

Mothers' parenting process for children with autism spectrum disorder: the modified grounded theory approach

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Objective: This study aimed to elucidate the process of mothers' experiences parenting children with autism spectrum disorder (ASD), especially from the viewpoint of their interactions with others who help provide them with support.

Methods: Sixteen Japanese mothers of children diagnosed with ASD were interviewed regarding their parenting experiences focusing on the support received from others. Transcripts of the interviews were processed using the modified grounded theory approach (M-GTA).

Results: The results of the M-GTA suggested that the process of the experiences of mothers raising children with ASD were comprised of "sharing" and "mental stabilization." "Sharing" occurs when mothers discuss their experiences with others, e.g., discussing the challenges they face and their personal feelings. "Mental stabilization" helps mothers when facing a heavy burden and potential mental health crisis. "Mental stabilization" supports mothers in the early stages of "sharing," when they cannot be understood well, and the process of "sharing" positively affects "mental stabilization."

Conclusion: Professionals should attempt to understand, through the processes of "sharing" and "mental stabilization," the exhausting experiences of mothers raising their children with ASD.

Key words: autism spectrum disorder, mothers, parenting, qualitative study, modified grounded theory approach

Introduction

Autism spectrum disorder (ASD) is characterized by persistent deficits in social communication and interactions, as well as restricted or repetitive behaviors, interests, and/or activities.¹ Parents of children with ASD often experience more stress than parents of children with typical development or with other disabilities² and are at an increased risk for mental health problems, such as depressive symptoms and general psychological distress.³ The parenting challenges they face are mainly attributable to their children's problematic behaviors such as tantrums.⁴ Owing to the physical invisibility of ASD,⁵ they may be misunderstood by others or judged as inadequate parents who are unable to control their children's behavior.⁶

It has been reported that mothers of children with ASD often experience isolation,^{5,7,8} and the powerful predictors of depression and anxiety in those mothers are low levels of social support.⁹ Given that ASD can impact

many aspects of mothers' family lives, such as marital quality,^{7,10} these mothers are also less likely to receive adequate informal support, which is generally considered an effective buffer against stress.⁹ Thus, support from professionals who are familiar with the challenges of parenting children with ASD may be especially important for mothers.

However, as support needs can vary,¹¹ it is important to understand the personal experiences of mothers caring for children with ASD, particularly regarding their relationships with others who could provide appropriate support. Previous studies have focused on parents' experiences of the ASD diagnosis,¹²⁻¹⁴ the services they received,^{15,16} and the support they would like to receive.^{17,18} However, these studies did not primarily focus on parents' interaction with others.

The purpose of this study, therefore, was to reveal the experiences of mothers of children with ASD, while mainly focusing on the processes of their relationships with others.

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Methods

Procedures

The participants of this study included mothers of children with ASD who visited a child psychiatry clinic in Tokyo. The inclusion criteria were that the participants were mothers of children in elementary or junior high school with a confirmed ASD diagnosis. These criteria were used to increase homogeneity and also because mothers are usually their children's primary caregivers; they also experience more stress and employ different coping strategies compared with fathers,¹⁹ and their emotions and coping strategies may change over time.²⁰

A total of 37 mothers were approached face-to-face by the first author between November 2019 and November 2020, who showed them a poster, designed to help recruit participants, and verbally explained the study to them. Subsequently, 16 mothers showed an interest in participating and gave written informed consent to participate in the study.

Ethical approval for this study was obtained from the Research Ethics Committee of Kitasato University School of Health Science.

Participants

Semi-structured interviews were conducted with 16 Japanese mothers in a consultation room at the psychiatry clinic. Prior to the interviews, each participant completed an information sheet that collected data on the child's gender, the mother's and child's ages, and the child's classes in school. Participants also completed a questionnaire asking their child's ages when they first had concerns regarding their child's behaviors, as well as any other places they consulted, including health care centers, educational counseling centers, clinics, and/or hospitals.

The participants were between 36 and 50 years of age. All the mothers were biological parents of the children who were formally diagnosed with ASD and communicate in Japanese. The children included 14 boys and 2 girls, 8–15 years old. Thirteen children attended regular classes and 2 attended special support classes at mainstream schools, while 1 child attended a special support school. The mothers regularly consulted the child psychiatrists at the clinic.

