Author manuscript

How physicians support mothers of children with Duchenne muscular dystrophy?

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Abstract

Communicating about Duchenne muscular dystrophy (DMD) and its prognosis can be difficult for affected children and their family. We focused on how physicians provide support to the mothers of children with DMD who have difficulty communicating about the condition with their child. The eligible participants were certified child neurologists of the Japanese Society of Child Neurology. Participants responded to questionnaires consisting of free descriptions of a vignette of a child with DMD and a mother. We analyzed 263 responses of the participants. We found four themes on advising mothers, involving encouraging communication, family autonomy, supporting family, and considering the child's concerns. These results provide a better understanding of the communication between physicians and family members who need help sharing information with a child with DMD. These findings will assist clinical practitioners in supporting families and the affected children throughout the course of their illness.

Keywords: Duchenne muscular dystrophy; physicians; mothers; communication; qualitative study

Introduction

In recent years, the circumstances of patients with Duchenne muscular dystrophy (DMD) have undoubtedly improved. Despite this progress, DMD is still a severe disease causing a significant burden to patients as well as their families. The lives of parents' with a child with DMD are profoundly affected, and they generally suffer from high levels of stress.[1]

DMD is a recessive X-linked progressive muscular disease, which is caused by a mutation in the gene responsible for dystrophin production.[2] DMD occurs primarily in boys. Boys with DMD have progressive loss of muscle function and weakness, resulting in a loss of ambulation and deterioration of respiratory and cardiac functions. Clinical management and care for DMD has improved in the last few decades due to corticosteroid treatment, non-invasive mechanical ventilation, and cardioprotective medications, resulting in prolonged life expectancies.[3-6]

It is a difficult process for the affected child and their family to receive the diagnosis of DMD and communicate about the child's prognosis. While pharmacological interventions and corticosteroid therapy have been reported as effective in slowing the decline of muscle strength and function in DMD,[2, 7, 8] there are no curative treatments in existence. Informing a family of the life-limiting condition of their child can be one of the most difficult and stressful events for a physician to experience.[9] Emotional responses of physicians could have consequences on how the diagnosis process progresses. In addition, the manner in which the condition is explained and communicated by medical professionals has an impact on the parents and child. Generally, one of the recommended communication styles is explaining the condition and providing information on the course of the disease at a level that is comprehensible to both the child and family.

Although there is a great deal of research on disease communication for major pediatric diseases such as childhood cancer,[10, 11] DMD differs in both prognosis and therapeutic potential. There are few studies focusing on communication between physicians and the families of children with DMD.[12]

This study aimed to explore how physicians explain the diagnosis and support families with a child with DMD. The original study was designed to reveal physicians' attitudes and examine how they dealt with the difficulties inherent in explaining the condition to affected children. This paper focuses on how physicians deal with and support mothers who ask for advice on explaining the condition to their children.

Methods

Participants

We obtained permission to mail survey questionnaires to board-certified child neurologists of the Japanese Society of Child Neurology. The eligible members of certified child neurologists were 1,022 physicians, the same number of participants as in our previous study.[12]

Thirteen participants were not eligible because their addresses were unknown. The final sample consisted of 1,009 pediatric neurologists in the Japanese Society. This survey was conducted between August 2010 and February 2011.

Procedure

We developed the questionnaires based on a review of the literature and an exchange of opinions among clinical psychologists (HF, OI) and experienced physicians (TS, TM, HF, SS) with experience in pediatric neurology and muscular dystrophy. The main part of the questionnaire consisted of free descriptions regarding a case vignette, which addressed how physicians deal with and support mothers who ask for advice on explaining DMD to their children. Additionally, it included domain items of physician's views about important factors in explaining the condition and their attitudes towards doing so. Details of the study methodology were reported elsewhere.[12]

This study was approved by the research ethics committee of the National Hospital Organization Toneyama National Hospital.

Case vignette

A hypothetical case depicting a mother who needs help in dealing with her child's needs was constructed for this qualitative study. A detailed description of the case is as follows:

"*An 11-year-old boy who was diagnosed with DMD at the age of 18 months is now in the fifth grade at elementary school. The boy started using a wheelchair in fourth grade because he had begun to experience difficulty in standing and walking at that time. For several years, the boy has gone to the physician about twice per year. No signs of mental retardation have been observed. According to his mother, the boy had a class at school in which pupils thought about 'living'. This class prompted him to vaguely think of the future and learn more about his disease. Although he had already been informed about his needs in daily life, and he knew his disease was a muscular disorder, the future or his prognosis had not been discussed at home. The mother did not know how to explain this to him and had come to the physician for a consultation".*

We asked an open-ended question about how to deal with the mother in this situation.

