

# Do Parents Understand Emergency Department Discharge Instructions? A Survey Analysis

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## Abstract

**Background:** Understanding discharge instructions is crucial to optimal healing but may be compromised in the hectic environment of the emergency department.

**Objectives:** To determine parents' understanding of ED discharge instructions and factors that may affect it.

**Methods:** A convenience sample of parents of children discharged home from the ED of an urban tertiary care pediatric facility (n=287) and a suburban level II general hospital (n=195) completed a 13 item questionnaire covering demographics, level of anxiety, and quality of physician's explanation. Parents also described their child's diagnosis and treatment instructions and indicated preferred auxiliary methods of delivery of information. Data were analyzed using the BMPD statistical package.

**Results:** Full understanding was found in 72% and 78% of the parents at the respective centers for the diagnosis, and in 82% and 87% for the treatment instructions ( $P = NS$  between centers). There was no statistical correlation between level of understanding and parental age, gender, education, level of anxiety before or after the ED visit, or time of day. The most contributory factor to lack of understanding was staff use of medical terminology. Parents suggested further explanations by a special discharge nurse and written information as auxiliary methods.

**Conclusions:** Overall, parental understanding of ED discharge instructions is good. However, there remains a considerable number (about 20%) who fail to fully comprehend the diagnosis or treatment directives. This subset might benefit from the use of lay terminology by the staff, institution of a special discharge nurse, or use of diagnosis-specific information sheets.

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Understanding emergency department discharge instructions is essential to ensure patients of optimal medical care and proper healing. Studies have shown that patients who receive more information show more satisfaction [1], less anxiety and increased compliance [2]. Similarly, poor comprehension of instructions has been found to be a major contributor to patient non-compliance [3]. In the hospital setting, factors that affect good patient-physician communication include the patient's general condition (level of consciousness, state of anxiety, and fatigue) [4] and level of education and culture on the one hand [5], and the physician's level of training, tiredness and ability to explain on the other. In the ED,

this interaction may be further complicated by lack of time, lack of privacy, and a noisy impersonal environment.

Previous studies have evaluated the understanding of ED discharge instructions by adult patients, but to the best of our knowledge there are no data on parental understanding of discharge instructions in pediatric emergency departments. The aims of the present study were threefold: a) to determine the level of parental understanding of pediatric emergency department discharge instructions, b) to analyze the factors that may affect such understanding, and c) to suggest other auxiliary methods for delivery of medical information.

## Subjects and Methods

The study was conducted at the ED of the Schneider Children's Medical Center of Israel, an urban tertiary care pediatric facility, and the Pediatric ED of Kaplan Medical Center, a general care facility located in a suburban area. The study population consisted of a convenience sample of parents of children who were discharged home after an ED visit at these facilities between March and November 1999. The parents were requested at discharge to complete a 13 item questionnaire distributed by the principal investigator (N.S.) at different times of the day. The questionnaire covered demographic data (parental age, gender and education; patient age and gender), parental rating of their level of anxiety before and after the ED visit (graded on a 3 point scale), and parental rating of the quality of the physician's explanation (3 point scale). The parents were also asked to describe in their own words the ED diagnosis and treatment instructions and to indicate (from a list) their preferred auxiliary means for delivery of ED instructions.

Parental understanding of the diagnosis and treatment instructions was assessed by comparing their free-style answer on the questionnaire to the physician's notes on the ED chart. Understanding was analyzed separately for diagnosis and treatment instructions according to three criteria for each. One point was given for a correct answer for each criterion. The diagnosis criteria included understanding of the nature of the medical problem (e.g., infection, allergic reaction, or trauma), its etiology (viral or bacterial for infection, or mechanism of injury for trauma), and the organ affected; the treatment instructions criteria included understanding of the nature of the treatment recommended (antibiotics, symptomatic, or bronchodilator), its frequency and its duration. We did not

ED = emergency department

demand that parents know the exact name of a medication, nor did we ask dosage details. Full understanding for each category was defined as a score of 3 (out of 3), partial understanding as a score of 2, and poor understanding as 1. Scoring was performed by a single investigator (N.S.) to avoid interobserver variability. The same investigator also provided assistance during completion of the questionnaire, when necessary.