Interviews were conducted by the first author based on the information sheet, and using a prepared interview guide, to ask mothers about their initial concerns for their children, their initial response, their emotions at that time, the time they faced the most challenges, their way of coping with those challenges, sources of helpful and unhelpful support, and their current needs and those

at the times they had found the most challenging. The interviews took 31–78 minutes. Each interview except one was conducted only once. However, that one interview was conducted twice because the participant had remembered some additional information. The interviews were recorded with the participants' consent, using an audio IC (integrated circuit) recorder and transcribed verbatim.

Data analysis

Qualitative data analysis was conducted using the modified grounded theory approach (M-GTA) proposed by Kinoshita.²¹ The M-GTA was developed by adapting the theoretical and content properties of the grounded theory approach.²² The M-GTA is an analytical method for generating substantive grounded theories and identifying and predicting social interactions, especially in the context of various human services such as health care in Japan. In the M-GTA, prior to analysis, the analytical theme and focus person are decided based on the research question. In this study, we determined the analytical focus person to be "mothers raising children with ASD in elementary or junior high school" and the analytical theme as "the process of parenting their child."

In the M-GTA, raw data are interpreted along with the context from the viewpoints of the analytical focus person and the theme. All concepts and their definitions were first generated based on data from one interview and recorded on an analysis worksheet. Each generated concept was examined using comparative analysis, in which similar or converse examples were searched for in other interviews. Consequently, the names and descriptive definitions were determined for each concept. Categories were created based on the relationships among multiple concepts. We received advice from experts in the M-GTA regarding generation of the analytical focus person, analytical themes, interview guide, and concepts and categories for analysis.

Results

To describe the experiences of the mothers of children with ASD, 2 categories, 3 subcategories, and 26 concepts were generated. One category was [Sharing], which included 3 subcategories: <cannot share>, <verbalizing>, and <shared>, and the other is [Mental stabilization]. The overall relationships among these categories, subcategories, concepts are summarized in Figure 1 and explained in the Storyline section below.

The following symbols were used to identify the content: brackets [] indicate a category, pointed brackets

< > indicate a subcategory, and quotation marks " " enclose the concept. *Italicized* sentences are participants' quotes. The results are described in the present tense, following the concepts in the *Teihon M-GTA* by Kinoshita,²³ because the purpose of the M-GTA is the generation of grounded theories to predict social interactions.

Moreover, in the M-GTA, researchers judge theoretical saturation on the basis of the completeness of the concepts and the integration of the results in a Storyline through supervision.²³ We confirmed

theoretical saturation through internal consultations based on the M-GTA.

Storyline

The process of mothers parenting a child with ASD consists of [sharing] their maternal experiences with others and their [mental stabilization]. [Sharing] is comprised of three sub-categories: <cannot share>, <verbalizing>, and <shared> (Figure 1).

Although mothers have concerns regarding their children's development, they <cannot share> feelings such

