

Parental Issues and Support Needs in Selective Mutism in Japan: A Quantitative Content Analysis

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ABSTRACT

Background Selective mutism (SM) is an anxiety disorder in which children struggle to speak in specific social situations, and parents often have trouble coping with their child's symptoms. We analyzed parents' issues and support needs regarding SM through their responses to two open-ended questions, examining how these needs varied with diagnosis and comorbid conditions.

Methods Quantitative content analysis was conducted on responses obtained from 70 parents of children with SM (ages 29–63 years) recruited through SM information exchange group and social networking service. The participants responded to two open-ended questions regarding the issues they faced and the support they needed for their children's SM symptoms.

Results The results showed that issues faced by parents of children with SM could be divided into five groups: (A) Regret over Delayed Initial Response, (B) School Non-attendance in Children with SM, (C) Inadequate Support from Teachers, (D) Inconsiderate Communication Lacking Empathy from Others, and (E) Communication Barriers Leading to Bullying and Social Isolation. The support needs of parents were categorized into four groups: (a) Places for Consultation and Obtaining Information, (b) Growth in the Number of Supporters Who Understand SM, (c) Opportunities to Improve Knowledge about SM, and (d) Specific Methods for SM Improvement. Furthermore, although comorbid conditions did not significantly affect parental issues and support needs, slight differences were observed based on the presence of a diagnosis.

Conclusion This study highlights that parents of children with SM are troubled by professionals' lack of knowledge and their children's symptoms, driving them to seek better understanding and more resources. The results also suggest that the support needs of these parents vary depending on whether their child is diagnosed with SM. Future research should globally identify parental issues and support needs, determine the core elements, and establish a more comprehensive support system.

Key words needs assessment; parent; selective mutism

Disabilities affect not only individuals but also their families. Many parents of children with disabilities experience significant stress in their daily lives and are at risk of mental health problems such as anxiety and depression.^{1, 2} Additionally, they must invest substantial energy and time to properly care for and respond to their children's special needs.³ Therefore, several surveys of parental issues and support needs have been conducted across various disability types to explore directions for supporting parents of children with disabilities, leading to the identification of appropriate parental support program proposals for specific disability types and information to improve current support methods.^{4, 5}

However, the parental issues and support needs remain unclear for some disabilities. One such example is selective mutism (SM), an anxiety disorder characterized by a failure to speak consistently in specific social situations, despite being able to speak in other contexts.⁶ The prevalence of SM worldwide is estimated to range from 0.18% to 1.90%, while its prevalence in Japan is 0.21%.^{7, 8} The average age of onset of SM is between 2.7 and 4.6 years, and it may continue into adulthood.^{9, 10} SM is comorbid with neurodevelopmental disorders (ND) such as autism spectrum disorder (ASD), as well as social anxiety disorder, excretory disorders, oppositional defiant disorder, and communication disorders.^{11–15} Support for children with SM has been increasingly established, and with early and effective intervention, SM can be improved.¹⁶ However, while many studies focus on children with SM, few report on the issues and support needs of their families.

Roe¹⁷ conducted a survey of 30 parents of children with SM and reported that these parents experienced self-esteem issues due to concerns about their child's

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Abbreviations: ASD, autism spectrum disorder; ND, neurodevelopmental disorders; SM, selective mutism

future and a lack of understanding of SM by others. Yamanaka and Inoue¹⁸ analyzed a book compiled from letters written by parents of children with SM, published in 1989.¹⁹ They revealed that parents experienced increased anxiety, shock, and regret upon recognizing their child's SM, and expressed a desire to quickly resolve the issue. However, these studies relied on outdated data, highlighting the need to update information on the issues and support needs of parents of children with SM. Recently, Keville et al.¹⁵ reported on the challenges faced by parents of children with co-existing SM and ASD. All participants ($n = 8$) in this study were parents of children with both SM and ASD. Their results showed that parents caring for children with SM and ASD face five key difficulties: "complexities from co-occurring issues", "the overwhelming impact of SM", "the diagnostic journey", "finding solutions", and "advocacy".

However, recent study on parents of children diagnosed with SM is limited, and no studies with large sample sizes have been conducted. Consequently, many aspects of the current issues and support needs of these parents remain unclear. Additionally, it remains uncertain whether the issues faced by parents of children diagnosed solely with SM differ from those faced by parents of children with both SM and ND. Revealing the issues and support needs of parents raising children with SM is important for understanding the concerns of these parents and providing material for developing appropriate support for these children. Developing support methods that address the issues and needs of parents of children with SM is expected to contribute to the maintenance of the mental health of families with children with SM.

This study aimed to achieve two objectives. First, by recruiting a large number of parents of children with SM, it aimed to comprehensively identify and understand their issues and support needs. Second, it aimed to determine whether differences exist in the issues and support needs of parents of children with SM based on

the presence or absence of co-existing conditions.

SUBJECTS AND METHODS

Participants

Due to the low prevalence of SM,^{7, 8} conducting large-scale sampling within a specific region is challenging. The advantages of Internet surveys include obtaining a relatively large sample across regions, focusing on specific groups for sampling, and receiving honest responses to sensitive topics.²⁰ Therefore, this study employed an Internet survey to recruit parents of children with SM through a members-only online bulletin board of an information exchange group related to SM in Japan and the social networking service X. A URL to a webpage containing the study overview and questionnaire was posted on the online bulletin board and the third author's X account.

