

EMPIRICAL RESEARCH QUALITATIVE

Supporters' experiences of sensory characteristics of children with profound intellectual and multiple disabilities in after-school daycare centres: A qualitative study

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Abstract

Aim: To examine how supporters working at after-school daycare centres, who are involved in the lives of children with profound intellectual and multiple disabilities in the community, pay attention to the sensory characteristics of these children and provide support.

Design: A qualitative descriptive design.

Methods: Data were collected through semi-structured interviews with 20 supporters in after-school daycare centres. Interview transcripts were analysed via qualitative content analysis.

Results: The participants' years of involvement in supporting children with profound intellectual and multiple disabilities ranged from 0.5 to 40 years, with an average of 9.8 years. Data were classified into 68 subcategories, 11 categories and three themes: understanding sensory characteristics and devising support, systematic support and challenges supporting the children. Supporters dealt with physical complications and cooperated with other caregivers to understand and respond to children's sensory characteristics. Difficulties dealing with sensory characteristics, challenges due to the supporters' own characteristics and challenges with the facility's infrastructure were identified. The findings could guide sensory characteristics considerations and support systems in after-school daycare facilities for children with profound intellectual and multiple disabilities. Both support content and challenges in supporting these children were identified.

KEYWORDS

after-school daycare centre, interview as topic, multidisciplinary cooperation, profound intellectual and multiple disabilities, sensory characteristic

Toshisaburo Nagai: Passed away in March 2023.

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1 | INTRODUCTION

The number of children with severe disabilities living at home or in the community has been increasing with the advancement of medical technology. Children with profound intellectual and multiple disabilities (PIMDs) are estimated to be over 40,000 in Japan (Ministry of Health, Labour and Welfare, 2017). Children with PIMD are defined as those with both severe physical and intellectual disabilities and serious secondary disabilities (van Timmeren et al., 2016). Serious secondary disabilities include sensory challenges such as visual and auditory impairments (van Timmeren et al., 2016). Based on the specific definition of PIMD in Japan, physical disability refers to those who cannot walk independently, and profound intellectual disability refers to those with an intelligence quotient of 35 or less (Oshima, 1971).

2 | BACKGROUND

In Japan, daycare centres and residential facilities provide social support for children with PIMD. Among these services, child developmental support services and after-school daycare centres are important, as they support the development of children with PIMD. As of 2020, there were 835 after-school daycare centres in Japan (Ministry of Health, Labour and Welfare, 2020), and this number is increasing as the number of children with PIMD increases. In 2021, an Act was enacted to promote the healthy growth of children with medical care needs and help prevent their families from leaving the workforce, thereby contributing to a society where children can be born and raised with peace of mind (Ministry of Health, Labour and Welfare, 2021). In Japan, after discharge from the neonatal intensive care unit (NICU), children with PIMD under 6 years of age live mainly at home with their parents. Some may attend nursery school with support systems. Those over 7 years are enrolled in special needs schools, where they spend approximately 7 h each day (9:00 AM to 3:00 PM), from Monday through Friday. Children with PIMD visit these facilities after kindergarten or school in the afternoon and stay there until the evening while receiving appropriate care. These facilities employ certified nurses, nursery teachers and child instructors and are important for the growth and development of such children and serve to reduce caregivers' burdens. Child instructors are supporters working with social workers, licensed teachers, etc. The child development support manager is responsible for making the support plans and policies for children together with their caregivers.

Children with PIMD experience various sensory challenges due to the central nervous system disorders associated with their primary disease. These challenges include visual abnormalities associated with the strabismus, hearing impairments and abnormal reactions to changes in temperature and touch (Soorya et al., 2018). A study on the prevalence of physical symptoms in children with PIMD reported that 87% had a visual impairment and 22% had a

hearing impairment (van Timmeren et al., 2016). Damasio (2003) suggested that there are two types of sensory signals in humans: interoceptive and exteroceptive. Interoception includes vestibular senses, whereas proprioception is related to muscles, body temperature and pain. Proprioceptive senses include the sensation associated with the position of a limb or trunk, senses of force and senses of heaviness by receptors in muscles, skin and joints (Proske & Gandevia, 2012). The vestibular sense detects changes in horizontal, anterior and posterior movements; acceleration and head tilt, with otoliths and semicircular canals as sensory organs (Garzorz & Deroy, 2020). The vestibular sense is also closely related to visual, tactile and proprioceptive sensation at the behavioural level, while the exteroceptive sense includes touch, taste, smell, vision and hearing. Due to possible hypersensitivity or blunting in multiple senses, both sensory receptive routes should be considered when supporting children with PIMD.

