Original Article

Aspects of the minds of mothers of children with developmental but no intellectual disabilities and the nature of these disabilities

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Abstract. [Purpose] This study aimed to elucidate the aspects of psychosocial adjustment of mothers of children with developmental but no intellectual disabilities and to clarify the nature of these disabilities. [Participants and Methods] We conducted an unstructured group interview with three mothers of children with developmental but no intellectual disabilities. [Results] The mothers who were not aware of the disabilities, because the disability characteristics made it difficult to recognize easily the disabilities, began to feel anxious about the unforeseeable future when their children began to fail in society outside the home, such as in school. This anxiety was made worse by the teachers' lack of understanding of the developmental disabilities and reduced self-esteem of the children themselves. Becoming aware of their children's ability that they had not seen earlier, a peaceful life and expectations for the future brought about by awareness led to the psychosocial recovery of these mothers. [Conclusion] The truth about the nature of developmental disabilities in the absence of intellectual disabilities, human consciousness does not accept diversity and allows the majority to force minorities to conform.

Key words: Developmental disabilities, Psychosocial adjustments, Acceptance of disability

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INTRODUCTION

Children interact most closely with their mothers while growing up. When a child is diagnosed as having a disability, the mind of the mother and her relationship with society start to change. Many studies have been conducted to date on the psychosocial adjustments of mothers of children with disabilities. However, most of these studies have been conducted on the mothers of children with intellectual disabilities, and there have been relatively few reliable empirical studies in Japan on the mothers of children with developmental, but no intellectual disabilities¹⁻³⁾. Nakata⁴⁾, who has long studied acceptance of disability, examined review articles on the acceptance of disability and showed that there had been few studies on parents of children with developmental, but not intellectual disabilities. He pointed out that this problem is difficult to understand with the conventional concept of disability and has to be studied from a different perspective from the acceptance of disability theory. Representative models to understand aspects of psychosocial adjustment in mothers of children with disabilities include Drotar et al.'s⁵⁾ stage theory, Olshansky's⁶⁾ chronic sorrow theory, and Nakata's⁷⁾ spiral model, which comprises the stage theory and chronic sorrow theory, in which there are always feelings of affirming and denying disability. However, it may be difficult to explain the psychosocial adjustments of mothers of children with developmental, but no intellectual disabilities using these models.

It is not usually easy for people to identify developmental disabilities in the absence of intellectual disabilities. What is the nature of developmental disabilities without intellectual disabilities? Under these circumstances, how do mothers psychosocially adjust to their children's disabilities?

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The Act on Support for Persons with Developmental Disabilities in Japan, which was enacted in 2004, defines developmental disabilities as autism, Asperger's syndrome, other pervasive developmental disorders, learning disabilities, attention-deficit hyperactivity disorder, and other similar brain dysfunctions. Although developmental disabilities are thought to manifest as difficulties in interpersonal relationships and communication disorders, a report published in 1944 by the pediatrician, Asperger⁸⁾, already showed that the condition is also characterized by developmental disabilities, including motor clumsiness. In addition, low motor skills have also been observed in children with autism^{9, 10)}, learning disabilities^{11, 12)}, and attention-deficit hyperactivity disorder^{13, 14)}. The clumsiness affects not only the daily lives, but also the learning in school, and social lives of the patients. Namely, for the management of developmental disabilities, close collaboration is required not only among experts in the field of education and welfare, but also among experts in various other fields.

The purpose of this study was to understand aspects of psychosocial adjustment of mothers of children with developmental, but no intellectual disabilities and to clarify the nature of developmental disabilities without intellectual disabilities.

PARTICIPANTS AND METHODS

The participants were 3 mothers of children with developmental, but no intellectual disabilities, who belonged to a parents' association, interacted with one another on a daily basis, and could communicate openly with one another: Ms. A who had a child currently aged 14 years (diagnosed as having disability at 6 years of age), Ms. B who had a child currently aged 17 years (diagnosed as having disability at 12 years of age), and Ms. C who had 2 children currently aged 18 and 21 years (diagnosed as having disabilities at 9 and 5 years of age, respectively).

An unstructured group interview was conducted, because we expected that the relationship among the 3 participants would help deepen the conversations. In this interview, the participants were instructed to freely talk about their experiences and feelings related to their children's disabilities in chronological order from childhood to the present. The researcher participated in the conversations by asking questions in the context that had been developed. The interview was recorded with an integrated circuit (IC) recorder with the permission of the participants. The interview lasted for 95 minutes.

