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ORIGINAL ARTICLE

Explaining Peers with Autism Spectrum Disorder to Others and Coping with Others' and Siblings' Negative Attitudes

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ABSTRACT

This study investigated support required by siblings of children with Autism Spectrum Disorder (ASD) after this referred to as "peers." We investigated words used by siblings for explaining school-aged peers and explored the siblings' attitudes, which were different from the negative attitudes of people around their peers. We conducted an interview survey with adult siblings of ASD children and inquired about siblings' perceptions about their peers, coping with questions about their peers, unpleasant experiences related to peers, and personal and environmental factors. The results indicated that supportive relationships between siblings and parents promoted siblings' knowledge and understanding of ASD and helped them develop the language for explaining their peer's condition to others. Moreover, positive experiences in environments that accepted their peers resulted in different attitudes to negative attitudes of others, regardless of support for siblings to manage negative experiences.

Key-words: Autism Spectrum Disorders, siblings of children with ASD, school age, perceptions of siblings towards children with ASD, siblings' environments and experiences

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I. Introduction

The situation of brothers and sisters (after this referred to as "siblings") of people with disabilities (after this referred to as "peers") affects various aspects of their lives^{13).} In particular, siblings in elementary and junior high schools have no choice but to identify with society's negative attitudes toward their peers¹¹⁾. It is questioned about their peers by other people¹⁾. On the other hand, siblings grow up without any problems if they do not share society's negative attitudes about their peers¹¹⁾.

Several Japanese and international studies have investigated the effects of ASD peers on siblings and related factors. Parents' educational involvement, stressful life events and family climate²⁾, severe ASD symptomatology⁷⁾¹⁰⁾ and behavioral problems, siblings' coping skills, knowledge about ASD, and lack of support networks³⁾ negatively influence siblings' adjustment, behavioral problems, and prosocial behaviors. In contrast, Meyer et al. cited the "unusual opportunities" that siblings have in terms of the potential for personal growth by having a sibling with special needs⁶⁾, suggesting the need to also focus on the positive aspects when examining the impact of peers on siblings⁵⁾.

Fewer negative emotions have been reported when siblings have a supportive parentchild relationship compared to less supportive relationships¹). Sibling relationships tend to be more positive when siblings perceive their parents and friends as reacting positively to their peers⁴). Furthermore, McHale et al. suggest that siblings' feelings and the value of their peers might be negatively affected when siblings perceive that their parents are busy caring for their peers and when siblings' friends and classmates have negative attitudes about their peers and disabilities⁴).

The above discussion suggests that siblings have problems explaining and managing their peers. Factors such as their relationship with their parents, including expected and actual support from parents, satisfaction with parent's support, and siblings' perceptions of their parents and people around them might influence how siblings manage their peers, siblings' feelings about their peers, and siblings' perception of the value of their peers. This study focused on elementary and junior high school siblings.' We investigated "how siblings responded when they are asked about their peers by people around them, and when they experienced negative experiences, such as bullying and teasing by people that do not understand their peers," and factors related to the siblings' responses. We designed this study to identify the support required for instilling a resistant mindset in siblings against negative attitudes about their peers. This interview survey requested adult siblings to reflect on their past to avoid any psychological burden on young siblings.

II. Participant and Methods

1. Participants

The participants were six adults aged between 21 and 24 years that had a peer with ASD or ASD and intellectual disability. The profiles of the siblings are shown in Table 1.