Analysis

Qualitative data were analyzed using the thematic analysis approach. Thematic analysis is a method of identifying and analyzing the themes within qualitative data.

The responses of the free descriptions were carefully read several times to identify themes and subthemes from the physicians' viewpoints on how to deal with and support the mothers. These processes resulted in the categorization of specific subthemes. Two researchers (HF, OI), male certified clinical psychologists with experience of psychological research in the field of muscular dystrophy, extracted the themes and disagreements were discussed until consensus was reached. Once the themes were identified, the responses were reviewed again, and the frequencies of the themes were calculated. A qualitative research software package was not used for the collating and coding. Consolidated criteria for reporting qualitative studies (COREQ) checklist was used as a reporting framework.[13]

Additionally, we performed χ^2 test, using SPSS Statistics 21.0 software (SPSS Japan Inc., Tokyo, Japan), to assess the difference in the approach by age.

Results

We received 311 replies (30.9%). Within the 311 replies, 263 were included for the analysis of the free description of the case vignette. Twenty-two were excluded because of no experience in the specialty field of muscular dystrophy. Twenty-six were excluded because answers for free description were missing. The majority of the participants were men (70.7%), with a mean age of 50.6 years. They had been working in pediatric neurology for a mean of 20.4 years and in the specialty field of muscular dystrophy for a mean of 13.4 years. Table 1 describes the demographic information of participants.

Four key themes were identified through thematic analysis and each theme contained several subthemes. There are no significant differences in frequencies of the themes and subthemes by age of the physicians. Themes and subthemes are summarized in Table 2 and the details are described below.

Help with communication

Explanation from the physician. The most common response was telling the mother that the primary physician would or could explain the nature of the condition to the child. In the case vignette, the mother asked the physician for advice because of her difficulty in explaining the condition. Telling the mother that the physician is able to explain the condition would provide support in such cases.

"It is about time to directly tell the child about the disease in detail and how to handle it in life. However, since telling everything at once would confuse the child, the

physician should talk to the child directly on several occasions". (P55)

"This child is 11 years old with no mental disability. So, if the child wants to know about the disease, the truth should be given accurately. I would tell the mother that the child's doctor could explain it to the child directly. Although the child might be bewildered at the time, the child would understand it better in the future". (P56)

Physicians take an active role in facilitating communication among family members and physicians. They thought it was better to have the primary care physician properly tell the child about the disease.

Suggests talking to the child because of his growth. According to the developmental stage of the child, how he views himself, and what he wishes to know about himself, the physicians encouraged the mother to provide an explanation and talk with her child.

"The child has reached the age of getting interested in his own things and of needing to prepare for positively confronting the disease. After telling the child the name of the disease, we should provide support so that the child can cope with what needs to be done from now on, particularly respiratory rehabilitation and cardiac management, on the child's own initiative". (P17)

"I would tell them that considering both the child's age and psychological state, it was the right time to start giving an objective explanation about the disease. As the child's doctor, I would help the child learn about the disease, while taking into account the parents' wishes". (P66)

"This must be properly discussed sooner or later, and if the child wants to know about the disease now, then it may be a good time". (P22)

Physicians referred to the growth of the child and the child's desire to know, and decided it was appropriate to talk about the disease with the child at that time. In addition, their perspective was that the child's desire to know was related to his growth.

No need for an explanation. A small number of the physicians thought it was not necessary to tell the prognosis and the future given the age and the developmental level of the child.

"I do not think it is necessary for the mother to explain about respiratory failure or heart failure, which could occur in the near future. Isn't it better to talk to the child after the child becomes more aware?"(P35)

"I would not tell the [child of his] prognosis until the condition becomes more advanced. We are not supposed to let him lose hope at this point". (P242)

The intention of the physicians in withholding the prognosis from the child was to allow them to maintain hope for the future. It is believed that being aware of the life-limiting nature of the disease could have a negative impact on the child's

adjustment.

Do not hide the facts. Parents of a child with an intractable disease often have trouble disclosing the facts of the disease, which could lead them to hide the nature of the disease from the child. Despite the difficulties in disclosing the facts, a small number of physicians emphasized the need to explain the facts.