Previous studies included children who had not been formally diagnosed with SM as participants to enhance sample representativeness.²¹ Similarly, this study included parents of children diagnosed with SM, with suspected SM, and who had SM in the past but have since improved, to increase sample representativeness. All participants responded to a screening item on SM developed by the authors based on the DSM-5 criteria.⁶ Individuals who met our screening criteria, either currently or in the past, were defined as parents of children with SM. Considering the reported co-occurrence of ND and anxiety disorders in children with SM, along with the objectives of this study, participants were also included if their children had co-existing conditions other than SM.¹⁴

The survey was conducted using a web-based questionnaire format. Explanations regarding the study and informed consent for participation were presented on the webpage. Consent was obtained from 85 individuals (82 women, 3 men). The participants responded to six items based on DSM-5 criteria to retrospectively confirm whether their children met the criteria for SM (Table 1). They also answered two open-ended

Table 1. Screening items for selective mutism

Q1	Please describe below the places, people, or situations in which your child failed to speak.
Q2	Please describe below the places, people, or situations in which your child was able to speak.
Q3	Your child has consistently found it difficult to speak in specific social situations (such as school, preschool, public facilities) where speaking is expected despite being able to do so in other contexts.
Q4	Your child's symptoms of selective mutism interfered with their academic performance, occupational performance, or interpersonal communication.
Q5	Your child's failure to speak was not due to a lack of proficiency in the spoken language required in those social situations or a lack of enjoyment in speaking.
Q6	Your child's symptoms of selective mutism lasted for at least one month.

questions: (1) Describe any concerns you have had since noticing your child's SM symptoms, and (2) Describe what support you felt would have been helpful when you were most concerned about your child's selective mutism symptoms. Participants were excluded from the analysis if they did not respond to Questions 1 and 2 from Table 1, answered "no" to any of Questions 3–6, or did not provide open-ended responses.

Statistical analysis

This study employed quantitative content analysis to examine open-ended data from the participants. While qualitative methods are often used for such analysis, they can be limited by subjectivity and lack of reproducibility.²² To overcome these limitations, we used text mining to quantify the data, allowing for an objective and systematic identification of patterns and trends in this study. This approach reduces subjective bias and enhances the reliability and reproducibility of the findings.²²

Therefore, in this study, co-occurrence network analysis was conducted, employing text mining techniques on the data from participants' responses to the open-ended items. KH-Coder Ver. 3 was used for analysis. The responses were analyzed in Japanese without translation into English.

To enhance the accuracy of our analysis, we corrected typographical errors in the responses and removed irrelevant content, including comments thanking us for the survey, and incomplete sentences. To prevent irrelevant topics from being connected in the co-occurrence relationships between words, commonly used words that appear frequently but do not carry significant meaning on their own were excluded (e.g., "is" and "be").^{23, 24} Additionally, settings were adjusted to ensure that compound nouns were not segmented during extraction (e.g., "selective mutism", "school non-attendance," and "elementary school").

Co-occurrence network analysis is used to investigate themes or topics in text data by identifying groups of words with similar occurrence patterns.^{23, 24} In co-occurrence network figures, lines connecting words are drawn based on the Jaccard coefficient. Thicker lines between words indicate stronger co-occurrence relationships.^{23, 24} The size of the circle surrounding a word represents the frequency of occurrence of that word. We used the top 60 most frequently appearing words for the analysis, and the subgraphs were detected using the modularity method.

We used keyword in context concordance^{23, 24} to examine how the most frequently occurring related words were used in context. We then checked the frequency of occurrence of words in co-occurrence

relationships and analyzed their meanings based on the context of their co-occurrence relationships and the original text. Subsequently, we classified themes within the responses, enclosed them using dashed lines, and assigned names to represent their content. To enhance the reliability and validity of the naming, we deliberated on provisional group names. Subsequently, consulted three clinical psychology experts with master's degrees to assess the name's appropriateness and accuracy, leading to the final group name decisions.

Correspondence analysis is used to represent the results obtained from extracted words in a two-dimensional scatter plot.^{23, 24} It is suitable for examining the characteristics of various parts of the data. Words closer to the origin (0, 0) indicate little difference, whereas those farther from the origin indicate more distinctive.^{23, 24} We categorized the data into four diagnostic types: "SM diagnosis only", "suspected SM only", "diagnosis of SM and ND", and "suspected SM and diagnosis of ND". Subsequently, we evaluated the relationships between the four variables and the extracted words.

Ethical considerations

All participants were informed about the study's aim, ethical considerations, data anonymization, and voluntary participation, with consent required to complete the questionnaire. This study was approved by the Research Ethics Committee of Shimane University (approval number: R506) and adhered to the ethical principles of the 1964 Declaration of Helsinki.

RESULTS

Screening

Following screening, 15 individuals were excluded: 14 who did not have children meeting the criteria for SM and 1 who did not complete the form. Consequently, we included 70 participants included in the final analysis, with a mean age of 45.6 years (range: 29–63 years, SD = 7.01, mode = 48). The average age of their children was 13.3 years (range: 3–35 years, SD = 5.81, mode = 11).

Diagnostic categories and participant demographics

Thirty-four participants reported that their children had been diagnosed with comorbidities. Of these, 23 were diagnosed with SM along with other conditions (23 had ND, 7 had anxiety disorders, and 2 had other conditions), 9 had suspected SM and a diagnosis of other comorbidities (nine had ND and six had anxiety disorders), 1 had a past diagnosis of SM along with ND, and 1 had a past suspicion of SM along with an anxiety disorder.