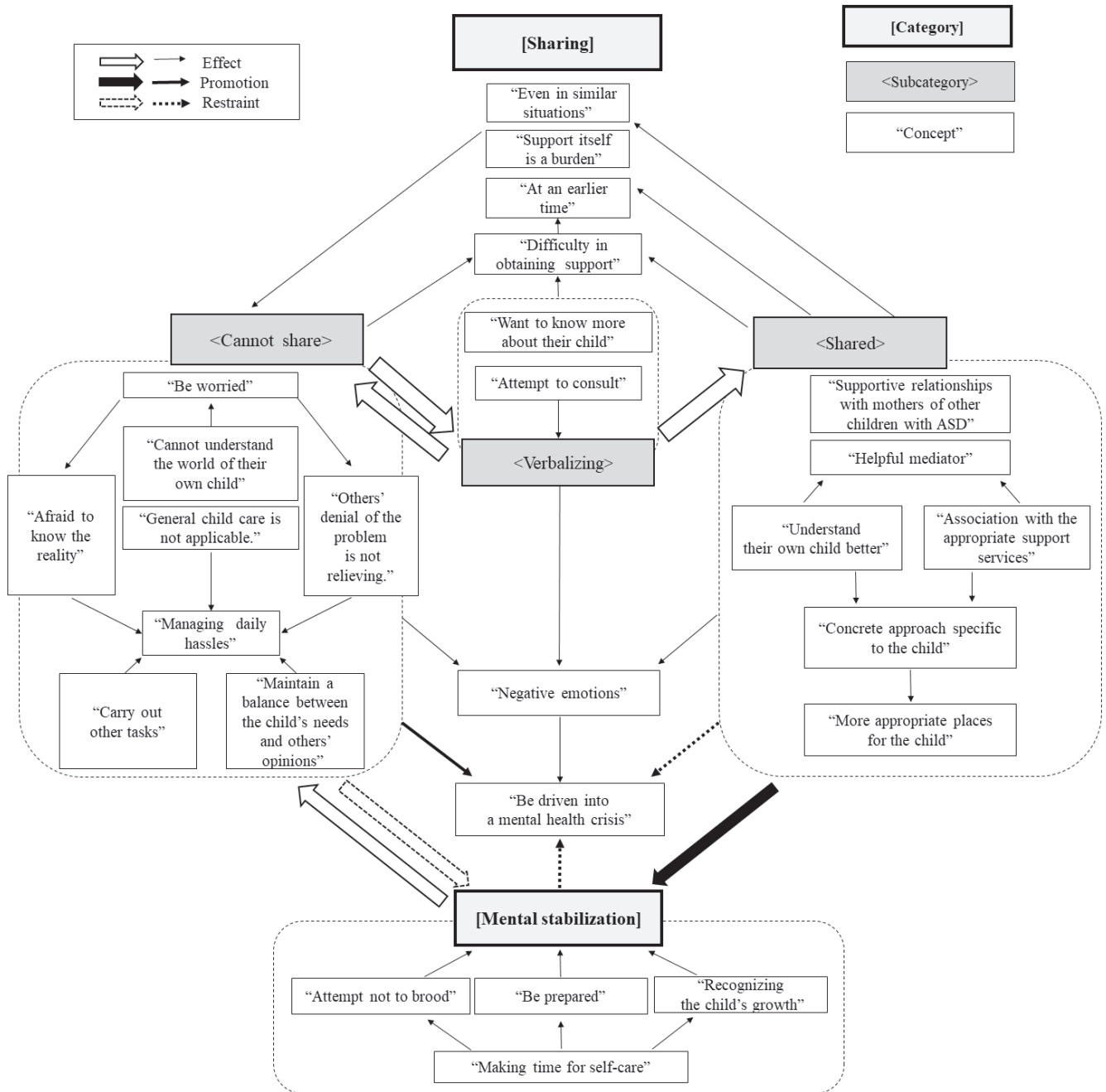


Figure 1. Mothers' parenting process for children with ASD
[Sharing] and [Mental stabilization] have a complementary relationship.

as anxiety or their daily struggles with others, not even family members, because ASD is an invisible disorder. Mothers often experience that their concerns are not understood. When parenting stress or worries regarding their children increase, some mothers will decide to consult professionals, which means that they must attempt <verbalizing>. And, by successfully <verbalizing>, the mothers' feelings and experiences are likely to be <shared> with others.

[Sharing] and [mental stabilization] have complementary effects on each other. [Mental stabilization] supports parenting in the early processes of [sharing], and the process of [sharing] positively affects [mental stabilization].

[Sharing]

<Cannot share>

"Be worried"

Mothers can "be worried" regarding the development of their children who do not talk smoothly, do not pay attention to them, or have restricted interests.

I began to feel the gap between my son and other children of the same age as my son grew up.

"Cannot understand the world of their own child"

Mothers "cannot understand the world of their own child" because they are unable to understand the reasons behind their children's way of talking or their behavior.

When my child used to eat only selected foods, I always wondered why. Why can't he eat most kinds of food?

"General child care is not applicable"

Although mothers of children with ASD attempt to refer to the behavior of other mothers with children of the same ages as theirs or receive advice from general parenting consultation facilities in the region, the challenges they face remain unresolved. This situation in which "general child care is not applicable" impacts how mothers feel, increasing their distress and feelings of isolation because nobody understands their challenges.

The other mothers (with children with typical development) often said that a certain method was useful for their child. ... However, those ways were not useful for my son at all.

"Managing daily hassles"

While feeling anxious and worried, mothers "manage daily hassles" such as their child's challenging behaviors.

(When my child was highly excited), I had to calm her down anyway I could, and take her home without knowing what happened.

"Others' denial of the problem is not relieving"

Mothers are also often told that their child is normal when they try to explain their concerns to health care or education providers. However, "others' denial of the problem does not relieve" mothers.

The health care providers always said that my son was all right, with normal development, but something felt strange to me.

"Afraid to know the reality"

Sometimes mothers have hesitations regarding consultations, because they are "afraid to know the reality" of their child's condition.

For me, consulting someone about my child involved the fear that I would know the reality of their condition.

"Carry out other tasks"

Mothers also need to "carry out other tasks" than those related to ASD, such as managing their child's food allergies or relocation to a new city.

