

Assessment of the Knowledge, Attitudes, Anxiety, and Coping Strategies of Pediatric Patients and Parents after Leukemia Diagnosis in Türkiye

Türkiye’de Lösemi Tanısından Sonra Çocuk Hastaların ve Ebeveynlerin Bilgi, Tutum, Kaygı ve Başa Çıkma Stratejilerinin Değerlendirilmesi

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To the Editor,

There is limited information on the issue of cancer disclosure to pediatric patients and their parents because most studies on disclosure have been focused on adult cancer patients [1,2,3,4,5,6,7,8,9]. Many pediatric leukemia specialists are unaware of whether pediatric patients know their diagnosis. This preliminary study evaluated how a leukemia diagnosis may affect the knowledge, attitudes, anxiety, and coping strategies of pediatric patients and their parents.

A total of 200 participants, including 100 children and 100 parents (n=70 mothers; n=30 fathers) completed questionnaires about the children’s leukemia diagnosis. Most items were designed as questions with short answers (yes/no) (Table 1). All children were over the age of 7 years at the time of the survey, and 81% had completed the leukemia protocol while the remaining 19% were still receiving chemotherapy. The relevant institutional review board approved the study. Data were analyzed using IBM SPSS Statistics 22.0.

All patients were referred to our center from different geographic regions of Türkiye. Only 17% of the parents had middle school or high school education, while 83% were uneducated or had only primary school education. Sixteen (16%) of the 100 participating pediatric patients declared that they were unaware of the leukemia in the course of completing the survey. Thirteen of those participants (82%) were younger than 7 years old and three (18%) were older than 7 years at the time of diagnosis. All of these 16 patients responded to the survey by stating that they wished they had known about their leukemia diagnosis. The remaining 84 (84%) patients stated that they were aware of the leukemia at the time of diagnosis. Nine of those patients (10%) responded to the survey by stating that they would have preferred not to have known about the

leukemia diagnosis. These nine patients were over 12 years old at the time of diagnosis. They received antidepressant treatment and psychological support. Four (45%) of them were receiving chemotherapy at the time of the survey. Anxiety about disease recurrence (92% vs. 73%) or chemotherapy side effects (57% vs. 12%) was significantly more likely among parents than patients ($p<0.05$). The rate of anxiety among parents was 4.09 times higher for disease recurrence and 5.53 times higher for chemotherapy side effects compared to the rate of anxiety among patients.

Most leukemia specialists accept some parental requests for non-disclosure of leukemia to children at diagnosis. Additionally, they often choose not to disclose the diagnosis to younger children because they assume it will be explained by the parents once the child is older. The main obstacles that parents in Türkiye face in disclosing a leukemia diagnosis to a child at an appropriate time are related to the Turkish family structure and the protective attitudes and behaviors of Turkish parents toward their children. The parents of the patients in our study originated from various geographical regions in Türkiye and had different educational backgrounds. Furthermore, the parents were more worried about the prognosis and side effects of chemotherapy. The survey’s main limitation was the absence of questions about support from other family members. Further research is required. We conclude that psychological support for coping with anxiety should be included in leukemia protocols for both adolescents and parents. Children’s leukemia knowledge must be updated at older ages when children are diagnosed before 7 years of age.

Keywords: Leukemia disclosure, Children, Parents

Anahtar Sözcükler: Lösemi bildirimi, Çocuk, Ebeveyn

Table 1. Survey to evaluate the knowledge and attitudes of study participants about the leukemia diagnosis.	
General questions	
1. Patient's age:	
2. Gender:	
3. City:	
4. Diagnosis:	
5. Chemotherapy: <input type="checkbox"/> Ongoing <input type="checkbox"/> Completed	
Questions for parents	
1. Education level:	
<input type="checkbox"/> Primary school or uneducated <input type="checkbox"/> Middle or high school	
2. Are you anxious about the leukemia diagnosis?	
<input type="checkbox"/> Yes <input type="checkbox"/> No	
1. If yes, why?	
<input type="checkbox"/> Disease recurrence <input type="checkbox"/> Chemotherapy side effects	
Questions for patients	
1. Do you know the name of your disease?	
<input type="checkbox"/> Yes <input type="checkbox"/> No	
2. If not, do you want to know about it?	
<input type="checkbox"/> Yes <input type="checkbox"/> No	
3. Have you received any psychiatric support?	
<input type="checkbox"/> Yes <input type="checkbox"/> No	
4. Have you taken any psychiatric medication?	
<input type="checkbox"/> Yes <input type="checkbox"/> No	

Ethics

Informed Consent: Obtained.

Authorship Contributions

Surgical and Medical Practices: Z.K.; Concept: Z.K.; Design: Z.K.; Data Collection or Processing: Y.Y., Z.K., S.K., Ü.K.; Analysis or Interpretation: Y.Y., Z.K., E.G.; Literature Search: Y.Y., Z.K.; Writing: Y.Y., Z.K.

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References

- Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Educ Couns* 2005;57:250-261.
- Farhat F, Othman A, El Baba G, Kattan J. Revealing a cancer diagnosis to patients: attitudes of patients, families, friends, nurses, and physicians in Lebanon-results of a cross-sectional study. *Curr Oncol* 2015;22:e264-e272.
- Alsirafy SA, Abdel-Kareem SS, Ibrahim NY, Abolkasem MA, Farag DE. Cancer diagnosis disclosure preferences of family caregivers of cancer patients in Egypt. *Psychooncology* 2017;26:1758-1762.
- Li JY, Liu C, Zou LQ, Huang MJ, Yu CH, You GY, Jiang YD, Li H, Jiang Y. To tell or not to tell: attitudes of Chinese oncology nurses towards truth telling of cancer diagnosis. *J Clin Nurs* 2008;17:2463-2470.
- Mostafavian Z, Shaye ZA, Farajpour A. Mothers' preferences toward breaking bad news about their children's cancer. *J Family Med Prim Care* 2018;7:596-600.
- Lavrentiadis G, Manos N, Christakis J, Semoglou C. The Greek cancer patient's knowledge and attitudes towards his diagnosis and prognosis. *Psychother Psychosom* 1988;49:171-178.
- Ozdogan M, Samur M, Artac M, Yildiz M, Savas B, Bozcuk HS. Factors related to the truth-telling practice of physicians treating patients with cancer in Turkey. *J Palliat Med* 2006;9:1114-1119.
- Kadan-Lottick NS, Robison LL, Gurney JG, Neglia JP, Yasui Y, Hayashi R, Hudson M, Greenberg M, Mertens AC. Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. *JAMA* 2002;287:1832-1839.
- Raz H, Tabak N, Kreidler S. Psychosocial outcomes of sharing a diagnosis of cancer with a pediatric patient. *Front Pediatr* 2016;4:70.