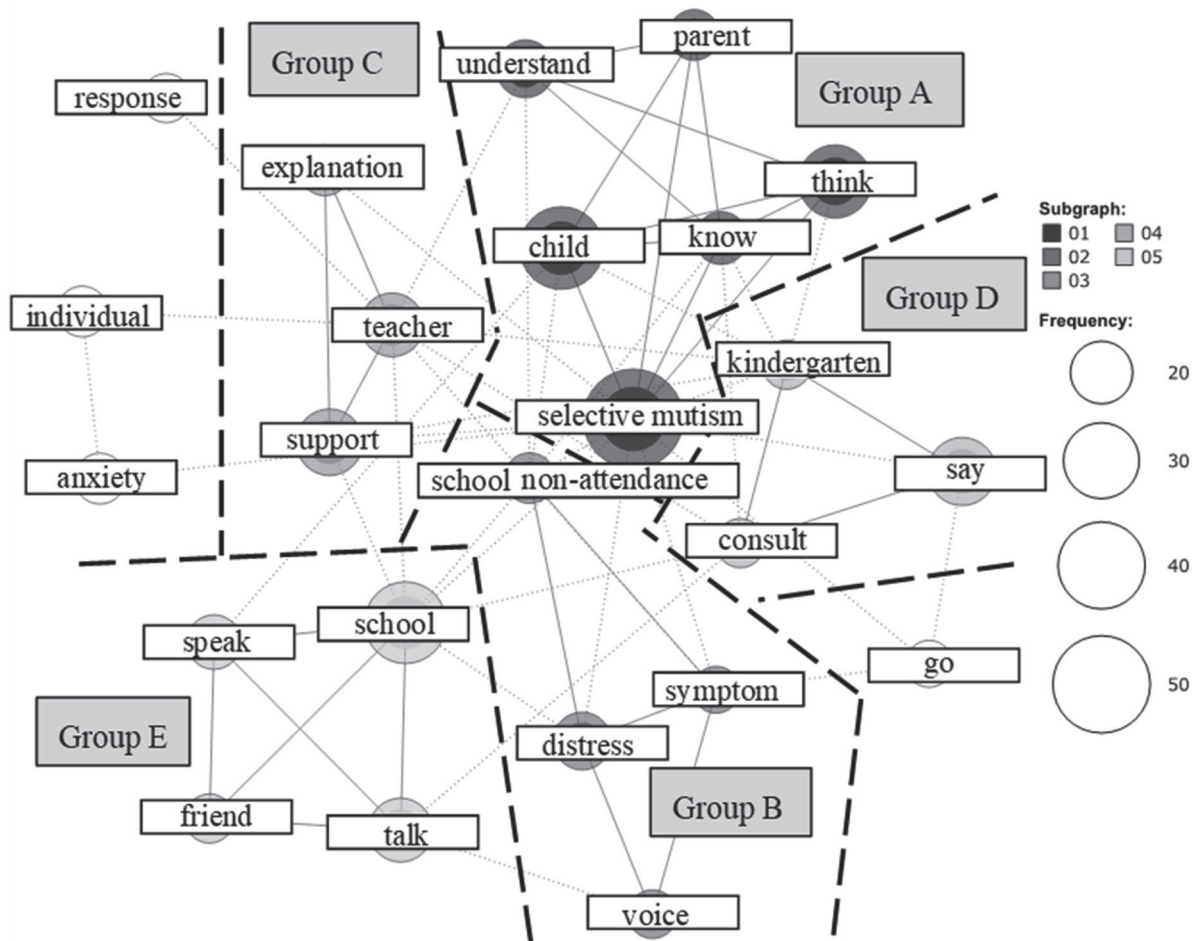


Fig. 1. Results of co-occurrence network analysis on parental issues of parents of children with SM. Group A: Regret over Delayed Initial Response, Group B: School Non-attendance in Children with SM, Group C: Inadequate Support from Teachers, Group D: Inconsiderate Communication Lacking Empathy from Others, and Group E: Communication Barriers Leading to Bullying and Social Isolation). The connections between keywords indicate the relationships and common themes shared within these groups. The thickness of the lines represents the strength of the relationships between keywords, while the sizes of the nodes (circles) reflect the frequency of each keyword.

Distribution of SM and ND diagnoses among participants

Of the 70 participants, 19 were parents of children diagnosed with SM alone, 18 were parents of children with suspected SM, 23 were parents of children diagnosed with both SM and ND, and 10 were parents of children with suspected SM and ND.

Parental issues of parents of children with SM

The analysis revealed a total word count of 5,931, with a unique word count of 1,057. The top 10 most frequently occurring words were “selective mutism” (53 words), “child” (36 words), “school” (35 words), “think” (28 words), “say” (24 words), “support” (23 words), “teacher” (21 words), “talk” (21 words), “distress” (17 words), and “understand” (17 words).

The co-occurrence network analysis was conducted using responses regarding the issues of parents of children with SM, revealing 5 distinct groups (Fig. 1). Group A was a cohesive group comprising 6 words: “selective mutism”, “know”, “think”, “child”, “parent”, and “understand”. These words were extracted from descriptions such as “As a parent, I deeply regret not knowing about selective mutism and unintentionally blaming or getting angry at my child”, “Until parents began to think that my child might have selective mutism, there was no opportunity for teachers to hear from them, whether in preschool or elementary school, about the child not speaking”, and “I am sorry to say that if I had known and understood about the selective mutism, my child would not have had a difficult time during his primary school years”. Therefore, Group A was named

“Regret over Delayed Initial Response”.