"I would suggest honestly talking to the child about the disease and the mother's views of life and death. In so doing, it is not necessary to choose words so that the child can understand, but rather, to be honest". (P34)

"The disease is gradually progressing, and the child shows no mental retardation. Since the child wants to know more about the disease, hiding it would jeopardize the relationship between the child and his parents as well as the medical staff". (P53)

Concealing the facts from affected children might give them an unrealistic image of the disease and set them up to have difficulties in accepting the facts of the disease and the natural course of the disease progression. Therefore, physicians thought they should not conceal the facts from the child, even though they did not tell the child "everything".

Family's autonomy

Confirm the family's intentions. The family's intentions affect the process of disclosure and communication about the condition. Parents might have different ideas about conveying the details of the condition. Physicians affirmed their attitudes and encouraged them to discuss the decision within the family.

"I would tell the patient's family to discuss and decide whether or not to talk about the disease including the prognosis and whether or not the doctor should be the one to do it". (P70)

"As I would like to explain about the disease and follow-up plans for the child, please set up a counselling (genetic) opportunity, or have a discussion about it between the parents". (P15)

To help parents be more autonomous in explaining the disease to the child, physicians encouraged parents to think about how they would explain the disease and they provided encouragement to them while they made their decision. Physicians also expressed a desire to respect the parents' decision.

Help the parents understand the disease better. Physicians offered to provide information about the disease so the parents could obtain a better understanding of the condition.

"The doctor should talk specifically about the symptoms, general prognosis, and treatments (steroid, respiratory, cardiovascular) so that the parents can first understand

the medical condition". (P90)

"Discuss with the mother, check her level of understanding, and answer her questions to enhance her understanding". (P174)

The mother's comprehension has an impact when she talks with the family about the child's condition. Some parents do not completely understand the nature and prognosis of the disease so physicians try to teach them so they are knowledgeable about the disease.

Talk about what the mother understands. Physicians also suggested that the mother should tell the affected child what she knows about the disease when her child has reached a certain age.

"Since the child has reached the age of being able to understand about 'living' and 'life,' I'd like to suggest telling the child the information deemed necessary in a straightforward manner". (P211)

Moreover, some physicians thought the child should be able to understand his disease by that time and suggested the mother try to talk to the child little by little about what she understood.

The family cares for and supports the affected child. Some physicians emphasized that the parents should tell the child that the parents would always provide care and support for the child. When informing the child of the nature of the disease, parents should make sure to let the child know that his family will always be there for him and care about him. When the child is given information about the challenges of the disease, the family should understand the child's response, provide support to him, and anticipate that he will react with shock.

Support for the family

Support resources and patients' associations. Another recommendation was that mothers be provided information about patients' associations and psychological counselling as support resources for the child and mother.

"Please try to provide accurate information about the disease, incorporating its positive aspects and helpful stories of other patients with the same disorder. In addition, how about hearing stories of families who have actually talked to their child patients?" (P40)

"I would suggest that the mother referred to support resources such as patients' associations and genetic counselling, and providing an opportunity for the patient, the patient's mother, and doctor to discuss the disease". (P112)

Parents with considerable experience of having a child with DMD could perhaps serve as role models for parents with less experience. Physicians related that sharing

information among families of different ages could provide support to younger families.

Support the mother's emotional responses. Physicians also focused on the emotional responses of the mother, including worry, anxiety, and confusion.

"Check on the mother's concerns first and learn what she is most worried about". (P138)

"Ask the mother what she understands and how she is feeling. Provide support for the mother and ask her wishes". (P139)

As the disease progresses, parents often repeatedly experience feelings of sorrow, loss, and guilt. Looking at the mother's emotional responses can help the physician encourage her to express her emotional distress, which might lead to her being able to construct a supportive relationship with the physician.

Consideration for the child's concerns

Talk to the affected child according to his level of understanding. When telling the child about his condition, physicians and the family should consider his age, understanding, and psychological state.

"It is important to give information to the child gradually, based on his level of understanding". (P79)

"When answering the child's questions, devise ways of explaining the disease according to his comprehension of the words being used and with the use of good judgment". (P151)

Physicians believed the child's cognitive development and psychological state should be considered in deciding how and what to tell.

Listen to the child's concerns. One of the recommendations was to listen to the child's concerns to figure out their needs and ease their anxiety.

