doctor's office. The corresponding proportions for the 100 parents were 54% (n=54) and 46% (n=46). Compared with healthcare providers, parents were significantly more likely to opt for disclosure in the doctor's office by the patient's parents (p<0.05). The rate of parents' disclosure in the doctor's office was 2.82 times higher than in healthcare providers' disclosure.

Of the 150 healthcare providers, 24% (n=36) indicated that the patient should be the first person to know their diagnosis, whereas 76% (n=114) stated that a patient's parents should be the first to know. For the 100 parents, the corresponding proportions were 3% (n=3) and 97% (n=97). Compared with healthcare providers, parents were significantly more likely to opt for knowledge of the first diagnosis by the patient's parents (p<0.05). The rate of parents' opinion about the first person who should know the first diagnosis of patients was 10.21 times higher than healthcare providers' opinion.

Of 150 healthcare providers, 32% (n=49) were willing to inform their pediatric patients of their leukemia diagnosis if they had not learned it previously, while 68% (n=101) were unwilling

to disclose it. Among 100 parents, the corresponding proportions were 36% (n=36) and 64% (n=64).

Healthcare providers responded to the questions about whether they had received “Delivering Bad News Training” before. Healthcare providers responded to the survey that 32% of the pediatrician, 16% of nurses, and 86% of interns received training on delivering bad news.

The Revised Child Anxiety and Depression Scale findings

There were 84(84%) pediatric patients who were aware of their leukemia diagnosis and 16(16%) children who were not during the survey. At the time of diagnosis, 68(80%) of 84 patients were over the age of 12 and the remaining 16(20%) were under the age of 12, but 13(82%) of 16 children were under the age of 7 and the remaining 3(18%) were over 7. Nineteen (19%) patients had already received chemotherapy when the study began; the remaining 81(81%) completed chemotherapy during the period the study was conducted. The parents' perceptions of their children's anxiety levels were significantly higher than the patients themselves ($p<0.001$). The anxiety scores of the parent's perceptions of their children's anxiety levels and patients' anxiety levels were strongly correlated ($p<0.05$, $r=0.99$) (Figure 1). The mean anxiety score for the nine adolescent patients who did not want to know their diagnosis was significantly higher than that for the 16 younger patients who desired to but did not know their diagnosis (50.6 ± 24.1 vs. 32.4 ± 15.1 , respectively; $p<0.05$).

Discussion

A recent comprehensive review and numerous systematic studies focused on the best way to inform pediatric patients and their families about a cancer diagnosis and prognosis [1-3]. It is unknown to many pediatric leukemia specialists whether pediatric patients are aware of their diagnosis. The majority of cancer disclosure studies have been designed for adult cancer patients [4-14], and there is little data on cancer disclosure to pediatric patients and their parents. This research examined the impact of leukemia diagnosis on Turkish pediatric patients, parents, and healthcare providers.

Many studies on cancer disclosure in various countries, including Lebanon, Egypt, Greece, and Iran, found that nearly all participants agreed that patients should be informed directly [6-8,11,12]. Consistent with these results, 96% of the healthcare providers and parents in our study stated that children with leukemia should know their leukemia diagnosis and be informed by the attending physician. However, 97% of patients' parents stated that information about diagnosis and prognosis should be provided to parents first, and 19% of this group indicated that they should be the one/s to disclose a cancer diagnosis to their child.

In the Lebanon study on the timing of cancer information disclosure, adult patients reported that they preferred to learn their diagnosis directly and prior to chemotherapy, whereas their family members preferred to learn after chemotherapy had begun [7]. Physicians and nurses stated that they were concerned about patients being shocked by the sudden disclosure of a cancer diagnosis. They also stated that they preferred to explain the diagnosis over a period of time according to each patient's personal characteristics and that it is best to inform the patient together with nurses and relatives, as opposed to a single person conveying the news. They indicated that these

approaches contribute to the success of treatment and healthy follow-up of cancer patients. In contrast, the majority of oncology nurses surveyed in China stated that cancer patients should be informed about their diagnosis in the early chemotherapy period [10]. Similarly, in our study, most healthcare providers declared that the appropriate time to inform a patient is before the start of treatment; however, 15% of parents felt that the news should be given after treatment has begun.

In total, 84 pediatric patients were aware of their leukemia diagnosis, but the remaining 16 were not at the time of the survey. Thirteen (82%) of the 16 patients were under the age of seven at the time of diagnosis. Similarly, in an adult survey conducted in Greece, 25% of patients stated that they did not want to know their diagnosis [13]. Another study conducted by Raz et al. found that quality of life was poor, and tolerance to mental pain was lower in children older than 12 years of age who were well informed about their disease [17]. A comprehensive study by Kadan-Lottick et al. investigated the negative impact of late cancer disclosure on 635 pediatric cancer patients [18]. Of the 216 patients who had leukemia, 32(5%) remained unaware of this at the time of the survey phone call at least 5 years after diagnosis. The authors stated that these patients should be informed about the leukemia diagnosis in order to monitor the long-term side effects of chemoradiotherapy [18]. Another study investigated disclosing a parent's cancer diagnosis to children at an appropriate time based on the developmental and emotional stages of children. Results showed that children 3 years or younger did not understand the concept of being sick, those of pre-school age (3 to 6 years) were able to understand the difference between being well and being sick, and those older than 7 were aware of cancer [19]. A study on the ethical reasons for disclosure of cancer information to pediatric patients indicated that preadolescents should be told of their diagnosis if the child has the mental maturation to make decisions [20]. Yaşar et al. previously reported preliminary findings from this study on the importance of updating leukemia diagnosis at an older age in small children diagnosed before the age of seven [21]. Disclosure should be done in a quiet setting by the parents and primary attending physician in this patient group. These steps are necessary to avoid adverse effects on a patient's psychological and mental health in the future. We plan to add this detail to our routine informed consent form that parents sign when they have received detailed information about leukemia diagnosis.

In a previous study conducted in Turkey, physicians were affected approximately 2.2 times by patients' relatives to disclose the diagnosis if they were not trained in delivering bad news [14]. In our study, 32% of the physicians and 16% of the nurses had received this type of training. Further, 86% of the interns had received this training before they graduated. Our study was limited with respect to sample size and diversity of patient groups, and all patients were not evaluated by a psychologist. Further research should be conducted with a higher number of various pediatric oncology patients in a prospective design. Based on our findings and the literature, we believe that “Delivering Bad News Training” education, which has been added to Turkey's medical curriculum in recent years, is a positive step. This will lead to more standardized rules and recommendations that will better equip physicians to explain cancer diagnoses to patients within a framework of ethics, pediatric age, culture, and Turkish family structure.

Conclusions

Our research shows that there is no agreement among healthcare professionals and parents on the appropriate person, time, and place to inform children of a leukemia diagnosis in Turkey. The findings also highlight the importance of re-informing children diagnosed at less than 7 years when they are older. Furthermore, delivering bad news training to healthcare providers and providing psychological support to parents and adolescents have a positive impact.

Author Statements

Conflicts of Interest

The authors have no conflict of interest.

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