	Age/Gender	Peer's age/gender (relationship)	Family structure	whether siblings have been to the same school as peers
А	24/Male	28/Male (Older brother)	Father、Mother、Older brother、Older brother (peer) 、Myself	No
В	23/Female	20/Male (Younger brother)	Father、Mother、 Myself、Younger brother (peer) 、Grandmother	No
С	21/Female	14/Male (Younger brother)	Father、Mother、 Myself、Younger brother (peer)	No
D	21/Female	19/Male (Younger brother)	Father、Mother、 Myself、Younger brother (peer)	Yes
Е	21/Female	25/Female (Older sister)	Father、Mother、Older brother、Older sister (peer) 、Myself	No
F	21/Female	19/Male (Younger brother)	Father、Mother、 Myself、Younger brother (peer)	Yes

<Table 1> The profiles of participants

2. Survey Method

We conducted online, one-on-one semi-structured interviews with the siblings from July to August 2020. Each interview lasted approximately one to one and a half hours. We first asked the siblings to respond to a face sheet and a questionnaire related to the interview questions. The interview questions were prepared in advance based on the siblings' responses, and the interviews were conducted using these questions. The interviews' narratives were recorded directly on a PC with the siblings' prior consent. The author developed the content of the questionnaire and interview questions with reference to previous studies¹⁾¹¹⁾⁸⁾⁴⁾.

3. Questionnaire items

1) Face sheet

This inquired the siblings' name, age, relationship to the peer, family structure, peer's age, and disability, and peer's schooling history and duration (if any).

2) Questionnaire

This consisted of the following seven Categories. (1) Responses of people around siblings regarding peers, (2) Contact between peers and siblings' friends, (3) Status of consultation with parents, (4) Image of parents and their relationship from the siblings' perspective, (5)

Attitude of others toward peers from the siblings' perspective, (6) Understanding of peers' disabilities, and (7) Influence of the peers on siblings. There were 23 items in the questionnaire.

The method of responding to the questionnaire varied depending on the item. Responses using the rating methods consisted of a four-point scale, (1 "applies well," 2 "applies about right," 3 "does not apply much," 4 "does not apply at all"), a two-point scale ("yes" or "no"), a one-point scale, and free-responses. The content of the question items is shown in Table $\mathbf{2}$.

Category Questionnaire items 1. Have you ever been asked about your peer or his disability by [Responses from people around you about your peer] people other than your family? 2. Have people other than your family ever said or done anything to you that made you feel uncomfortable about your peer? 3. Has anyone other than your family ever said anything to you that made you happy or made you feel good about your peer? 4. Have you ever had the experience of play or activities with your [Contact between your friends and peers] friends, including your peers? 5. Have you ever invited your friends to your home when your peers were present? 6. (If you attended the same school at one time or another), did you or your friends or classmates have opportunities to interact with your peers at school? 7. Did you consult with your parents when you had problems with [Support from parents, Relationship between sibling and parents] your peers outside home, for example, at school? 8. (Those who answered "Yes" to question 7) Did you consult your father or mother more often? 9. How satisfied were you with your parents'support? 10. Did your father or mother take care of your children more often than you did? 11. Were you satisfied with the way your father and mother treated and interacted with your siblings? [Attitudes of other people toward peers and siblings' attitudes 12. Do you think that there were people around you (other than your toward their peers] family) who had a negative view of your disability? 13. I think some people around me (other than my family) negatively view "having a family member with a disability 14. I think I had a negative view of "having a disability." 15. I think I had a negative view of having a sibling with a disability. [Understanding disabilities of my peers] 16.Do you think you understood your peers' disabilities? 17. Have you ever received some explanation about your peers disabilities from people around you? 18. (Those who answered "Yes" to 17) From whom did you receive the explanation 19. Did you ever feel that you wanted to know more about your sibling's disability? [Influence of the presence of a compatriot on your sibling] 20. Did you ever feel lucky to have your peer (or not)? 21. Have you ever felt that your peers are excellent? 22.Have you ever felt pessimistic about peers? 23.Have you ever had any problems with your peer?

<Table 2> List of Question Categories

3) Interview contents

The following questions inquired about "Experiences of being questioned about peers (referred to as "Experience A")" and "Experiences of being treated unpleasantly because of the peers (referred to as "Experience B"). The time of the experience, the specific situation, the sibling's feelings at the time of responding, the action taken, the reason for the action, and the impression of other people as a result of the experience. We also interviewed the siblings about their impressions of other people and their changes resulting from the experience. We asked the siblings about their relationship with their parents and how they consulted with their parents when they were in elementary and junior high school, how they perceived their parents and others around them, including friends, classmates, and relatives, among others, their level of knowledge and understanding about disabilities, how they obtained this knowledge, the advantages of having their peers in their opinion, and the impact of their peers' presence on them.

