Refusal of medical treatment in the pediatric emergency service: analysis of reasons and aspects

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Refusal of treatment for acutely ill children is still an important problem in the emergency service. When families refuse medical treatment for their acutely ill children, healthcare professionals may attempt to provide information and negotiate with the family concerning treatment refusal and its possible adverse outcomes, and request consent for refusal of medical treatment. There is insufficient data about refusal of treatment in our country. The purpose of this study was to analyze the causes of treatment refusal in the pediatric emergency service. We collected data recorded on informed consent forms. During a 2-year-study period, 215 patients refused treatment recommended by acute health care professionals. The majorty of patients were in the 0–2 year age group. Hospitalization was the type of treatment most commonly refused; restrictions regarding family members staying with their children during hospitalization and admission to another hospital were the major reasons for refusal of treatment. Clarifying the reasons for treatment refusal may help us to overcome deficiencies, improve conditions, resolve problems and build confidence between healthcare providers and service users, increasing users' satisfaction in the future.

Key words: treatment refusal, pediatric emergency service, informed consent.

Medical care in the pediatric emergency service is provided at the request of service users for the benefit of their children's health. "Consent to treatment" refers to the principle that parents must give permission before their children receive any type of medical care, investigation or treatment[1].

Consent is required from a service user regardless of the type of treatment. For consent to be valid, the person consenting must have the capacity to make the decision, must do so voluntarily and must be informed about the possible consequences. This decision must be respected even if the decision could result in fatal consequences[1].

The American Academy of Pediatrics Committee on Bioethics and the Ethics Working Group of the Confederation of European Specialists in Pediatrics (CESP) recommend that pediatricians give detailed information about diagnosis; this information should be simple, clear and should not include unnecessary professional language. They should also discuss probable risk factors and side effects of the treatment[2-5].

In recent years, more attention has been paid to treatment refusal and its consequences in developing countries[6]. Treatment refusal is defined as the overt rejection by the service user or his/her legal guardian of any type of investigative procedure, medical care or surgery recommended or ordered by healthcare professionals for a potentially curable disease[7].

Adults have the right to refuse medical treatment, because they have the right to self-determination. Children can neither give informed consent nor refuse treatment. Thus, in the field of pediatrics, there are legal implications when a parent or legal guardian refuses medical treatment for a dependent minor[7-10].

The Turkish Ministry of Health has legalized the right of treatment refusal for adult patients (Regulation No. 25). Legal guardians also have the right to refuse any type of medical treatment on behalf of the minors under their guardianship (Regulation No. 24)[11].

Reasons for treatment refusal include financial problems, anxiety and emotional turmoil, and fears concerning advanced technology used at the time of diagnosis; quality of the healthcare system, education of both healthcare providers and service users and communication between them, and lack of information about and confidence in therapy are also factors that affect treatment refusal[12]. Religious beliefs and cultural practices may also influence parents' decisions about a child's medical care[13-16].

The aim of this study was to determine the reasons for refusal of treatment for acutely ill children admitted to our emergency service.

Material and Methods

This cross-sectional descriptive study was conducted in the emergency service of Ankara Pediatric Hematology and Oncology Research and Training Hospital between 15 September 2011 and 15 December 2013. Our data were collected from hospital records. Two hundred and fifteen service users whose children were admitted to our emergency service during this period and refused the recommendations of healthcare professionals for medical investigation or treatment were asked to fill out informed consent forms. These forms were evaluated retrospectively by medical doctors .

The informed consent form includes information regarding the gender, age and educational status of service users (parents or legal guardians). The educational status of service users is classified as no education, elementary school, high school and university. The form also specifies gender and age of minors, history of previous admission to the emergency service, type of treatment and reason for refusal of treatment.

The study was approved by the Medical Ethics Committee of Ankara Pediatric Hematology and Oncology Research and Training Hospital.

Statistical analyses were performed using SPSS version 15.0. Categorical variables were shown as frequencies.

Results

A total of 215 patients, 101 male (47%) and 114 female (53%), were included in the study. Demographic properties of the service users are presented in Table I. Most of the service users who refused treatment were the parents of the patients; only 5.2% were other legal guardians. Demographic properties of the patients are given in Table II; 57.2% of the patients were in the 0–2 year age group, and 46.5% had a history of previous admission to the emergency service. The most common type of treatment to be refused was hospitalization (77.7%) (Table III). Reasons for refusal of treatment are shown in Table IV.

Discussion

We investigated reasons for and aspects of medical treatment refusal in our pediatric emergency service. In developing countries, more attention has recently been paid to the reasons for treatment refusal and its consequences[6]. In our country, the regulations regarding patients' rights promulgated by the Ministry of Health give adult patients the right to refuse medical treatment. Parents and legal guardians have also the authority to give or withhold consent on behalf of children under the age of 18[11].