He had a food allergy then, so I had much more difficulty dealing with that than his development.

"Maintain a balance between the child's needs and others' opinions"

Mothers have to "maintain a balance between the child's needs and others' opinions" including those of their husband, relatives, neighbors, and school officials.

My husband cannot understand the developmental disorder well. He thinks (that our son's behavior is the) result of bad discipline.

"Difficulty in obtaining support"

Mothers often need help and may want to consult others regarding their concerns. However, they also often experience "difficulty in obtaining support."

If it was easier to find out where to go for consultations, I would be thankful for it.

"Negative emotions"

These daily struggles evoke mothers' "negative emotions," such as anxiety, sadness, heartache, self-blame, irritability, anger, and isolation.

I used to get very angry at my son then, because I was frustrated due to not knowing why he didn't do his homework.

"Be driven into a mental health crisis"

For these various reasons, mothers <cannot share> their struggles and negative feelings with others. While continuing to face challenges without being understood,

mothers may "be driven into a mental health crisis."

Other children do not act that way, but my child does. I thought it was because the way I got angry at my son was bad. ... I was driven more and more [into a mental health crisis].

<Verbalizing>

"Want to know more about their child"

They gradually want to consult professionals because mothers "want to know more about their child." In cases where mothers are initially not worried about their children, they visit professionals to know more about them when others, such as teachers, mention their concerns about the child.

I was anxious that we had not received a diagnosis [about his development] until I went to the hospital.

"Attempt to consult"

Mothers "attempt to consult" about their child's development, although some may wonder whether they should consult professionals or do not know whom to consult first. Mothers find a place, where they can discuss their concerns, through trial and error. After these steps, they often consult professionals at a hospital either to receive a confirmed diagnosis and treatment or because others recommend that they visit a hospital.

I honestly did not know whom to talk to and how to talk [about my worries].

<Verbalizing>

These consultation processes are managed through the interactions between mothers and professionals, which encourages <verbalizing>. Thus, mothers are able to use language to express their experiences appropriately and listen to new viewpoints about their child from professionals. <Verbalizing> convinces mothers of the reasons behind the child's behavior, which correspond to what they were worried about; although, this may temporarily generate "negative emotions" such as shock.

Of course, I was shocked [when I received the diagnosis] but there was a part [of it] that convinced me.

"Difficulty in obtaining support"

Mothers may experience "difficulty in obtaining support" while <verbalizing>.

I was very lonely and did not know which place I can rely on, in spite of hoping to find somewhere reliable.

<Shared>

For mothers, <verbalizing> means that their experiences and feelings are <shared> with others, which gradually

alleviates "negative emotions" regarding their child's diagnosis.

"Understand their own child better"

When their experiences and feelings are <shared> with others, it allows mothers to "understand their own child better" because they can understand the reason behind their child's behavior.

I feel that my child would go to school with great hardships, even though I did not find out about it at that time.

"Association with the appropriate support services"

Mothers obtain specialized information regarding ASD and "associate with the appropriate support services." This association promotes the mothers' actions, since they would not know what to do based only on the diagnosis.

I asked what I should do from now on, because I did not know what to do when told that my child had the disorder, and I was referred to a child rehabilitation facility.

"Concrete approach specific to the child"

Through the appropriate support services for their child, mothers come to learn a "concrete approach specific to the child," although they always do so through trial and error. General knowledge about ASD may not always be useful, because ASD symptoms and personal situations vary. Thus, mothers tend to view concrete advice regarding their children as useful.

Even if I had studied a lot [about ASD] by myself, I would not know what to do or how to approach my child after all. I resorted to trial and error.

"Supportive relationships with mothers of other children with ASD"

Through these processes, mothers are likely to meet other mothers and establish "supportive relationships with mothers of other children with ASD." When one's own feelings and experiences are <shared> with other mothers, it decreases their negative emotions such as isolation. Even if mothers do not have the opportunity to meet with other mothers, it generates the same effect for mothers when their feelings and experiences are <shared> with their families, friends, and professionals.

[Being able to feel at ease] may be the reason why I go to a place, where I felt most comfortable to meet with other mothers with the same circumstances and talk with them.

"Helpful mediator"

If mothers <cannot share> their thoughts and experiences with a specific person, a "helpful mediator" can promote sharing. In Japan, public service systems are available that can provide mediators, such as psychologists who visit nursery or elementary schools, although the services provided differ among districts.