4. Ethical Considerations

We distributed a written request to the siblings before conducting the survey explaining the purpose of this study, its contents, methods, and research ethics. The siblings were also informed that their responses to the questionnaire and interview questions were voluntary. They could omit to respond to any questions they were unwilling or unable to answer. We also explained that they would face no disadvantages if they did not answer any questions. Moreover, we explained that the survey results would be used only for research purposes and that we would take care taken not to identify any individuals when the results of the study were published. We conducted this survey after obtaining the written informed consent of the siblings.

5. Method of Analysis

We analyzed the participant's responses using the procedure described by Tokuda⁹⁾.

Tokuda classified qualitative data according to narrative content and characteristics, and coded them with labels as appropriate. Then, he compared the labels among the data and generated categories by organizing and integrating the individual labels based on the similarities and differences among the narratives.

Experiences such as those focused on in this study (Experience A and B) have only been reported in previous studies in Japan as mere narratives that emerged during interviews with siblings.

However, no attempt has been made to typify the siblings' feelings or the actions they take when they have such experiences.

Therefore, by referring to Tokuda's method of analysis, the author attempted to create a typology of the feelings and behaviors that siblings have when they have Experience A or Experience B.

1) "Making sense of experiences" and experience generating process

First, we extracted "what I felt during the experience" and "the impact of the experience on siblings" from siblings' narratives about Experiences A and B, which we designated as "meaning-making about the experience. Next, we categorized and coded these narratives as (1) the meaningfulness of the other person's response and (2) the meaningfulness of the experiences' impact. As a result of (1), we extracted one subcategory, "making sense of the other person's feelings" as "positive," "not positive or negative," or "negative. Moreover, as a result of (2), we extracted three categories: "Opportunity to understand," which referred to the experience as an opportunity to understand the disability and siblings' characteristics better; "difference in consciousness," which referred to the experience of feeling a difference in values and attitudes toward peers and their disability; "negative influence," which referred to the experience of siblings having a negative influence on their values and subsequent behavior toward their peers and their disability. Following this, the obtained categories were combined, and the sibling's coping behavior type during the experience was considered for categorizing the "meaning-making of the experience

2) Perspectives on the analysis capturing characteristics of other narratives and the process of their construction

The narratives other than those used to generate analytical categories, including "meaning-making of experience," were designated as other narratives and were analyzed to examine their relationship with the siblings "meaning-making of experience." First, the participant's narratives were classified and organized according to the time series from the past to the present and the content. As a result, we generated 11 categories summarizing each narrative. The names of these categories included "the specific situation and reasons for coping," "peers' condition at that time," "awareness/knowledge of the disability," "relationship with parents," "relationship with people other than the peers' family members," "relationship with children with disabilities other than the peers," "perception of peers and disability," "narrative of peers' advantages," "impact of peers' on siblings," "concerns about peers," and "disclosure of peers' existence." The characteristics of the categories are discussed below. Then, we compared and examined the categories.

3) Typology of "meaning-making of experiences" and characterization of other narratives

We developed the "meaning-making of experience" typology based on the analytical categories described above. Then, we developed the typology of "meaning-making of experiences" by analyzing the siblings' narratives using these categories. The characteristics of the siblings' other narratives were identified based on the categories and analytical perspectives obtained from the above procedure and compared between individuals having each pattern based on similarities and differences from other patterns.

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III. Results and Discussion

We obtained five patterns with connotations from the typology of "meaning-making of experiences" and the corresponding characteristics of other narratives; three patterns from narratives of Experience A and two patterns from narratives of experience B. The summary of each pattern and characteristics of other narratives are shown in Tables 3 and 4. The following is a brief description of patterns for "meaning-making of the experience" and other narratives and specific characteristics of siblings' coping strategies. The siblings' coping strategies are classified into "active" and "passive," based on the author's criteria based on whether or not the siblings acted to resolve the situation or problem about which they were responding.