The contents of the interview were analyzed by the following procedure: (1) the conversations were transcribed verbatim and ordered chronologically for each participant; (2) experiences and feelings common to 2 or more participants were selected and placed in chronological order; (3) sentences were shortened in such a manner as to leave the words of the mothers intact as much as possible; (4) clauses of the shortened sentences were categorized to extract common concepts.

Ethical approval for this study was obtained from the Research Ethics Committee of University of Kochi and also by the Social Welfare Research Ethics Committee of University of Kochi (Approval number: 18-31). Written informed consent was obtained from all participants before the study.

RESULTS

Table 1 shows the results.

Table 1. Aspects of psychosocial adjustment in the mothers

A	B	C	Common concept	
When attending kindergarten, the child was active and able to chat, and I did not think that he had low intelligence.	I wondered why my child could not do what was expected of him.	The child was not good at writing until second grade. I thought she would be able to write sooner or later.	I just thought that he was a very energetic boy. I thought he would be able to talk before long.	Difficulty in seeing the disabilities
Upon entering elementary school, he took a very long time to read, write and do simple math, which made me wonder if something was wrong.	The child worked hard, but could not read or write kanji.	The child had attended English classes for 4 years until third grade, but could not write alphabets and could still not distinguish between upper- and lower-case letters.	He liked things that rotated, and our house was filled with ventilation fans. If there was an outdoor unit of an air conditioner along the elementary school route, he crouched to watch it and forgot to return home on time.	Failure in society outside the home
I wondered what would become of the child. I was scared of the unforeseeable future.	I wondered what would become of the child. I was in a tunnel with no end in sight.	At third grade, the child could not write alphabets, and I became rather anxious.	After the diagnosis, I had difficulty in getting out of the tunnel.	Anxiety about the unforeseeable future.

Table 1. Continued

A	B	C	Common concept
The teachers instructed the child to do the same things as everyone else, like nothing was wrong.	Teachers thought he was bored and playing.	After a teacher condemned him, he began to wash his hands using about one whole bottle of detergent.	The teachers' lack of understanding of the developmental disabilities
The child who could not write, wrote a letter saying he did not want to go to school any more. The child said, "I cannot do it, even if I try".	The child stopped attending school and did not want to learn any more. He put the pencil down and kept saying, "I want to die. I hope I die. It makes no sense for me to live".	He said, "If there was no drum, maybe I would have died".	Decrease in the self-esteem of the children
	I took the child to see a doctor so that he would not discontinue attending junior high school and can find a place in school.	I took the child to see a doctor, because I was worried that she could still not write alphabets or distinguish between upper- and lower-case letters.	Health checkups revealed an abnormality, and I was not surprised by the diagnosis.
Being with people who understand the disabilities and support the child is encouraging.	My knowledge has increased, and I no longer think that he must do something.	Being able to share difficult experiences with other parents, I could empathize with them with a sense of security. It was also helpful that I could obtain information.	Reason for seeing a doctor
When I gave the child some tips, the child's grades increased only in that subject.	When he began to be taught by a teacher who had learned how to support children with learning disabilities, the child, who had not written kanji since the third grade, suddenly began to learn kanji characters with a large number of strokes.	A favorable change in the method of teaching enabled the child to write katakana within a few days.	Support by the parents' association
The child enjoys attending school.	Although the child temporarily stopped attending junior high school, he has been attending high school without any great problems.	Now the child has taken up animal husbandry.	Apparent improvement in the children's abilities
	If I had learned how to manage the disability earlier, I would not have made my child suffer as much as I did.	Now he is a student of engineering at a university.	A peaceful life/ expectations for the future
		I repeatedly held the child's hand to make the child practice writing. A change in the method of teaching enabled the child to write easily. I was shocked and felt really sorry that she had to practice writing with me in the wrong way.	Reflection on their actions that were inappropriate for the disability characteristics

DISCUSSION

Aspects of psychosocial adjustment in the 3 mothers are summarized as follows. The mothers who were not aware of the disabilities, because the disability characteristics made it difficult to easily recognize the disabilities, began to feel anxious about the unforeseeable future when their children began to fail in society outside the home, such as in school. This was made worse by the teachers' lack of understanding of the developmental disabilities and the reduced self-esteem of the children themselves. Becoming aware of their children's ability that they had earlier not seen, a peaceful life and expectations for the future brought about by the awareness, and the presence of a space where they could interact with other mothers with the same worries led to the psychosocial recovery of these mothers.