In the International Classification of Functioning, Disability, and Health model, the sensory functions are included in body functions, suggesting that it is important to understand and support the sensory characteristics when considering the life functions of children with PIMD (World Health Organization, 2001). Neurological rehabilitation focused on neural plasticity can be considered for children with cerebral palsy that overlaps with PIMD to support nerve and sensory impairments, and collaboration with nurses and teachers, as well as doctors, is important (Aisen et al., 2011). It is also important to support children with PIMD to improve their self-awareness, and an instrument has been developed to help supporters monitor such children's development (Dind & Petitpierre, 2022). This instrument can be used to assess psychological development and evaluate the results of professional educational interventions.

Nurses and other supporters can provide more individualised support with a better understanding of the sensory characteristics underlying the developmental and daily life challenges of children with PIMD. It is also necessary to evaluate the quality of care and quality of life (QOL) of children with PIMD based on their sensory characteristics. However, objectively assessing the sensory characteristics of children with PIMD who have difficulty communicating through verbal and body language is challenging. While a checklist has been developed to assess their sensory characteristics, it is not sufficiently reliable due to methodological challenges in confirming reliability and concerns about inter-rater differences (Vlaskamp & Cuppen-Fontaine, 2007). Several other scales have been developed to assess the mental aspects of children with PIMD; however, none focus on sensory characteristics (Flynn et al., 2017). The relationship between children and their caregivers in assessing the QOL of children with PIMD is not fully understood. Currently, we need qualitative research on the experiences of (including awareness of slight responses in children with PIMD) and support methods employed by caregivers and supporters. There are limited qualitative studies on caregivers and supporters of children with PIMD, and these studies focus on the children's QOL or participation in activities. However, these studies were

not able to provide insights into how the supporters understand children's sensory characteristics (Kruithof et al., 2022; Sato & Araki, 2022).

3 | THE STUDY

3.1 | Aims and objective

This study aimed to examine how supporters working at after-school daycare centres, who are involved in the lives of children with PIMD in the community, pay attention to the sensory characteristics of these children and provide support. Specifically, the study aimed to (1) determine if supporters consider the impact of sensory characteristics; (2) identify how supporters help children mitigate these sensory characteristics and (3) explore the collaboration between supporters and other professionals.

4 | METHODS

4.1 | Design

This study employed a qualitative and descriptive design, as proposed by Sandelowski (2010). An inductive approach to qualitative content analysis was used to ensure rigour in the analysis and the reporting results (Kyngäs et al., 2020).

4.2 | Sampling and recruitment

The participants were 20 healthcare professionals from after-school daycare centres in Japan. They included seven nurses (including practical nurses), four child instructors, three nursery teachers, two physiotherapists, two facility administrators, one child development support manager and one person who concurrently served as child development support manager and facility administrator. No exclusions were made based on the type of qualification. Although nurses are capable of practicing medical care, other healthcare personnel can also practice medical care after receiving training; therefore, the differences in support by occupation are not clear. Although each occupation has its own expertise in providing support at the after-school daycare centres, the children's individual needs are addressed while adopting a holistic approach to daily care and play. Furthermore, most facility managers serve as direct care providers. Therefore, all occupations that supported children with PIMD were defined as 'supporters' and included in this study.

The participants were recruited via snowball sampling, a method in which the first participant introduces another potential participant, gradually increasing the number of participants (Kirchherr & Charles, 2018). Initially, a nurse (No. 7) from a facility where the first author had worked was asked to participate in this study. The staff

at the facility (No. 1–6, 8–9), one physiotherapist (No. 10) and one nurse from another facility (No. 15) were referred to participate. Then, participant No. 15 introduced us to the staff at the same facility (No. 11–14, 16–18). Finally, to obtain more information regarding the experiences of physical therapists and facility administrators, two additional participants (No. 19–20) were referred by the third author.