I think a mediator is necessary. That kind of support is necessary. ... Mediators are not connected directly with the support of the child, so they are relatively calm when talking with the parent.

"More appropriate places for the child"

Through these processes, mothers learn what kind of environments are best for their child, and they try to find "more appropriate places for the child." Finding "more appropriate places for the child" greatly impacts mothers' mental health; even if they <cannot share> their experiences regarding their child with others, these places tend to play a protective role for mothers who are "driven into a mental health crisis." However, as their children grow older, they may have more interpersonal problems arising from increased interactions with classmates who cannot understand the child's difficulties. In these situations, mothers tend to "be driven into a mental health crisis."

(In the regular class, the teacher and I) discussed how the learning environment was not suitable for my son's situation. ... I moved him to a special support class. ... Now, he does not seem to be as stressful.

The relationships among <cannot share>, <verbalizing>, and <shared>

These processes of [sharing] do not move in linearly from <cannot share> to <shared>. Some mothers <cannot share> their feelings and experiences well enough even after <verbalizing> them with professionals, which leads them to experience "negative emotions," and they tend to be "driven into a mental health crisis." This situation then encourages mothers to make another attempt at <verbalizing>.

"Difficulty in obtaining support"

Some mothers also experience "difficulty in obtaining support," even after having <shared> their experiences.

Even if I know of one [means of] support, it takes too much time until we actually receive it, for example, half a year.

"Support itself is a burden"

Even after finally receiving support, some mothers may

feel that the "support itself is a burden." For instance, if their child has a tantrum that makes it difficult to take them to the support center, the mothers feel that they <cannot share> their challenges with the professionals. In other cases, mothers may be shocked by what the professionals say.

I was told that my child was restless, because I was restless once [with them], and I wondered if it was my fault.

"At an earlier time"

Moreover, after experiencing useful support, some mothers feel that they would have wanted to receive support "at an earlier time," which may mean that they regret not having shared their concerns with others in the past.

As I was involved in therapy for the first time, I felt that the professional did such a [good] thing, and I thought that they made my child grow in this way without me telling them to do it. So I wish I had visited them earlier.

"Even in similar situations"

Mothers occasionally <cannot share> their experiences with other mothers of children with ASD "even in similar situations," because difficulties vary among mothers.

The relationships between mothers are sometimes difficult, because each tends to say that their own child is severe or mild [in relation to other children].

This process of [sharing] is repeated with changes in content over time, as mothers' worries and needs vary as their children grow.

[Mental stabilization]

"Attempt not to brood"

Mothers may "attempt not to brood"; instead of facing up to and change a challenging situation, when they are not easily rectified.

I thought it would be better if I avoided [worrying]. So [I thought] I should not brood very much.

"Be prepared"

Mothers tend to "be prepared" by: 1. understanding more about their child and ASD, 2. the positive words and attitudes of others, and 3. recognizing the hereditary influence by noticing their own symptoms of ASD or those of their family members. This encouraged mothers to take actions or to outright accept their child with ASD.

The clinical psychologist said that she thought that raising children with ASD required careful child care

... So I felt that I did not need to be overly concerned (for parenting a child with ASD).

"Recognizing the child's growth"

Mothers often "recognize the child's growth" by paying attention to the changes in their child and the improvements their child makes, which enhances positive parenting. However, some mothers might sometimes expect too much of their children, even though they understand the burden this places on them.

I thought that I could recognize my child's growth and that he started being able to control himself.

"Making time for self-care"

[Mental stabilization] may be derived from positive feelings regarding parenting based on mothers' mental capacity, which requires "making time for self-care." This includes finding some respite, talking with others, engaging in hobbies or work, and taking good care of themselves. When some mothers are "driven into a mental health crisis," they may receive counseling for their own mental health, which then results in [mental stabilization].

I went to the shopping center alone, without my child, anyway. ... I wanted to be alone most of all.

The relationship between [sharing] and [mental stabilization]

[Sharing] feelings and experiences with others helps mothers feel supported, which may strengthen their [mental stabilization]. However, during the <cannot share> and <verbalizing> stages, [mental stabilization] supports mothers and protects mothers from being "driven into a mental health crisis." This suggests that [sharing] and [mental stabilization] have a complementary relationship. [Mental stabilization] supports mothers in the early stages of [sharing], and the progress of [sharing] enhances [mental stabilization].

Discussion

Our study suggests that the experiences of mothers parenting a child with ASD involves the process of sharing, wherein mothers try to share what is difficult to share with others because ASD symptoms are diverse and often invisible. Furthermore, the mothers' mental health conditions seem to influence this process of sharing.