According to the Drotar et al.'s⁵⁾ stage theory, after parents are informed of the disabilities in their children by doctors, their psychosocial adjustment progresses through the stages of shock, denial, sadness and anger, adjustment, and recovery. The 3 mothers' reasons for seeing a doctor indicate that all the 3 mothers were already aware of their children's disabilities before seeing a doctor. Ms. B took her child to see a doctor because she needed her child to find his place in school. Ms. C was not necessarily very shocked when informed of the diagnosis. In addition, Todo¹⁵⁾, who has a child with developmental, but no intellectual disabilities, described that when her child was diagnosed with dyslexia (disability characterized by difficulties in reading and writing) at 16 years of age, she was shocked, but felt that she had suddenly obtained the answers to long-standing questions, and did not pass through the process of acceptance of the disability. According to a study by Nagira et al.¹⁾, when mothers of children with Asperger's syndrome were informed of the diagnosis, they fully understood and expressed their perception of the disability in the following words: "I knew it" and "the disability has not allowed the child to play with others well". There was no obvious denial or anger, suggested by Drotar et al.'s⁵⁾ stage theory, in the words of these mothers.

In addition, from the results of this study, it is unclear whether chronic sorrow explained by Olshansky⁶⁾ persists and whether the feelings of affirming and denying disability proposed by Nakata⁷⁾ are always present in the mothers of children with developmental, but not intellectual disabilities. Ms. B and Ms. C reflected on their actions that had been inappropriate for their children's disability characteristics. However, the consciousness of all the 3 mothers was directed toward the current peaceful life and expectations for the future. If chronic sorrow represents the emotion generated by always directing consciousness toward the past, it can be easily said that the 3 mothers do not live with chronic sorrow.

Comparison with aspects of psychosocial adjustment of mothers of children with severe motor and intellectual disabilities revealed the characteristics of the psychosocial adjustments in the mothers of children with developmental, but no intellectual disabilities. Everyone can see severe motor and intellectual disabilities, and obvious functional improvement cannot be expected. On the other hand, it is not easy for people to see disabilities in children with developmental, but no intellectual disabilities, and if the children were allowed to interact with those having an understanding of their disability characteristics, their functioning will obviously improve.

From the above, the nature of developmental disabilities without intellectual disabilities that lower the self-esteem of the children themselves and make their mothers anxious seems to stem from the difficulty in easily recognizing the disabilities, which is a characteristic of such disability. However, people without developmental disabilities have difficulty in recognizing the disabilities, while people with developmental disabilities have difficulty in seeing the sense and cognitive characteristics of people without developmental disabilities. Kikuchi¹⁶⁾, who has developmental, but no intellectual disabilities, stated that throughout her life, even long before the diagnosis, she repeatedly accepted disability, i.e., adjustment to a world that is not designed to allow her to live easily. She talked about the reality as follows: I have lived in the world of my own sense and cognition since I was born; for a person with developmental disabilities, my physical sensations and cognitive patterns are normal, and they have developed in such a manner as to conform to my society; and even if my efforts at conforming reach their limit, no one tries to redesign the world for me. Kataoka¹⁶⁾, who, likewise, has developmental disabilities, described that having a large deviation from the mean can be an obstacle in a society designed to be convenient only for average people, and not in one based on different concepts. Namely, developmental disabilities without intellectual disabilities are disabilities caused by the majority forcing minorities to conform. Nonaka¹⁷⁾, who is a psychiatrist, cited Procrustes, a monster in Greek mythology who cut off the legs of his guests or stretched them so that they would fit the golden bed, as an example, and pointed out that there is still a monster called standards for non-handicapped people in this world. Difficulty in seeing the disabilities is not the true nature of the problem. Our consciousness that does not accept diversity and allows the majority to force minorities to conform is the true nature of the problem. So far, the words "psychosocial adjustment to disability" and "acceptance of disability" have been used, and as long as we continue to use the words "adjustment" and "acceptance", we cannot see the monster called standards for non-handicapped people lurking behind our consciousness.

The truth about the nature of developmental disabilities in the absence of intellectual disabilities, in which the self-esteem of the children is lower and their mothers become anxious, is that our consciousness does not accept diversity and allows the majority to force minorities to conform.

Conflicts of interest

None.

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