A previous study from our hospital indicated that parents' socioeconomic status, the hospital's physical conditions, the child's wishes, and lack of information and/or confidence were the main reasons for treatment refusal[16]. The results of the present study showed that hospitalization was the type of treatment most commonly refused. Restrictions regarding family members staying with their children during hospitalization and admission to another hospital were the major reasons for refusal of treatment.

Thirty patients from the emergency, inpatient and outpatient services were included in the previous study[16], whereas our study group was more comprehensive and homogeneous, comprising 215 patient from the emergency service only.

Similar to what was shown in our previous study[16], lack of confidence in the therapy due to lack of sufficient information, time limitations and the physical conditions of the hospital can also lead to treatment refusal and desire on the

Table I. Demographic Properties of Service Users

		Number (%)
Service users who refused treatment	Mother	86 (40.0%)
	Father	118 (54.8%)
	Legal guardian	11 (5.2%)
Educational level	No education	8 (3.6%)
	Elementary school	74 (34.8%)
	High school	67 (31.1%)
	Academy and university	27 (12.5%)
	Unknown	39 (18.0%)
Age group	18-35	92 (42.9%)
	35-50	56 (26.0%)
	Unknown	67 (31.1%)

Table II. Demographic Properties of Patients

		Number (%)
Sex	Male	101 (47.0%)
	Female	114 (53.0%)
Age groups	0–2 y	123 (57.2%)
	3–5 y	29 (13.5%)
	6–9 y	24 (11.2%)
	10–12 y	26 (12.1%)
	13–18 y	13 (6.0%)
History of previous admission to the emergency service	Yes	100 (46.5%)
	No	72 (33.5%)
	Unknown	43 (20.0%)

part of parents for admission to another hospital for further examination and treatment. Arnold[17] suggests that healthcare professionals should clarify families' understanding of the clinical situation and should also clarify the goals of care and elicit family members' expectations concerning the course of illness and care.

We also found that lumbar puncture was the second most commonly refused treatment (16.8%), followed by establishment of vascular access (3.2%). Thus, fears regarding these painful procedures caused patients to decide to refuse treatment. Wang et al.[18] found that parents were dissatisfied with doctors' skill, especially when intrathecal chemotherapy was frequently administered to their children. Due to fear of such painful procedures, they decided to abandon treatment[18]. Howard et al[19]., also found that a less experienced physician may reduce the cure rate for childhood leukemia[19]. He recommended that lumber puncture and intrathecal chemotherapy should be performed by experienced physicians.

The majority of the patients included in our study were infants aged less than 2 years (123; 57.2%), whereas 26 (21.1%) were pre-adolescents (aged 10–12 years) and 13 (6.0%) were adolescents (aged 13–18 years). Treatment was refused by their families or legal guardians. Even when older minors (pre-adolescent and adolescent) are not authorized to consent on their own, globally there is a movement to include them in the decision-making process[9]. Attention has been refocused

Table III. Types of Treatment Refused

Type of treatment refused	Number (%)
Hospitalization	167 (77.7%)
Lumbar puncture	36 (16.8%)
Establishment of vascular access	7 (3.2%)
Other	5 (2.3%)

Table IV. Reasons for Refusal of Treatment

Reason for refusal of treatment	Number (%)
Restrictions on family companion staying with the patient	52 (24.2%)
Lack of confidence in the therapy	32 (14.9%)
Admission to another hospital	25 (11.6%)
Physical conditions of the hospital	24 (11.2%)
Family reasons	9 (4.2%)
Child's wishes	9 (4.2%)
Lack of information	8 (3.7%)
Financial problems	0 (0)
Other	56 (26.0%)

on the proper balance of parental and minor authority in making medical decisions for adolescent minors[20-23].

Even though financial difficulty has been reported as the most common reason for treatment refusal in many studies[16,18,24-26], we found that financial problems played no role in treatment refusal. In our country, the government health insurance policy covers all expenses of patients admitted for emergency care services and mandates that no hospitals may charge any patient requesting emergency service.

Refusal of treatment for acutely ill children is still an important problem in the emergency service. This study suggests that the medical team should pay more attention to patients' complaints, spend enough time during examination, show sensitivity and flexibility in their behavior toward families and respect the latter's opinions and decisions, give explanatory information, and negotiate concerning treatment refusal, with attention drawn to its possible adverse outcomes. This may build confidence between medical teams and families, minimize patients' anxiety, reduce the incidence of refusal and increase users' satisfaction.

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