This study included individuals who provide after-school daycare services. In Japan, such facilities typically take care of approximately five children with PIMD on a temporary basis during the day. The services include daily care, medical care and developmental play. Most facilities offer child development support services and after-school daycare services for children aged from birth to 18 years. The use of these facilities begins after discharge from the NICU and upon certification of disability. There was no age difference among the three facilities included in this study; approximately five children spent time in one room, regardless of their age.

4.3 | Data collection

Data were collected through face-to-face semi-structured interviews conducted between January and July 2021. The interviewer—the first author—explained the purpose and methods of the study to the participants and obtained written informed consent. We informed the participants that the interview could be held at a place of their choice; all participants preferred the interviews to be conducted in a room at their facility. The interviews were recorded using a voice recorder with the consent of the participants. If work-related or other matters arose during the interview, the interview and recording were interrupted as appropriate and only resumed with the participant's consent.

The recruitment of participants continued until we had enough information to meet the study objectives. To confirm data saturation, we first analysed verbatim interview transcripts from participants No. 1–10 and coded and created categories. Then, verbatim transcripts from participants No. 11–18 were sequentially analysed to confirm that no new categories emerged after participant No. 15. However, given the influence of the participants' occupations, we additionally recruited participants No. 19 and 20, but since no new categories emerged, we considered the data to be saturated and completed the sampling.

4.4 | Semi-structured interviews

At the beginning of the interview, we asked about the participants' previous support experience. After that, the following question was asked: 'Please tell us about any sensory characteristics that you consider when supporting children with PIMD.' When it was difficult for the participants to talk about the term 'sensory characteristics,' the interviewer asked them an additional question: 'What are your

thoughts about each of the following senses: seeing, hearing, touch, taste, smell, vestibular senses, and proprioception?' As some participants may not understand the words vestibular/proprioceptive, the interviewer explained these terms before asking them questions. The interviews lasted between 10 and 60 min, with an average of 22 min. The interviews were conducted in Japanese.

4.5 | Data analysis

The audio-recorded interviews were transcribed verbatim and then entered into NVivo (version 1.5.2) for analysis. After the perusal of the transcripts of participants No. 1–10 by the first and second authors, the transcripts were coded by the first author. Then, the second author reviewed the list of codes and transcripts and discussed modifications to the code list with the first author. After that, the first author inductively classified the code lists into categories and subcategories based on similarities in the semantic content using the qualitative content analysis method (Kyngäs et al., 2020). The second author reviewed these categories and subcategories. Transcripts of participants after participant No. 11 were analysed the same way. After creating categories based on all the transcripts, the first through fourth authors discussed the classification. It was decided that the categories would be merged into three themes. All the authors approved the process of classification and the naming of categories.

After the authors finalised the classification, the participants were debriefed. During the debriefing, the authors confirmed that the classification results and theme names did not contradict the participants' experience or intuition. All the participant quotes presented in this article were translated from Japanese into English.

4.6 | Ethical considerations

This study was conducted with the approval of the research ethics committee of the first author's institution. We provided written and oral explanations to the participants and obtained their informed consent. The respondents were informed that their participation in the study was voluntary, that they could withdraw their consent, that their personal information would be protected, and that the data would be properly stored and destroyed. Information on the participants' ages and facility affiliations was withheld in this paper to protect their anonymity. Each participant received 1000 yen as a token of gratitude for their cooperation.

4.7 | Rigour and reflexivity

To ensure rigour, we used the criteria that Kyngäs et al. (2020) proposed for credibility, dependability, authenticity and transferability, which constitute trustworthiness. The influence of the

interviewee's experiences and preconceptions on the research was explicitly noted to ensure credibility. In addition, the data were sequentially categorised to ensure data saturation. To ensure dependability, the analytical procedure was described in detail, and the authors fully discussed the categorisation, and interpretation of the results. In addition, Table 1 was added to facilitate the structure of the results. For authenticity, each category described one or more raw data points. Participants' attributes are shown in Table 2. The system and content of care in after-school daycare centres in Japan are presented in the Introduction to increase the transferability of the findings of this study. Furthermore, to improve the quality of the descriptions, we referred to the critical appraisal tools for qualitative research published by the Joanna Briggs Institute (Lockwood et al., 2020). Specifically, this study interpreted the experiences of supporters caring for children with PIMD, and appropriate methodologies were selected to interpret the results. Additionally, the cultural background and experiences of the researcher, as well as ethical considerations for this study, were clearly stated.