"Go on with the discussion slowly after fully understanding the child's knowledge and concerns, and also giving careful consideration to his personality". (P210)

"Start by asking the affected child what he wants to know and is concerned about. Then, discuss that with him, explain whenever possible, and respond to him with affection if there is anything unknown". (P291)

Physicians also stated that supporting resources are needed to assist in providing support for the emotional response of the child. They recommended confirming whether the child is able to get support from family members, schoolteachers, and friends.

Discussion

This study focused on how physicians dealt with and supported mothers of patients with DMD who asked for advice on explaining the disease to their children. For

physicians, tailoring the explanation of the diagnosis and prognosis for the level of comprehension for the child and the family can be a challenging task.[14]

Because of the progressive nature of the disease, there should be a gradual approach to the process of disclosure and the explanation of DMD. Each time the disease progresses (e.g., use of wheelchair, loss of ambulation, or decline of respiratory function), physicians provide the child and the family with relevant information for that level of functional impairment. In case the child has not been informed about the fundamental nature of the disease, sessions where the child knows about severe prognosis can be a difficult moment for parents. In this study, physicians' attitudes towards parents' needs were found to consist of four themes. They were not affected by age of the physicians, suggesting other factors determine the approaches to those kinds of families.

Help with communication

The first was "help with communication". Having the responsibility to tell their child with DMD about the disease and its genetic nature could be a burden for mothers. As the child grows, mothers have more opportunities to talk about the child's future and the nature of the child's illness. However, mothers of children with DMD are often reluctant to talk about the condition.[15] The physician told the mothers that he or she is willing to tell the child about the disease, which might ease the mother's distress and facilitate communication about the disease. Additionally, talking about the growth of the child can work supportively, alleviating her pain and difficulties. These experiences could facilitate open conversation about the difficult condition between the child and family. Parents of children with severe chronic genetic diseases, like DMD, tend to think that because the children experience the effects of the condition in their everyday life, they know what is going on.[16] Usually, there are difficulties in communicating a genetic condition with an affected child; however, communications between parents and affected children cultivate shared understanding and knowledge. Six fact sheet could a useful tool to encourage the autonomy of young patients, managing their care and making decisions about their health interventions. [17] This is particularly important in transition process.

Family's autonomy

The second theme identified was "family's autonomy". Autonomy in parents and patients is an essential part in advancing the process of sharing information about the disease. Physicians recommended that the mother obtain more information and tell the affected child what she understands. They also emphasized the role of the family in supporting and caring for the affected child. These attitudes support the parents'

capacity to manage difficult conditions. In our previous study, pediatric neurologists agreed that parents' understanding and acceptance of the condition were critical for explaining the condition.[12]

In a previous study conducted in the UK, about a half of the parents of children with DMD did not tell the diagnosis to the child because of the life-limiting nature of the disease.[18] It can be a very difficult problem when the parents are not prepared to communicate about the disease to the child. Therefore, medical professionals or counsellors could help prepare them and provide support while they decide on how to talk with the child. Medical staff are considered to have an important role in facilitating such communication and thus improving family adjustment.[14] However, some children prefer that the parents discuss the condition in a less formal way, and this may reduce anxiety in the children.[19]

Although parents think it is critical that they talk about their child's condition with him, many desire to delay such a talk until the progression of the disease seems more imminent. In other words, there is a tendency for parents to avoid reality to limit their distress.[15, 16] The family history of DMD also affects the process.[20]

Support for the family

"Support for the family" was the third theme identified. Caring for a child with DMD is emotionally difficult for parents. As the disease progresses, parents often feel strong emotions, such as feelings of sorrow, loss, guilt, anxiety, depression, and frustration,[1, 18, 21, 22] whereas parents of patients with muscular dystrophy could have positive consequences from caregiving, despite practical difficulties. [23] Support resources from outside of the family have been found to be important in parents' adjustment and coping with DMD.[24] As such, physicians should refer the parents to support groups and recommend that they participate with the child. Peer groups can be a vital source of support for families and children, [25] however, parents and affected children can have ambivalent feelings toward support groups.[26] By going to a group and meeting older children and families, they have to confront the progressive nature of the disease; thus, some parents experience strong negative feelings about attending these groups. This is a very difficult problem, as feeling connected to other people is a very important contributor to psychological adjustment.[27]

Consideration for the child's concerns

Patients with DMD experience repeated losses during adolescence as they develop and establish their own self-concepts. The disease influences their psychological adjustment and personality development; therefore, some of them may seek psychological support, whether consciously or unconsciously, during a difficult time.