Group B was a cohesive group comprising 4 words: “voice”, “distress”, “symptom”, and “school non-attendance”. These words were extracted from descriptions such as *“I was distressed, wondering how to get them to find their voice”* and *“My child also struggled with symptoms of selective mutism, but the bigger issue was their school non-attendance starting from the fourth grade, and they couldn’t attend school at all until graduation”*. Therefore, Group B was named “School Non-attendance in Children with SM”.

Group C was a cohesive group comprising 3 words: “teacher”, “support”, and “explanation”. These words were extracted from descriptions such as *“I explained every time, but different teachers responded differently”*, *“I try to explain each time, but it’s difficult because of the low level of awareness about selective mutism”*, and *“School education knew about selective mutism but did not take a ‘supportive’ stance”*. Therefore, Group C was named “Inadequate Support from Teachers”.

Group D comprised 3 words: “kindergarten”, “consult”, and “say”. These words were extracted from descriptions such as *“I consulted with a specialized teacher in early childhood development at kindergarten, but the response I received was along the lines of ‘There is nothing we can do, so hang in there, Mom,’ which only added to my distress”* and *“Teachers and other children said heartless things to my child when they had selective mutism symptoms in kindergarten”*. Therefore, Group D was named “Inconsiderate Communication Lacking Empathy from Others”.

Group E was a cohesive group comprising 4 words: “school”, “friend”, “talk”, and “speak”. These words were extracted from descriptions such as *“Continued harassment by classmates because my child could not speak”* and *“My child couldn’t talk to classmates at school, which strained their relationships and led to being bullied”*. Therefore, Group E was named “Communication Barriers Leading to Bullying and Social isolation”.

Characteristics of parental issues by diagnosis type

We conducted a correspondence analysis to examine whether there were differences in parental issues experienced by participants based on their children’s diagnosis type (Fig. 2). The analysis revealed distinct characteristic words within each category and overlapping words across categories. The words such as “talk”, “understand”, “friend”, and “parent” were positioned near the origin, suggesting that they are common across all diagnosis types. These words were found in sentences

such as *“People don’t understand that children with selective mutism aren’t choosing not to speak, but that they feel unable to speak”*, *“My child cannot talk to friends”*, *“It’s hard to find someone with the knowledge and understanding to help you”*, and *“The barriers are too high for parents who are working full time to get a diagnosis and support”*.

For both the “SM diagnosis only” and “suspected SM and diagnosis of ND” categories, the shared characteristic words for parental issues included “cope”, “school”, and “anxiety”. These words were found in sentences such as *“Even after my daughter started primary school, she did not receive the appropriate support, and I was troubled when the homeroom teacher said she was just spoiled and lazy”*, *“When my child advanced to elementary school, the school staff listened to my concerns but stated that individualized support was not possible”*, *“Worried about being able to cope in an emergency situation”*, and *“Year by year, the characteristics are getting stronger and they are getting more anxious about things and places that are new to them”*.

The characteristic words for issues in the “diagnosis of SM and ND” category included “individual” and “teacher”. These words were found in sentences such as *“Despite wanting to work and participate in society, my child gives up on various opportunities due to communication difficulties and feels as if his path is closed off”* and *“Unable to communicate with classmates, they could not say no to things they did not like and could not point out mistakes, so they blamed themselves or got angry with the teacher”*.

The characteristic words for issues in the “suspected SM only” category included “distress”, “consult”, and “symptom”. These words were found in sentences such as *“I consulted with a specialized teacher in early childhood development at kindergarten, but the response I received was along the lines of ‘There is nothing we can do, so hang in there, Mom’, which only added to my distress”* and *“Even when taken to the hospital, it takes time to convey symptoms to the doctor because they cannot communicate their symptoms themselves”*.

“SM diagnosis only”, “diagnosis of SM and ND”, and “suspected SM and diagnosis of ND” are positioned to the left of the origin in the Fig. 2, while “suspected SM only” is positioned to the right.

Support needs of parents of children with SM

The analysis revealed a total word count of 3,125, with a unique word count of 656. The top 10 most frequently occurring words were “child” (34 words), “selective mutism” (31 words), “school” (29 words), “teacher” (23