Human

[The condition of peers at the time]			Waves of condition
		In elementary school, with explanation	
[Awareness and knowledge of disability]	from parents		from people other than family
	There is a difference in the evaluation of each parent. The parent with the lower rating ~ "inappropriate" about peers	Low evaluatio	Low evaluation of both parents, dissatisfied with their relationship to their peers and themselves
[Relationship with parents]	(1 person) Relationship with parents' support \bigcirc	(1 person in pattern 4 and 5) Unable to talk to parents about peers.	
To Jational in with some actual la the	None of my friends around me had a negative view of peer		Many people around me had a negative view of my peers, including classmates, teachers, and classmates.
[netationships with peers outside the family] [Feelings toward peers]	(One Prese peers	(One person in Patterns 4 and 5) Presence of people who mention the merits and growth of their peers (friends, teachers in special classes, among others.)	vth of their hers.)
[How do you perceive your personality and your peers?]	I rarely felt negative about my disability or my peers with disabilities	peers with disabilities.	I did feel negative about them.
[Relationship with children with disabilities other than my own]		(At the time of el them at school ar (From high schoo	(At the time of elementary and junior high school) I had opportunities to get involved with them at school and in parent groups. (From high school onward) I was involved in volunteer activities.
[Strengths of your peers (past/present)]	Past/present narratives		Present only
		Impact on the current career path	
[Influence of the presence of peers on siblings]	Worries about the future (past/present)		(Past) I am harassed, and it is all my peer's fault (Present) Worries about the sibling's mother's physical and mental condition and the lives of peers
[Influence of the presence of peers on siblings] [Worries related to peers (past/present)]		(Before the exper	(Before the experience) I avoided disclosing the existence of my peers.

Human

1. Pattern 1: Meaningfulness others' responses: "Positive/Meaningfulness of experiences" impact: "Opportunity to be understood/Coping style; "Active"

1) Characteristics of "Making sense of an experience

The siblings classified into this pattern did not have any negative feelings about the other person's questions and made sense of it positively by responding, "I was happy." They also made sense of this experience as an opportunity to understand their peers' disabilities and characteristics from other people. One sibling expressed satisfaction that her explanation deepened her friend's understanding of her sibling and led to a good relationship between her peer and friend.

2) Characteristics of siblings' coping

The siblings were asked questions about their peers by their friends who visited them at home, including questions on their siblings' peculiar behaviors, reasons for their inability to speak, or specific details of their siblings' disabilities. During this experience, Pattern 1 siblings stated that they explained the situation to their friends using words and expressions that were easiest to understand. In addition, one sibling asked her parents in advance about what her friends might ask about her peer and her peer's disabilities, which the parents explained.

Pattern 2: Meaningfulness of others' responses: "Neither negative nor positive" / Meaningfulness of the experiences' impact: "Difference in consciousness" / Coping style: "Active"

The siblings classified into this pattern did not have a high awareness of their peers' disabilities. Their sense of the value of their peers and their disabilities were not negatively affected. However, they were exposed to values about their peers' disabilities that differed from their own. They made sense of this experience as "differences in consciousness" between themselves and their friends.

The questions that two siblings were asked included those about the nature of the disability of their peers and the reason for their peers being enrolled in special needs classes rather than regular classes. Both siblings gave specific explanations in response to these questions similar to those in Pattern 1. One of the siblings gave the explanation made by his parents and his experiences with his peer his friends.

3. Pattern 3: Meaning-making from others' responses "Negative" / Meaning-making from the experiences' impact: "Negative" / Coping style: "Passive"

1) The siblings classified into this pattern told us they were aware of negative impressions about their peer's disability. In addition, they made sense of this experience as harming their perception of their peers' disability and their subsequent behavior.