While parents and physicians sometimes have difficulties in facing the emotional responses of the child when informing him of the disease and its life-limiting nature, communicating about the condition with medical professionals could help patients and their families hope for more out of life.[28]

Limitations

Several limitations should be noted in the present study. Response rate was low in this study. Because all the certified child neurologists do not engage in specialty field of muscular dystrophy, the proportion of responders of our research seemed reasonable. All the responders included in current study had experience of practice in the field of muscular dystrophy. This study was a questionnaire survey, which employed a case vignette to investigate how physicians would deal with and support mothers who ask for advice on explaining the diagnosis of DMD to their children affected by it. Generally, the process of supporting families of children with DMD begins at the child's diagnosis and continues as the disease progresses, with continuous interactions between the physician and family. Further research is needed to investigate the actual roles of physicians and the interactions with the families during the disease progression. Participants of this study were Japanese physicians with experience of practice in the field of muscular dystrophy; therefore, their responses were naturally affected by the conditions of medical care in their specific region and cultural background.[29] Experience of practice in the field of other pediatric and neurological disorders may also contribute to their approaches. However, several themes were similar to those found in a previous study examining the experience of genetic counsellors in another setting and region[30]; thus, it suggested that the important themes of the current study could apply in other countries and cultures. Novel treatments, such as exon skipping therapy, are being developed, and these will lead to more effective interventions for improving muscle strength and functioning in DMD patients.[31, 32] The perception of DMD could change with the development of efficacious treatment, which may affect the disclosure process between parents and affected children.

Conclusion

Despite these limitations, to the best of our knowledge, this is the first study that has examined physicians' recommendations to mothers of children with DMD regarding the disclosure of information about the condition to their child. Although there is no single or best way to deal with the difficulties the parents of children with DMD face, keeping these key themes in mind could aid physicians in their clinical practice. Further studies are required to establish helpful guidance for physicians on suitable ways to disclose

information about the diagnosis and prognosis of DMD to parents and their children.

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Author Contributions

Fujino, Saito, Matsumura, Fujimura, Shinno and Imura designed the study and wrote the protocol. Shibata and Iwata contributed to data collection and interpretation of data. Fujino and Imura conducted qualitative analysis. Fujino wrote the first draft of the manuscript. All authors contributed to and have approved the final manuscript.

Declaration of Conflicting Interests

All authors declare that they have no conflicts of interest.

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Ethical Approval

This study had ethical approval from the research ethics committee of the National Hospital Organization Toneyama National Hospital.

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Table 1. Demographic information of participants

	n		
Gender			
Male	186		
Female	77		
Age group			
35-39	37		
40-49	80		
50-59	109		
≥60	37		
Workplace[a]			
Public hospital	82		
University hospital	77		
Private hospital	59		
Clinic	45		
National Hospital Organization	24		
	Mean	SD	Range
Age	50.6	9.1	35–86
Years working in pediatric neurology	20.4	8.9	1–55
Years working in muscular dystrophy	13.4	10.4	1–55

[a] Some of the participants' responses included two or more locations

Table 2. Key themes of the physicians' responses

Theme	*n*	Content
Help with communication		
Explanation from the physician	94	The doctor takes on the role of disclosing the information to the affected child or tells the mother that he/she can talk to the child.
Suggests talking to the child because of his growth	81	The physician suggests talking to the affected child since he is growing and wishes to learn more about the disease.
No need for an explanation	21	The physician says to the mother that she should not explain what does not need to be explained at that time.
Do not hide the facts	11	Even though you do not need to tell everything, you should not hide the facts about the disease or lie to the child.
Family's autonomy		
Confirm the family's intentions	57	Have a discussion with the family of the affected child and determine what to do.
Help the parents understand the disease better	25	The physician provides an explanation to the parents to enhance their understanding of DMD.
Talk about what the mother understands	24	Suggest that the mother should tell the affected child what she knows about the disease.
The family cares about and supports the affected child	11	Tell the child that his family cares about and supports him.
Support for the family		
Support resources and patients' associations	32	Refer the family to patients' associations, family associations, and counselling.
Support for the mother's emotional responses	16	Support the mother as she experiences confusion and emotional responses.
Consideration of the child's concerns		
Talk to the affected child according to his level of understanding	26	Think about the child patient's current age, understanding, and emotional state.
Listen to the child's concerns	23	Talk to the child while asking about his concerns and what he wants to know.