### Statistical analysis

Statistical analyses were performed with the BMPD statistical package [6]. Two-tailed Student's *t*-test was used for comparison of continuous data. Pearson's chi-square test, log linear for three-way associations, Mann-Whitney test, and Kruskal-Wallis test were used, where appropriate, for analysis of differences and for correlation of non-parametric data. All statistical testing was two-tailed, and a *P* value of <0.05 was considered significant.

### Results

The questionnaire was completed by 287 parents at the SCMCI and 195 at the KMC, representing 67% of all parents offered the questionnaire at both institutions. Median patient age was 3 years at the SCMCI and 2 years at the KMC; the respective median ages of the parents were 33 and 32 years, with a mother:father ratio of 2:1 at both institutions. Average level of parental education was 12 years at both institutions. No significant differences were found for any of these variables between the two groups. Since there were no significant differences between hospital groups in all other parameters analyzed, data from both hospitals were pooled and are presented as one combined group.

### Anxiety

Survey participants were asked to grade their level of anxiety as high, moderate, or low at the time of arrival to the ED and at the time of discharge. At both medical centers, high levels were noted in 47% of parents, moderate levels in 37%, and low levels in 13%. The difference in parental level of anxiety between arrival and discharge is demonstrated in Table 1. There was no significant difference between the hospital groups in level of anxiety before treatment and after discharge, or in the change in level of anxiety. There was also no significant correlation between parental level of anxiety and parental gender, age, or level of education. Comparison of the questionnaire results of the parents who reported an increase in anxiety at discharge [*n*=20, 4%, at each hospital, Table 1] and the parents who reported either a decrease or no change yielded several interesting findings. Significantly more parents in the high anxiety group had less than 11 years of education (*P* = 0.005), found the explanation for the child's illness insufficient (*P* < 0.026) and too short (*P* = 0.009), and claimed that their anxiety and fatigue interfered with their understanding of the medical information (*P* = 0.045).

### Level of understanding

As shown in Table 2, the majority of parents in both medical centers understood the ED discharge instructions: 75% fully understood the

diagnosis and 84.5% fully understood the treatment instructions. Interestingly, no correlation was found between the level of understanding of either the diagnosis or the treatment instructions and parental gender, age or level of education. Furthermore, there was no correlation between parental level of understanding and level of anxiety on arrival to the ED or at discharge, or the degree of change in anxiety. Finally, there was no correlation between level of understanding and time of visit to the ED.

### Contributory factors to lack of understanding

Table 3 shows that the use of professional terminology by physicians was the factor named most often by parents as interfering with their comprehension.

**Table 1.** Change in level of parental anxiety between arrival and discharge

Change in level of anxiety	SCMCI & KMC (n = 482)
Decrease	74%
No change	19%
Increase	4%
No response	3%

**Table 2.** Parental level of understanding of ED diagnosis and treatment instructions

Level of understanding	SCMCI & KMC (combined) (n =482)	
	Diagnosis	Treatment instructions
Full	75%	84.5%
Partial	20.5%	15.5%
Poor	4.5%	0%

*P* = NS for comparison of the medical centers

**Table 3.** Factors contributing to poor understanding of discharge instructions: parents' opinion

Factor	SCMCI & KMC (n = 482)
Use of professional medical terminology	25%
Anxiety and fatigue	19.5%
Lack of time for questions	16.6%
Language barrier	6%
No response	32%

**Table 4.** Parents' preference of adjuncts to medical information delivered by physician\*

Adjuncts to physician's information	SCMCI & KMC (n = 482)
Discharge instructions by nurse	54.5%
Information sheets	45%
Telephonic medical advice service	27%
Video programs	23%
Computer programs	10%
No response	1.6%

\* Parents could choose more than one item out of five.

SCMCI = Schneider Children's Medical Center of Israel

### Auxiliary methods of delivering medical information

The parental preferences for auxiliary methods of delivering medical information are ranked in Table 4. The most popular suggestion was the institution of a special discharge nurse, followed by the use of information sheets.