The first author, a nurse with experience caring for children with PIMD, conducted all interviews in this study. Moreover, the interviewer had worked at the same facility where some participants had worked before the study was conducted, which was an advantage for data collection, given that the interviewer has experience with the support systems used in the facility. However, there is a possibility that the matters tacitly understood between the interviewer and the participants were not included in the data.

The interview was conducted after the interviewer's background was introduced to the participants. Knowing that the interviewer was a nurse, the participants may have revealed more about medical matters and relationships with nurses from their experiences.

The article was written according to the COREQ (COnsolidated criteria for REporting Qualitative research) checklist (Tong et al., 2007).

5 | FINDINGS

5.1 | Participants

We interviewed 20 supporters from three after-school daycare centres. Participants No. 1–10, 11–18, and 19–20 belong to the same centres, respectively. Eighteen participants were female, and two were male. The participants' involvement in supporting children with PIMD ranged in length from 0.5 to 40 years, with an average of 9.8 years (Table 2).

5.2 | Integration of findings

We classified 1012 codes into 68 subcategories, 11 categories and 3 themes: understanding sensory characteristics and devising support, systematic support and challenges supporting the children

TABLE 1 Integrated classification of themes, categories and subcategories.

Themes	Categories	Subcategories
1. Understanding children's sensory characteristics and devising support	1.1. Sensory characteristics of children with PIMD	1.1.1 Visual characteristics
		1.1.2 Auditory characteristics
		1.1.3 Tactile characteristics
		1.1.4. Taste characteristics
		1.1.5. Olfactory characteristics
		1.1.6. Vestibular sensory characteristics
		1.1.7. Proprioceptive sensation characteristics
		1.1.8. Characteristics of pain
		1.1.9. Less active sensory reception
	1.2. Responding to sensory characteristics	1.2.1. Responding to visual characteristics
		1.2.2. Responding to auditory characteristics
		1.2.3. Responding to tactile characteristics
		1.2.4. Responding to taste characteristics
		1.2.5. Responding to olfactory characteristics
		1.2.6. Responding to vestibular sensory characteristics
		1.2.7. Responding to proprioceptive sensation characteristics
1.2.8. Awareness of sensory integration		
1.2.9. Providing care and play activities that promote sensory development		
1.2.10. Providing prior information about receiving stimuli		
1.2.11. Providing support with respect to personal items		
1.3. Observing children's reactions	1.3.1. Observing children's reactions and expressions to support	
	1.3.2. Understanding based on the child's physical signs	
	1.3.3. Considering the child's individual differences	
	1.3.4. Comparing the child with healthy children	
	1.3.5. Understanding the growth and development of the child	
1.4. Direction underlying support	1.4.1. Having insufficient experience	
	1.4.2. Increasing the number of experiences and become accustomed to it	
	1.4.3. Supporters' values and support goals for sensory characteristics	
2. Systematic support for children with PIMD	2.1. Collaboration with others	2.1.1. Collaboration among supporters within the facility
		2.1.2. Collaboration with caregivers
		2.1.3. Collaboration with kindergartens and schools
		2.1.4. Collaboration with therapists
		2.1.5. Collaboration with other support facilities
		2.1.6. Building community relationships
		2.1.7. Connecting to provide support at home
	2.2. Building trusting relationships	2.2.1. Building trusting relationships with children
		2.2.2. Communicating with children
	2.3. Responding to physical symptoms	2.3.1. Preventing seizures
		2.3.2. Responding to body deformities
		2.3.3. Striving for postural stability
		2.3.4. Exercising precautions when using a respirator
		2.3.5. Providing motor function training
		2.3.6. Considering fatigue
		2.3.7. Addressing challenges and responses related to swallowing
2.3.8. Addressing challenges and responses related to tube feeding		
2.4. Planning support	2.4.1. Developing individualised support plan	
	2.4.2. Revising the plan based on an evaluation of the results	
	2.4.3. Creating a group program	
	2.4.4. Making efforts to experience seasonal stimuli and cultural events	

TABLE 1 (Continued)

