

The nursing that patients with Duchenne muscular dystrophy expect: Questionnaire survey on the psychological aspect of the patients

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Abstract

The nurse does not find how the patients who do not talk about most think, and think whether there is not something that they can do it. Therefore, a questionnaire survey was conducted on what patients expected of nurses psychologically. As a result, it was recognized that the patients had the following hopes, classified into four categories. 1) Patients want nurses to hear a story as imminent presence. 2) They want nurses to understand them. 3) They want answers to questions about medical problems. 4) They want the service side to improve. In reference to these results, we want to improve our nursing to patients in future.

Keywords: Duchenne muscular dystrophy, relation of the nurse, psychological aspect of the patients

Introduction

In preliminary research on Duchenne muscular dystrophy (DMD), it has been revealed that patients have great uneasiness about the loss of body function with the progress of the illness. There are patients who tell nurses about their uneasiness about the disease in our ward. On the other hand, there are patients who do not mention problems and uneasiness. The nurse does not find how the patients who do not talk about most think, and think whether there is not something that we can do it. Therefore, a questionnaire survey was conducted on what patients expected of nurses psychologically.

Subjects and methods

The investigation period was from

September 30, 2014 to October 15 . The subjects were 25 patients with DMD, hospitalized at our ward. Original questionnaire items were devised, including a choice pattern and a free mention pattern. The data were placed into simple tabulation form using EXCEL. Free mention was coded with the similarity of contents, and coded contents were analyzed into a middle category and a large category. Ethical consideration: The purpose of the study was explained to the study patients in a document, and a signature indicating consent was obtained. The patients could end their participation at any time. However, the agreement withdrawal after the questionnaire collection explained a difficult thing. The information obtained was not to be used for any purpose besides that of the study. The patients' names were coded and analysis did not include the patients' names.

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The data collected was deleted after the study end by appropriate methods. After we obtained approval from the in-hospital ethical review board, this study was carried out.

Results

The questionnaire was implemented with 24 people obtained its consent among 25 investigation subjects. The collection rate was 100%. The average age of the 24 patients was 28.6 (+5.4) age. Mean hospitalization several a year were 12.6 (+6.7) years. Twenty-one patients had problems and uneasiness and three patients did not. The people the patients talked to about their problems and uneasiness were family, other hospitalized patients, instructors, and nurses. Eighteen patients had talked with nurses but six patients had not. The subjects that patients talked about with nurses were as follows: Gastric fistulas and tube feeding (16%), diet and water to drink (14%), respirators (14%), and support of physicians and nurses (13%). Among 18 patients with the experience of consultation with a nurse, nine patients felt their problems were resolved, but the other nine did not. The nine patients whose problems were not resolved did not expect a solution but wanted the nurses to listen to them. The reasons that six patients did not consult with nurses were as follows. 1) There were advisers elsewhere (13%), 2) Secrets might not be kept (13%), 3) They did not want to talk about personal problems (13%), 4) Nurses looked busy (13%). Thirteen patients hoped to talk about their problems and uneasiness with specialized staff, but 11 patients did not. The contents of free mention were classified in a category and four large

categories in 12. (Table 1).

Discussion

The most common advisers to patients in order of a family, inpatients, instructors, and nurses. The patients with DMD decline for a family and there are mental issues and dissatisfaction [1]. However, for most of the study patients, the communication with the family was good. The patients with DMD spend a long time in hospital. It may be said that the nurses came to be more imminent. It is important that nurses adopt a listening attitude to patients in their daily care. The patients accepted a decline in their body functions with the progress of illness even if they have various kinds of problems. The patients felt that the nurses wanted to understand their problems. The nurse has to be associated after having understood thought of the patients with a manner of sympathizing. The patients had concerns and uneasiness about medical problems. The things they asked about included gastric fistulas and tube feeding, diet and water to drink, and respirators, which accounted for 44% of the whole. It is necessary for nurses to have specialized knowledge and techniques relevant to the medical problems experienced by individual patients. Also, patients expect an improvement in the service provided by nurses.

Reference

1. Pangalila RF, van den Bos GA, Stam HJ, et al. Subjective caregiver burden of parents of adults with Duchenne muscular dystrophy. *Disabil Rehabil.* 2012; 34: 988-996.

Table 1

Large category	Middle category
I want to hear a story as imminent presence	Nurses are imminent persons
	I want to talk to a friendly person
	There are some nurses who are easy to talk to
	I want to hear a story
I want to understand oneself	I want to know the present situation
	I want to understand a thought
I want answers about medical problems to resolve my uneasiness	Because I cannot settle it by myself
	Because I do not have specialized knowledge and experience.
I want the service side to improve	If there is the improvement in the service side of the nurses, the employment is not necessary
	I want language to be gentle
	I want to set a time to talk
	I am reserved when speaking to nurses