2)

The sibling classified into this pattern said that a friend asked her whether her peer had a disability. Still, she gave a vague explanation because she did not know that her peer had a disability, although she was aware that her peer was different from other children of the same age.

The siblings also said they did not discuss this experience with their parents because they were uncomfortable discussing it.

- 4. Pattern 4: Meaning-making of others' responses "Negative" / Meaning-making of the experiences' impact: "Difference in consciousness" / Coping style: "Active or passive"
- 1) The narratives of both siblings were pessimistic about the experiences' content. One of them was shocked, and the other felt that others had biased views about her peer and low regard for her peer's abilities. The siblings complained about the negative experience.
- 2) The siblings classified into this pattern told us of being teased about their peers at school and relatives' unkind words about their peers. In contrast to other patterns, these siblings took both active and passive measures. One of the siblings talked to their parents about the experience, but as mentioned earlier, they did not get the support they expected from their parents. On the other hand, the other sibling said that she did not discuss the experience with her parents because the parents were nearby when she had the experience. She did not want to remind them of her negative feelings by discussing them.

Pattern 5: Meaning attached to the others' responses: "Negative/Meaning attac hed to the experiences' impact: "Negative" / Coping: "Active → passive"

- 1) As seen in Patterns 3 and 4, meaning-making is based on negative feelings toward people that responded unpleasantly. They clearly expressed these negative feelings by saying, "My friends and classmates became my enemies." In addition, statements such as, "I disliked my peer (because of the experience)" and "I thought that my peer was the cause of all the things I cannot do" indicated that the siblings gave meaning to negative values about their peers and their disabilities.
- 2) One sibling talked about her experience of being bad-mouthed and harassed by her classmates because of her peer. The siblings with this pattern once spoke to their grandmother, who was living with them at the time. However, the siblings' expectations of their grandmother decreased, and they did not talk to her again even when they had other similar experiences because they did not get enough support from their grandmother. They also found it difficult to talk to their parents.

6. Results and discussion

1) Factors in siblings' language acquisition to explain their peers

The results showed that siblings with Patterns 1 and 2 had prior knowledge of ASD or good relationships with their parents, which facilitated them obtaining adequate support when they had questions and concerns. We suggest that these factors resulted in acquiring the language for explaining their peers.

In addition, the results indicated that siblings refer to three primary sources for explaining their peers and their peers' disabilities: (1) Prior explanations from parents, (2) personal experiences, and (3) parents' interactions with peers. The content of (1) was often based on the siblings' everyday life. Explanations from parents might have the advantage of being readily adopted by siblings as skills for interacting with their peers and facilitating young siblings' understanding of required behaviors for specific situations with others. This finding suggests that siblings must first have explanations from their parents or other adults for developing words to describe their peers to others. In addition, the content of explanations should be specific to the sibling's daily life to facilitate the sibling's understanding and verbalizations to others. Furthermore, parents must support siblings' verbalization in formal situations and encourage them to make appropriate and satisfactory meanings from daily interactions with their peers. Therefore, parental support is required to develop sibling's verbalization.

2) Factors necessary for siblings' preparation for negative attitudes about their peers

This study suggested that siblings' knowledge and understanding of ASD and the relationship with their parents for obtaining these are helpful for siblings' explanations. They also contribute to the sibling's resistance to others' negative attitudes. Consistent with the findings of this study, Jones et al. also reported that more positive perceptions of the sibling relationship were associated with more knowledge about ASD⁹⁾.

The two experiences (Experience A: experiences of being questioned about peers and Experience B: experiences of being treated unpleasantly because of the peers) that were the focus of this study differed significantly in their content. However, most siblings felt negative rather than positive reactions to their peers from people they encountered in their daily lives, regardless of specific negative experiences. When they felt negative attitudes about their peers from people in their daily lives, siblings that responded actively felt no adverse consequences, whereas those that responded passively experienced negative consequences. On the other hand, specific siblings taking passive action did not experience any adverse effects on their values toward their peers and their disability. Some of them had experienced a negative impact in the past but maintained positive feelings toward their peers at the time of the study.

