

The analysis of the demand in the hospitalization life of patients with Duchenne muscular dystrophy

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Received 17 February 2011 ; received in received from 1 March 2011 ; accepted 16 March

Abstract

We focused on the psychosocial aspects of patients with DMD, and we determined what kinds of demands and thoughts the patients had in regard to life in hospital. The subjects were four patients with DMD, men, average age 33 years old. They needed full-scale assistance in everyday life, and they used a respirator 24 hours a day. The patients were prepared to carry out activities using an electric wheelchair equipped with an artificially respirator during the daytime.

We recorded their remarks in an interview, and these were analyzed after being categorized in a word for word record. The core categories that were common to the four people were, "I wanted to keep good relations with the nurse" and "Worry that current activity would not be possible if the condition became aggravated". Four patients did consideration to a nurse in each methods. At the time of normal nursing service, it was difficult to obtain information on the true feelings of the patients. Based on this information, hospitalization support to satisfy psychosocial demands seemed to be facilitated.

Keyword: Duchenne muscular dystrophy, hospitalization life, demand

Introduction

1). A report on an investigation of satisfaction with hospital life of Duchenne muscular dystrophy (DMD) patients found that the patients were satisfied with how their physiological needs were met. 2). However, Yamamoto et al. described that it was difficult to obtain satisfaction in regard to psychological social needs associated with contact between nursing staff and patients. Therefore, we focused on the psychosocial side of patients with DMD, and their demands and thoughts regarding hospital life were determined.

The subjects were four patients with DMD. They were hospitalized in Tokushima National Hospital. The study period was from May, 2008 to October, 2008. We made an interview guide using the psychosocial side in basic nursing 14 items of Henderson. Using this, we conducted an interview with every patient for 30 minutes, three times in total. The patients with DMD talked freely. The interviews were recorded with the approval of the subjects and were assumed a word for word sentence, and were coded. The coded data are connected with a purpose of study, and were classified into categories. Three researchers analyzed interpretation and meaning. Consent was received from the Ethical Review Board of the Tokushima

Subjects and methods

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National Hospital. We explained the research to the patients, and we obtained their consent in written form.

Results

The average age of the four study patients was 33 years. The classification stage of the muscular dystrophy functional disorder degree was 8. The ADL level was full-scale assistance. The patients used a mouthpiece in the daytime, and a nasal mask was attached when they went to bed at night. They used a respirator for 24 hours a day. A demand in the hospitalization life.

From the remarks of Patient 1, the following four core categories were extracted from 11 categories: [I want to keep good relations with nurses], [I want mother to understand the disease, but we cannot say], [I want to hear future uneasiness and thought], [Worry that current activity will not be possible in future due to progress of the condition].

From the remarks of Patient 2, the following four core categories were extracted from 10 categories: [I hope for correspondence in accord with my pace], [I want to keep good

relations with nurses], [Worry that current activity will not be possible in future due to progress of the condition], [I do not want to subject my family to unnecessary worry]

From the remarks of Patient 3, the following four core categories were extracted from 21 categories: [I want to keep good relations with nurses], [I hope for correspondence in accord with my pace], [If my father understood the disease, the burden on my mother would decrease], [Worry that current activity will not be possible in future due to progress of the condition]

As for Patient 4, four core categories were extracted from 15 categories: [I rely on my family], [Worry that current activity will not be possible in future due to progress of the condition], [I want to keep good relations with nurses], [I hope for correspondence in accord with my pace]

The list of categories based on the remark contents of the four subjects is shown in Table 1. In these categories, the two most common items are as follows. [I want to keep good relations with nurses], [Worry that current activity will not be possible in future due to the progress of the condition]

Table 1. List of categories based on the remark contents of four patients with DMD.

Patient	1	2	3	4
I want to keep good relations with nurses	+	+	+	+
I want my mother to understand a disease, but we cannot say	+			
I want to hear future uneasiness and thought	+			
Worry that current activity will not be possible in future due to progress of the condition	+	+	+	+
I hope for correspondence in accord with my pace		+	+	+
I do not want to subject my family to unnecessary worry		+		

Discussion

The patients did consideration to a nurse in each methods since they needed nursing assistance in everyday life. The slightest expression and manner of the nurses affected the psychological condition of the patients. Okado et al. describe this as follows. A person who depends on another person for assistance feels great dissatisfaction when swiftness and precise correspondence is not possible for one's desire 3). A nurse must conduct duties with several patients, and promotion of efficiency of care is demanded. Furthermore, it is necessary that the nurse understands the feelings of the patients, and can cope. Four patients were satisfied with current one's activity, and it was thought that a place of the self-expression was obtained. Also, they regard one's activity as a person as a place of the communication with the person. Okado et al. describe as follows. The handicapped person thinks that we should be interested in human nature not the disorder of another person. He is afraid of the refusal from a partner and wants to build normal human relations. It is necessary for the co-medical to understand this 4). The patient experiences aggravation and the death of patients with disease in a ward. He understands the medical measures that are necessary for himself and for the course of illness in the future. Also, he has an uneasy feeling about the disease progressing. The present results showed that a problem was that they could not express this uneasiness. At the time of normal nursing service, it was difficult for the information about the true feeling of the patients to be heard. Based on this information, hospitalization support to satisfy psychosocial demands is facilitated. An effort to make a place and opportunity for patients to express their feelings is necessary.

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