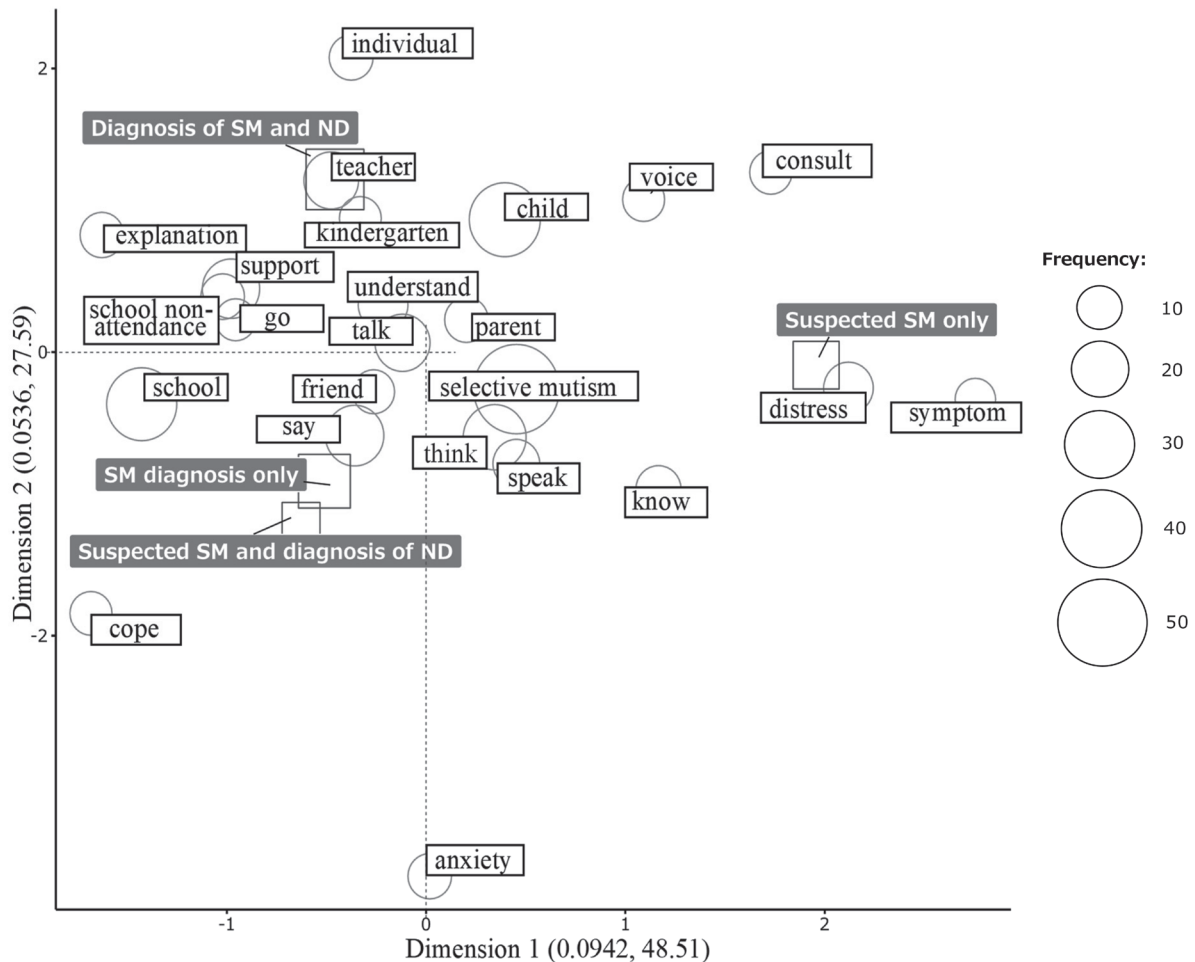


Fig. 2. Results of correspondence analysis on parental issues of parents of children with SM. The words closer to the origin are presumed to have higher commonalities, while those farther from the origin have lower commonalities. The sizes of the nodes (circles) represent the frequency of each keyword. In this figure, ND refers to neurodevelopmental disorders and SM refers to selective mutism.

words), “think” (22 words), “support” (22 words), “understand” (16 words), “parent” (13 words), “consultation” (13 words), and “knowledge” (13 words).

The co-occurrence network analysis was conducted using responses regarding participants’ support needs, revealing 4 groups (Fig. 3). Group a was a cohesive group comprising 3 words: “consultation”, “information”, and “want”. These words were found in sentences such as “I wanted information or guidance on where I could seek advice” and “I felt that there was still a lack of knowledge about selective mutism in childcare consultation in local authorities, so I wanted a place where I could talk to someone knowledgeable about selective mutism”. Therefore, group a was named “Places for Consultation and Obtaining Information”.

Group b was a cohesive group comprising 5 words: “child”, “support”, “understand”, “feel”, and “monitoring”. These words were found in sentences such as “Since

there were no specialized doctors available, visiting the developmental outpatient department resulted in merely monitoring the situation without receiving any treatment or therapy”, “I feel that teachers’ specialist knowledge and skills are left to the individual, so I would like to see the understanding of and support for selective mutism included in teacher training”, and “Educators in preschools and schools who understand the child’s selective mutism and are willing to work at the child’s pace”. Therefore, Group b was named “Growth in the Number of Supporters Who Understand SM”.

Group c was a cohesive group comprising 6 words: “selective mutism”, “knowledge”, “teacher”, “homeroom teacher”, “parent”, and “think”. These words were found in sentences such as “I think that I wanted teachers to know about selective mutism”, “I have wished that my child’s homeroom teacher had knowledge of selective mutism”, and “A presentation for parents of children