Why were siblings able to grow up without being affected by the negative attitudes about their peers? We might find the answerer to this question in the siblings' environment their own experiences. There might be negative factors in the environment,

including people with negative views of their peers and their peers' disabilities, The time of associating with others with negative opinions, and positive factors, including people focusing on the merits and growth potential of their siblings. It might be challenging to mitigate these negative factors through intentional interventions. Therefore, it is critical to provide positive and accepting places for peers and children with disabilities, such as opportunities to participate in events in which children with disabilities gather and promote sibling awareness of peers' strengths and growth. These opportunities include providing speech-language pathologists (SLP) and special classes with teachers for teaching siblings about their peers' strengths and abilities.

Simultaneously, we expect siblings' experiences of living with their peers to play an essential role. Siblings develop their sense of values about their peers and their disabilities through the experiences investigated in this study (Experience A and B). These include what siblings learn from their parents, such as their peers' disabilities and how to interact with them, among others, and what they see and hear in their daily lives from their parents, peers, and other people with whom they interact daily. In addition, as mentioned above, the siblings' experiences might also include visiting places providing positive attitudes about the siblings and their peers that might increase their understanding of their peers' disabilities, facilitate interactions with other children with disabilities, and provide learning opportunities about the peers' strengths and growth potential.

We suggest that siblings develop relationships with their parents and family members and discuss their questions and concerns about their siblings to develop positive experiences. These relationships will increase the likelihood that siblings will better understand ASD and their peers. Simultaneously, they will learn to take proactive measures such as explaining the situation to others and discussing their questions and concerns. Moreover, the results of this and Quintero et al. indicate that siblings perceive maternal stress; and it is challenging for siblings to discuss with their peers, which makes them vulnerable to cumulative risks⁷. These findings suggest the need to develop relationships between siblings and their family members rather than merely design interventions for siblings.

IV. Conclusion

We investigated episodes in which siblings of children with ASD faced questions and unpleasant situations related to their peers. The results indicated that the supportive relationship with parents and knowledge of ASD were closely related to the siblings' values and explanatory ability. On the other hand, this study's results suggested that regardless of positive factors described above, siblings can gradually develop a mindset unaffected by negative evaluations of surrounding people from developing a positive and

supportive environment for siblings and peers, and accumulating "experiences," including an understanding of their peers and recognizing peers' positive potential. Therefore, this study suggests that changing elementary and junior high schools' environments for siblings to experience positive meanings in their daily lives is supportive. It is necessary to consider disseminating programs such as Sibshops⁵⁾ (Meyer & Vadasy, 2009) practiced in the U.K. to give more positive experiences to siblings in Japan. In Sibshops, experts teach disabilities and peer interaction methods geared to siblings' developmental stages. In addition, there is a need to improve the support provided for parents for explaining and supporting siblings and stabilizing the entire family.

V. Research Issues and Future Directions

Specific limitations constrain the findings of this study. The first limitation of this study is the control of personal and environmental factors of target siblings. Previous studies have indicated that various personal and environmental factors around siblings determine the effects of peers. It might be necessary to conduct another survey that further controls conditions such as age, gender, and birth order of siblings. The second limitation is that this study is based on retrospective narratives of adult siblings. Retrospective narratives of adult siblings do not always accurately reflect what they felt and experienced at the time of interest for the study. Examining support for elementary and junior high school siblings based on retrospective narratives has limitations. Therefore, it is necessary to develop surveys and methods that reduce the psychological burden of elementary and junior high schools' siblings in the future. In addition, it is necessary to focus on positive experiences while taking the issues identified in this study into account. Specifically, it is necessary to examine the possibility of experiences that positively impact siblings' feelings and values about their peers, as suggested in this study. We recommend that future studies also examine factors maintaining siblings' ability to have positive experiences.

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