Most mothers feel that they cannot share with others when they first start caring for their child with ASD. First, they are often aware of their child's unique development by comparing it with that of other

children.^{13,16,18} Additionally, some mothers attribute their child's condition to bad parenting or are in denial of the need for medical or psychological attention.¹³ In this study, the mothers hoped for an opportunity to gain knowledge about ASD, through general situations, such as their children's medical examinations, because they were unsure about consulting a professional or found it difficult to do so.

However, when discussing their concerns with others, mothers often think that others do not take them seriously,²⁴ or offer advice based on general child care that does not apply to their child. In worse-case scenarios, others may think that the child's problematic behavior is due to poor parenting.²⁰ Then the experiences that mothers cannot share tend to mount up and affect them negatively. When their concerns are frequently dismissed, mothers may not want to consult with professionals. For instance, a participant stated that she did not want to go to the hospital, even though it was recommended that she did, because her concerns had been repeatedly ignored.

This suggests that mothers may have already experienced negative emotions such as grief, fatigue, anxiety, self-blame, anger, and isolation when they met professionals for consultations. Moreover, the responsibility of parenting is still a burden for mothers⁶; mothers sometimes feel pressured due to the great expectations placed on them by society,²⁵ especially with respect to managing their child's disorder.⁶ If mothers do not share their experiences with professionals, they may have negative feelings toward hearing, what to them are, inadequate responses, such as "no problem," or "all right," or receiving one-way, all-cures-all advice from professionals.

When a diagnosis is given, mothers experience various emotions, such as shock, grief, and relief.^{14,15,26} Professionals should be careful not to demand too much from mothers, because this may drive them into a mental health crisis. Joosten and Safe⁶ reported that, when mothers were the most stressed, they felt the need to be understood by someone rather than be offered practical advice. Parents of children with ASD often wish that professionals would listen to them properly and share their decisions.¹⁸ Mackie et al.²⁷ reported that bi-directional processes through clinical interactions promote parents' understanding of their child's behavior within the ASD interpretive frame.

Even if negative feelings are initially strong, positive feelings, such as acceptance, tend to increase gradually. Receiving a diagnosis allows mothers to acquire more accurate information, stop blaming themselves, and develop new strengths and visions for the future.^{13,24,28} Moreover, mothers are able to use the ASD diagnosis to

explain the etiology of their children's concerning behaviors.²⁷ Understanding their child's diagnosis and receiving appropriate support may result in mothers sharing their experiences with others, which may serve to further empower them.

Promotion of [mental stabilization] is also important when supporting mothers of children with ASD. Mothers may need respite care^{11,29} and making time for self-care is important, as was shown in our study. Unlike in previous research,³⁰ some participants in this study mentioned their work as being a source of encouragement for them. This was possibly because the participants in our study had children who were in elementary school or junior high school, which left them with more free time than mothers with younger children.²⁵

In a systematic review, Legg and Tickle¹⁴ reported that parents raising children with ASD have three types of needs: emotional, informational, and relational. The process of [sharing] and [mental stabilization] may be a means to cope with these three needs among mothers. Health care providers are expected to have a good understanding of mothers' needs; however, this is exceedingly difficult because mothers have different needs. This task of understanding their needs is managed by knowing the experiences and feelings of mothers, which necessitates [sharing]. It is important that professionals recognize that [sharing] is actually a difficult task, because parents, as well as health care and education providers, have different feelings and experiences.

Limitations

Mothers' perspectives are influenced by various factors, such as social stigma, economic status, and the added conditions of concurrently raising children who are siblings of children with ASD^{6,25}; however, this study did not purposefully address these background factors. All participants in this study accepted medical and psychological support; thus, mothers of children with ASD who do not have opportunities to consult with professionals at a hospital, or some other facility, may have different experiences. Moreover, the influence of different kinds of support that mothers received was not considered.

Conclusions

The findings of this study revealed that the processes by which mothers raising children with ASD may help to engage them in "sharing" and "mental stabilization." "Sharing," in this concept, is the process in which the experiences that mothers cannot easily talk about with

others, eventually come to be "shared" through verbalizing. We proffer here that service providers assess how mothers have shared their experiences in the past, how they currently share their experiences, and help continue supporting and encouraging these mothers to share their emotions and needs. This will likely help improve the mental health of mothers of children with ASD.

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Conflicts of Interest: None

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