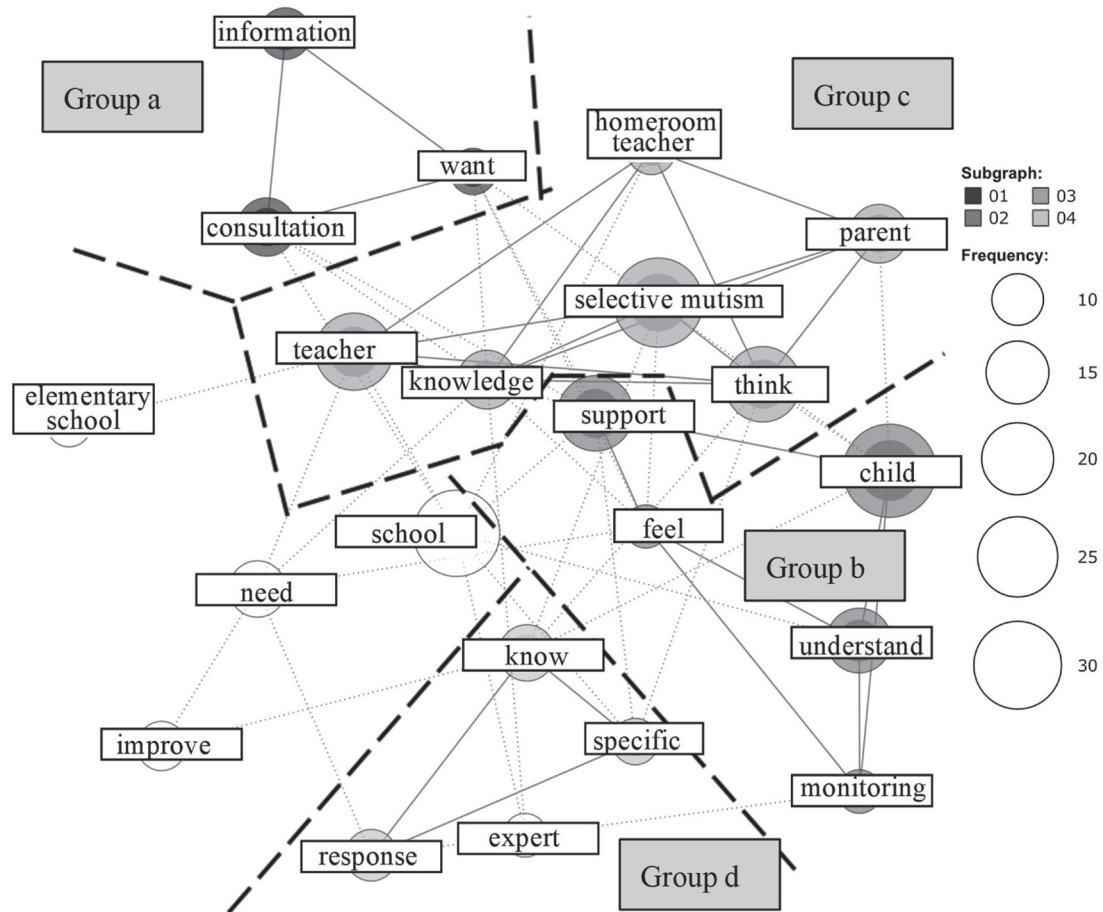


Fig. 3. Results of co-occurrence network analysis on support needs of parents of children with SM. Group a: Places for Consultation and Obtaining Information, Group b: Growth in the Number of Supporters Who Understand SM, Group c: Opportunities to Improve Knowledge about SM, and Group d: Specific Methods for SM Improvement). The connections between keywords indicate the relationships and common themes shared within these groups. The thickness of the lines represents the strength of the relationships between keywords, while the sizes of the nodes (circles) reflect the frequency of each keyword.

with selective mutism”. Therefore, Group c was named “Opportunities to Improve Knowledge about SM”.

Group d was a cohesive group comprising 3 words: “specific”, “response”, and “know”. These words were found in sentences such as “I wish I had known more examples of specific responses to children with selective mutism” and “Specific ways of communicating when requesting reasonable accommodation from school”. Therefore, Group d was named “Specific Methods for SM Improvement”.

Characteristics of parental support needs by diagnosis type

We conducted a correspondence analysis to examine whether there were differences in participants’ support needs based on their children’s diagnosis type (Fig. 4). The analysis revealed distinct characteristic words within each category and overlapping words across

categories. The words such as “teacher” and “school” were positioned near the origin, suggesting that they were common across all diagnosis types. These words were found in sentences such as “I needed the knowledge to explain selective mutism so that school teachers would not force my child to talk” and “We would appreciate the presence of a support person who would work with the school and support from the school teachers, as well as emotional support for parent to talk to (e.g., a medical institution, school teachers, school counselor, etc.)”.

For both the “SM diagnosis only” and “diagnosis of SM and ND” categories, the shared characteristic words for support needs included “elementary school”, “know”, and “information”. These words were found in sentences such as “I wanted information or guidance on where to get help” and “I wished I had received more advice from the elementary school teachers”. The