### Discussion

Our study shows that in the hectic and stressful environment of the ED only about 80% of parents, on average, fully understand ED discharge instructions – 75% for diagnosis and 84.5% for treatment – leaving about 20% who do not. This relatively high rate of poor understanding is particularly worrisome considering that our requirements for a full score were quite low. When parental understanding was compared with that in adult ED patients, similar findings were noted for overall comprehension – 80% vs. 77% in the study of Spandofer et al. [7], and for understanding of the diagnosis – 75% vs. 79% in the study of Logan et al. [8]. However, parental understanding was considerably higher for treatment instructions – 84.5% vs. 49% reported by Logan et al. [8]. This difference might be explained by the better attention paid by parents who are not themselves sick but concerned about their children.

Interestingly, both for the all-cohort and by medical center, the treatment instructions were understood significantly better than the ED diagnosis [Table 2]. This suggests that parents may be more focused on understanding the process (and their role in the process) that will lead to the recovery of their child rather than the nature of the disease. Furthermore, the use of medical terminology by the staff, which the parents felt to be the biggest barrier to good comprehension of the discharge instructions [Table 3], is probably more of a problem during explanation of a diagnosis than instructions regarding the implementation of care. It is also reasonable to expect parents to be more familiar with antibiotic and antipyretic administration than with the specifics of the diagnosis of croup or pneumonia.

A high level of anxiety has been found to negatively affect patient ability to understand or cope with medical information [4]. Level of education and time of day may also play a role [1,2]. We expected similar results, although these studies did not specifically address the effect of these factors on comprehension of ED discharge instructions. Our study showed that almost half the parents reported a high level of anxiety on arrival to the ED, and almost 75% reported a decrease in this anxiety at discharge. Unexpectedly, however, there was no correlation between the initial level of anxiety and understanding of the ED discharge instructions. Possible explanations for this finding are, firstly, the majority of the ED diagnoses were simple, well-known to the general public, and easy to understand. Secondly, our definition of good understanding mandated general, not detailed comprehension. The finding of equal understanding between parents who reported a decrease and those reporting an increase in anxiety at the end of the ED visit suggests that even though more of the latter found the explanation inadequate, the solution may not be additional information or explanation, but rather increased personal contact with the staff. This is supported by the additional finding that many of these parents felt that the time devoted to the explanation was too short

and that their anxiety and fatigue prevented them from fully comprehending what was being said.

Israel has a multiethnic population with a large Arab minority and a large number of new immigrants from Russia and the former USSR, Eastern Europe, Ethiopia and South America who have not yet mastered Hebrew. Although formal translation services do not exist in hospitals, we found that language constituted a barrier to communication in only 6% of the population surveyed [Table 3]. This rate is lower than that reported by Woloshin and colleagues [9] in the United States.

The majority of parents felt that the ideal aid to medical information delivery would be the institution of a special discharge nurse. Other authors have also reported that parents prefer human contact to any other form of information delivery [4,10]. This finding concurs with our recent survey of the nursing and physician staff of the participating EDs (unpublished data). The parents' second favorite option was the use of diagnosis-specific discharge instruction sheets. Other studies have reported improvement in patient understanding with simplification of the ED discharge instructions [11] and the addition of illustrations to the discharge instructions [12]. In our case, however, budgetary constraints did not allow for the addition of another nursing position. Therefore, for future use, we drew up 20 diagnosis-specific sheets for the most common problems encountered in the ED.

This study has a number of limitations: firstly, no data were collected on parents who declined to participate in the study so it is not known if they differed in any way from those who took part. Secondly, parental understanding was evaluated by application of a "template" geared to their use of certain key words in their free-style description of the child's diagnosis and treatment. The parents received no prompting regarding the expected content, e.g., questions like: "Is your child to receive an antibiotic? How many times a day? Is your child's illness referable to the respiratory or gastrointestinal system?" Therefore, even some who understood their child's illness and treatment instructions might not have been able to express this on paper. This would bias the results toward the null.

In summary, this study demonstrates that overall parental understanding of the ED diagnosis and discharge instructions is good and that anxiety usually does not pose a barrier to understanding and is reasonably mitigated during the ED visit. Nevertheless, physicians and other relevant medical personnel should be aware that about one-fifth of parents require additional staff time or information. This subset might benefit from the use of lay terminology by the instructing physician, the institution in the hospital of a special discharge nurse, or the distribution to parents of diagnosis-specific information sheets.

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