Thoughts on patients with muscular dystrophy for gastrostomy

Rika Ohsaka[#1], Ai Kudo[#1], Asami Haruki[#1], Aki Sawada[#1], Hiromi Fujimoto[#1], Harue Saimi[#1], Yui Mukaiyama[#2], Mariko Inoue[#2]

#1. Department of Nursing department, Tokushima National Hospital, National Hospital Organization, 1354 Shikiji, Kamojima, Yoshinogawa, Tokushima 776-8585 Japan

#2. Department of Guidance on Medical Treatment Education, Tokushima National Hospital, National Hospital Organization, 1354 Shikiji, Kamojima, Yoshinogawa, Tokushima 776-8585 Japan

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Abstract

From three patients with Duchenne muscular dystrophy (DMD) who were not undergoing gastrostomy during hospitalization in A ward, we heard their thoughts on receiving a gastrostomy. Six categories of "pain"> "surgery" <skin trouble> <abdominal symptom> <behavioral restriction> <weight loss> were extracted regarding "anxiety after gastrostomy formation". Regarding "image for gastrostomy", four sub categories were extracted: <vague negative image> <body image> <image to oral intake> <image to surgery>. For "meaning of bivalent emotion in oral intake", four sub categories were extracted: <desire for oral intake> <concern about deterioration of physical condition due to oral intake> <enjoyment of meal> <oral ingestion as a criterion for gastrostomy setting >. For "How to catch and face the gastrostomy", six sub categories were extracted: <passage point> <distraction / conflict> <posture to put distance> <posture to accept> <interest in gastrostomy> <a positive attitude>

Key words: thoughts on gastrostomy, decision support for gastrostomy setting

Introduction

There were 37 patients with muscular dystrophy in A ward, of which 21 had undergone gastrostomy. According to the questionnaire survey on the psychological aspects of patients with Duchenne muscular dystrophy in FY 2004, the content that I had consulted with a nurse was "mostly about gastrostomy / tube feeding nutrition". However, we could not spare time for each patient. Therefore, I was not able to grasp what kind of anxiety the patients had with respect to the gastrostomy. Therefore, in this study, I listened to the patients' descriptions of their feelings about gastrostomy and analyzed what they said from a psychological perspective.

Subjects and methods

The subjects were three patients with Duchenne muscular dystrophy (DMD) who had not received gastrostomy during hospitalization in A ward. As a method of collecting data, we conducted an interview with a semi-structured interview method according to our own interview guide. Regarding the data analysis method, we prepared a verbatim record from the record of the voice recorder that recorded the interview contents, and used it as basic data. I extracted and coded the elements related to the patients' thoughts before gastrostomy. Based on the meanings and similarity of what they said, we organized groups and extracted sub categories and categories. In the process of categorization, we discussed repeatedly until agreement was reached among the researchers and clinical psychologists.

Correspondence to: Rika Osaka., Tokushima National Hospital, National Hospital Organization, 1354 Shikiji, Kamojima, Yoshinogawa, Tokushima 776-8585 Japan Phone: +81-883-24-2161 Fax : +81-883-24-8661

Ethical considerations

This research was approved by the Research Ethics Committee of the institution in which it was conducted. Before requesting permission to conduct the survey by the interview method, we explained that participation was optional and participants could cease to participate at any time without giving a reason. Also, we explained that information and personal information obtained from the interview would not be used other than by this research, and individuals could not be identified. After explaining that refusal would not affect the treatment or nursing currently being received, we received consent to conduct the study. We made it anonymous when making it word-by-word, so that individuals were not identified. After verbatim transcription, the voice recorder recording was erased. Keeping and managing serialization in a place where only researchers can see it.

Results

As regards the results of the interview, from among 109 codes, the following categories were extracted[Anxiety about after gastrostomy] [image of gastrostomy] [meaning of bivalent emotions in oral intake] [way of catching and faced gastrostomy] (Table 1).
Categories are represented as [], subcategories as <> and raw data as "".
With regard to [anxiety after gastrostomy creation], six sub categories were extracted: <pain> <surgery> <skin trouble> <abdominal symptom> <behavior restriction> <weight loss>. Regarding the image of gastrostomy, four subcategories were extracted: <vague negative image> <body image> <image to oral intake> <image to surgery>. With respect to the meaning of bivalent emotions in oral intake, four sub categories were extracted: <the desire for oral intake> <concern about deterioration of physical condition due to oral intake> <enjoyment of diet> <oral ingestion as a criterion for gastrostomy setting>. Regarding [How to catch and face gastrostomy], six subcategories were extracted: <passage point> <distraction / conflict> <posture to put distance> <posture to accept> <interest in gastrostomy> <positive attitude>.

Discussion

The patients had never done themselves about gastrostomy. They had various gastrostomy fears
[anxiety after gastrostomy] and [image of gastrostomy]. There was a possibility that listening to remarks on gastrostomy by gastrostomy patients or nurses or actually observing patients who had already undergone gastrostomy had an influence. Also, three patients took <posture to keep distance>. Yoshihara et al. stated that "Patients know that they are not the only people with disabilities at the outset when they are hospitalized, will act at first glance, but they will see their own prognosis by looking at other patients". It is necessary to listen to the expressions of anxiety of patients and reduce their anxiety. The patients strongly felt that they wanted to eat but that they would not be able to eat if they had a gastrostomy. On the other hand, they also believed that if they were unable to eat and their physical condition worsened, they would have to have a gastrostomy. As a time to have educational involvement, it is desirable during oral ingestion. It is thought that it is necessary to provide information at that time. They had various concerns about gastrostomy but there were also <transit points> or <attitudes of acceptance >. On the other hand, some patients said "I do not want to do much". [How to catch and face gastrostomy] also varied from person to person. In the process of accepting the present situation by patients, nurses need to be involved so that conflicting decision-making can be carried out while conflicting. It is thought that nurses should start educational involvement from an early stage. There is a possibility that it can lead to more decision support by pursuing the inner process of a patient who intends to accept gastrostomy setting by qualitative research in the future.

Table 1. Impression of gastrostomy setting

Category	Anxiety about gastrostomy	Image of gastrostomy	Meaning of bivalent emotions in oral intake	How to catch and face gastrostomy
Sub category	Pain	Vague negative image	Desire for oral intake	Passage point
	Surgery	Body image	Concern over deterioration of physical condition due to oral intake	Confusion
	Skin trouble	Image of oral intake	Enjoyment of meals	Attitude of acceptance
	Abdominal symptoms	Image of having surgery	Oral ingestion as a criterion for gastrostomy setting	Positive thinking
	Weight loss			Interest in gastrostomy
	Behavior restriction			Posture to keep distance