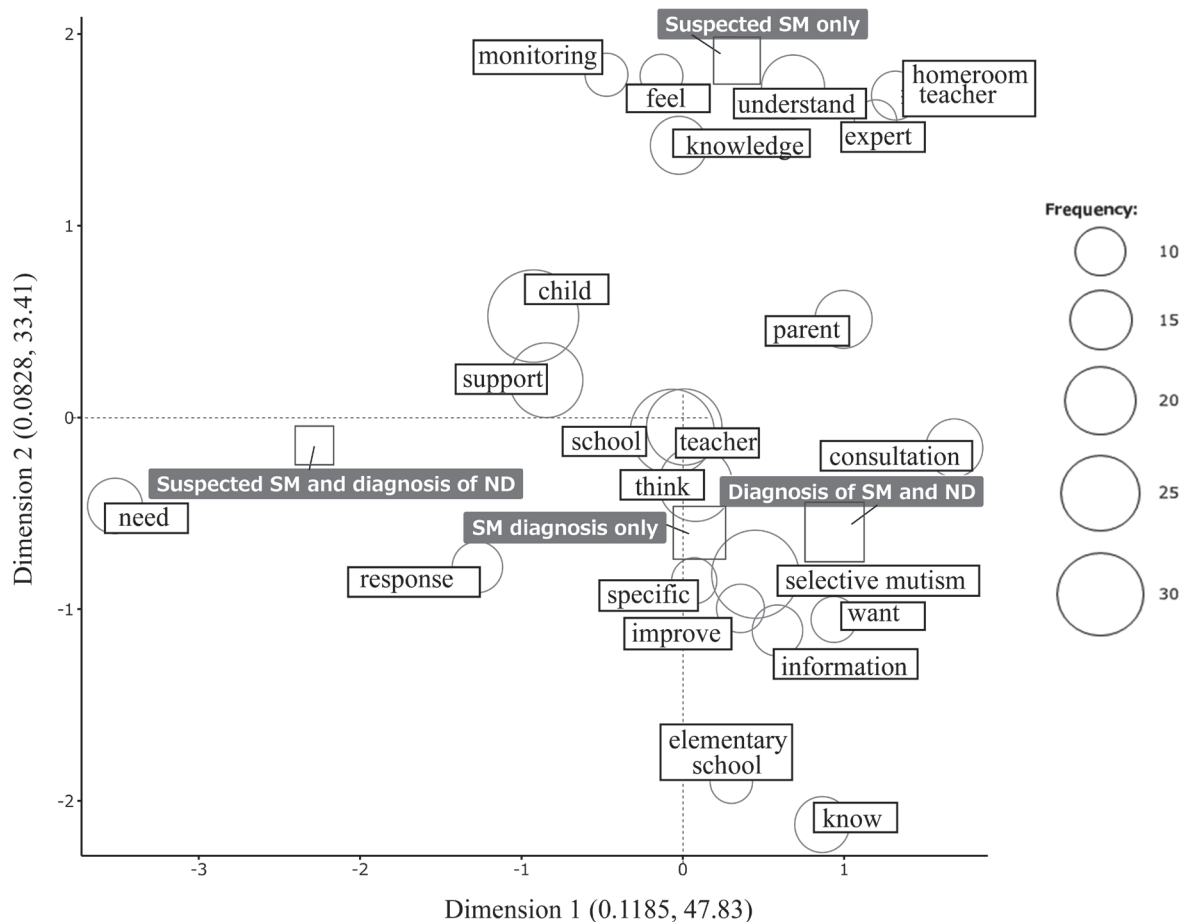


Fig. 4. Results of correspondence analysis on support needs of parents of children with SM. The sizes of the nodes (circles) represent the frequency of each keyword. In this figure, ND refers to neurodevelopmental disorders and SM refers to selective mutism.

characteristic words for support needs in the “suspected SM and diagnosis of ND” categories, included “need”. This word was found in sentences such as “*I’m not sure what kind of support is needed*” and “*I needed a place for training that my child could receive in the early years of preschool and early primary school*”. For both the “SM diagnosis only” and “suspected SM and diagnosis of ND” categories, the shared characteristic words for support needs included “response”. This word was found in sentences such as “*I wanted information on how to support my child in specific response and how to treat*”. The characteristic words for support needs in the “suspected SM only” category were “understand”, “monitoring”, and “expert”. These words were found in sentences such as “*It would be helpful to have opportunities to see videos of my child in the nursery, capturing their behavior, expressions, and gestures, to better understand my child*”, “*Since there were no specialized doctors available, visiting the developmental outpatient department resulted in merely monitoring the situation*

without receiving any treatment or therapy”, and “*I am seeking expert advice on how to treat my child*”.

“SM diagnosis only”, “diagnosis of SM and ND” and “suspected SM and diagnosis of ND” are positioned below the origin in Fig. 4, whereas “suspected SM only” is positioned above.

DISCUSSION

This study aimed to comprehensively identify the issues and support needs of parents of children with SM. We also investigated whether there were differences in their issues and support needs depending on the presence of a diagnosis or comorbidity. The analysis of text data from open-ended items provided by parents of children with SM revealed five categories of issues: (A) Regret over Delayed Initial Response, (B) School Non-attendance in Children with SM, (C) Inadequate Support from Teachers, (D) Inconsiderate Communication Lacking Empathy from Others, and (E) Communication Barriers Leading to Bullying and Social Isolation. Furthermore,

the results of the correspondence analysis suggest that parents of children with SM, regardless of the presence or absence of comorbid conditions, face various issues, including the symptoms of SM itself, lack of understanding from others, difficulties in their child's communication within friendships, and the need for parents to take the lead in managing support.

Issues (C) Inadequate Support from Teachers and (D) Inconsiderate Communication Lacking Empathy from Others are presumed to arise when parents of children with SM seek assistance or advice from their surroundings. This finding is consistent with previous research suggesting that a lack of understanding from others can negatively affect parents' self-esteem.¹⁷ (A) Regret over Delayed Initial Response was similar to the findings of a previous study.¹⁸ These issues seem to persist for several years and continue to affect parents of children with SM. These parents may experience psychological distress while raising their children, partly due to the ongoing lack of understanding from those around them. Therefore, it is important to expand the availability of parent support programs^{25, 26} for these parents, to help them learn how to manage their children's SM symptoms and how to help others understand SM. Additionally, standardized training programs should be developed for school teachers and healthcare professionals to deepen their understanding of SM and address issues such as the lack of understanding and the burden on parents to take the lead in providing support.

Issues (B) School Non-attendance in Children with SM and (E) Communication Barriers Leading to Bullying and Social Isolation have not been reported in prior study. However, a scoping review of clinical reports on SM in Japan revealed that a significant number of cases include primary complaints such as school non-attendance among children with SM.²⁷ Therefore, parents of children with SM are distressed not only by SM symptoms but also by related problems. Treatment typically aims to improve SM symptoms by gradually exposing individuals to social situations that heighten anxiety.²⁸ However, social participation becomes more complicated when a person experiences school non-attendance, which may also hinder treatment. This suggests the importance of establishing intervention methods when social participation becomes difficult for children with SM. Additionally, psychoeducational methods should be developed to educate classmates of children with SM about the condition to improve issues related to peer relationships and bullying.

Research on parents of children with ASD who do not have SM has also identified common issues such as difficulties in diagnosis, treatment, and household

stress. For example, Hosseinpour²⁹ and Giannotti et al.³⁰ found that parents of children with ASD face complex issues such as financial burdens and a lack of social support. Parents of children with both SM and ASD may face compounded issues, including understanding the complexities of both conditions and difficulty obtaining adequate support from teachers and other networks. This suggests the need for a comprehensive, multilayered support system to address the issues encountered by these families.

The support needs of parents of children with SM were categorized into four groups: (a) Places for Consultation and Obtaining Information, (b) Growth in the Number of Supporters Who Understand SM, (c) Opportunities to Improve Knowledge about SM, and (d) Specific Methods for SM Improvement. Furthermore, the correspondence analysis suggests that for parents of children with SM, understanding from school teachers is an important support need, regardless of the presence or absence of comorbid conditions. These four support needs likely arise from the environment surrounding parents of children with SM, such as (C) Inadequate Support from Teachers and (D) Inconsiderate Communication Lacking Empathy from Others.

The correspondence analysis revealed that the support needs of parents of children with SM may vary not according to the presence of ND comorbidity, but rather based on whether the children have a formal diagnosis of SM, ND, or both. Regardless of whether their children have only an SM diagnosis or both SM and ND diagnoses, parents of children with SM experience difficulties in managing SM-related behaviors and securing appropriate support in school. As a result, these parents actively seek resources that provide information on SM and practical strategies for effective intervention. However, parents of children who are only "suspected of SM" tend to seek supporters who understand SM. When a formal SM diagnosis is absent, parents of children showing SM symptoms often face difficulties in obtaining support from doctors and teachers, and are likely to encounter challenges in coordinating with medical institutions and schools. Therefore, their primary need is considered to be finding supporters who understand their child's condition. These findings suggest that parents of children with SM face substantial barriers to obtaining adequate support, which may contribute to their psychological burden.¹⁵

In conclusion, this study, by involving a substantial number of parents of children with SM, comprehensively elucidated the issues and support needs faced by these parents. These findings underscore the urgent need for the prompt establishment of an environment

in Japan that facilitates rapid and effective support for children with SM and their parents. Key measures that should be implemented include introducing early screening processes, developing SM-specific support guidelines, and training local experts. While co-existing conditions do not significantly alter parental concerns, differences in issues and needs arise depending on whether a diagnosis has been made. Therefore, expanding opportunities for parents to seek advice and obtain information on symptom management is essential to strengthen the support network for families affected by SM. Specifically, developing training programs to enhance the knowledge of school and healthcare professionals is crucial. To ensure broad accessibility, these programs should be offered in various formats, including face-to-face, online, and on-demand.

This study has some limitations. First, the generalizability of findings are limited, despite being consistent with some international research, as they are based solely on Japanese participants. Japan's support system for SM differs markedly from those in other countries, particularly in terms of clinical treatment approaches and parental support. Iimura et al.²⁷ highlighted that SM treatment in Japan primarily involves parent interviews and play therapy, with minimal use of exposure therapy, in contrast to the widespread use of behavioral therapy and systemic approaches in other countries. These differences in treatment methods may have shaped the specific issues and support needs identified for parents in this study.

Second, we did not collect data on whether the participants sought medical consultations. Even within the category of "suspected SM only," support needs may differ between parents who visited a healthcare provider but did not receive a diagnosis and those who did not seek consultation. Therefore, suspected SM in this study needs to be defined as cases wherein SM is suspected but no formal diagnosis has been made, regardless of whether medical consultation has been sought. Future research should collect data on parents' experiences with medical consultations to gain a deeper understanding of their support needs.

Third, the reliance on online surveys may introduce bias. Future research should use diverse recruitment strategies, like recruiting at PTA meetings or distributing flyers at government offices, to reduce selection bias. Moreover, to obtain more reliable results, it is crucial to verify whether the findings of this study can be replicated using a combination of diverse data collection methods, including interviews, focus groups, and observational studies.

Fourth, the reliability of the screening items was

not confirmed. Although the screening items in this study were based on the DSM-5 diagnostic criteria for SM, which suggests content validity, formal pilot testing and validity verification were not conducted. Therefore, uncertainties may exist regarding the effectiveness of the screening process.

Future research should rigorously verify the reliability and validity of the screening items used in this study to ensure appropriate participant selection. Once confirmed, efforts should focus on replicating these findings outside Japan. This approach will help verify the transferability of the findings and identify issues and support needs across different contexts. Ultimately, this process will help clarify the core elements of these needs and establish a foundation for a more comprehensive support system informed by international perspectives.

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The authors declare no conflict of interest.

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