Themes	Categories	Subcategories
3. Challenges in supporting children with PIMD in after-school daycare centres	3.1. Challenges in responding to sensory characteristics	3.1.1. Challenges in responding to hearing characteristics
		3.1.2. Challenges in responding to olfactory characteristics
		3.1.3. Challenges in responding to vestibular sensory characteristics
		3.1.4. Challenges in responding to proprioceptive sensation characteristics
		3.1.5. Lacking study opportunities pertaining to sensory characteristics
		3.1.6. Not knowing to what extent sensory characteristics should be considered
	3.2. Challenges for supporters	3.2.1. Differences in care based on experience of providing support
		3.2.2. Learning about supporting children with PIMD
		3.2.3. Role differences by supporters' qualifications
		3.2.4. Differences in supporters' viewpoints
		3.2.5. Influence of personality and characteristics with respect to the supporters
		3.2.6. Concerns regarding differences in how supporters perceive themselves and children
		3.2.7. Failure to use appropriate orthotics and tools
	3.3. Challenges at the facility	3.3.1. Facility environmental issues
		3.3.2. Limited time available for support
		3.3.3. Safety considerations
		3.3.4. Considering the role of after-school daycare centre
		3.3.5. Differentiating yourself from other facilities
3.3.6. Difficult to work with school supporters		

Abbreviation: PIMD, profound intellectual and multiple disabilities.

(Table 1). While debriefing the participants, no opinions were expressed on the classification or names of themes.

5.2.1 | Understanding sensory characteristics and devising support

This theme consisted of four categories: (1) sensory characteristics of children with PIMD, (2) responding to sensory characteristics, (3) observing children's reactions and (4) direction underlying support.

Sensory characteristics of children

The participants tried to understand the child's sensory characteristics from various perspectives. Of the seven sensory characteristics, they were particularly interested in visual, auditory and tactile ones. The participants expressed their difficulty in understanding each sensory characteristic.

I have not yet been able to grasp how good a child's eyesight is in terms of children with severe/serious disabilities.

(No. 11, female, nursery teacher)

I feel like they often..., um..., hate the palms of their hands and the soles of their feet.

(No. 18, female, nurse)

In the participants' narratives, the sensory characteristic could be hypersensitivity or hyposensitivity, but in both cases, they were grouped into subcategories as corresponding sensory organ characteristics.

Meanwhile, some participants did not pay attention to olfactory characteristics. The participants also assessed the taste characteristics of children who could take food orally but found this difficult.

I felt like sometimes, in terms of taste, even for children who had a good sense of taste, it would be a bit difficult to have them eat at our center.

(No. 14, female, nurse)

Furthermore, vestibular and proprioceptive sensations were observed during postural retention and activities.

In terms of balance, it might be the case that there are a lot of children who have a more serious disability, so there are quite a lot of children who can't acquire these skills.

(No. 10, female, physiotherapist)

Responding to sensory characteristics

For each sensory characteristic, the participants tried to make children with PIMD as comfortable as possible and promote their development. The participants' statements included a diverse range

TABLE 2 Characteristics of the participants.

No.	Gender	Main occupation	Qualifications	Years ^a
1	Female	Practical nurse	Practical nurse, Nursery teacher	13
2	Female	Child instructor	Certified care worker, Dental hygienist	15
3	Female	Child instructor	Junior and senior high school teacher (Physical education)	2
4	Female	Nurse	Registered nurse, Child development support manager	15
5	Female	Nurse	Registered nurse, Care manager, Consultation support specialist	10
6	Female	Nurse	Registered nurse	4
7	Female	Child development support manager	Registered nurse, Child development support manager, Consultation support specialist, Care manager	16
8	Female	Child instructor	Junior and senior high school teacher (Japanese)	9
9	Male	Administrator	Senior high school teacher (Social studies, Civics)	7
10	Female	Physiotherapist	Physiotherapist, Care manager	6
11	Female	Nursery teacher	Nursery teacher, Certified social worker	0.5
12	Female	Nurse	Registered nurse, Child development support manager	10
13	Female	Nursery teacher	Nursery teacher, Certified care worker	1.5
14	Female	Nurse	Registered nurse	2
15	Female	Administrator and Child development support manager	Registered nurse, Certified nurse specialist in paediatric, Child development support manager, Public health nurse	34
16	Female	Nursery teacher	Nursery teacher	0.5
17	Female	Child instructor	Senior high school teacher (English)	2
18	Female	Nurse	Registered nurse	1.5
19	Male	Physiotherapist	Physiotherapist	7
20	Female	Administrator	Nursery teacher, Certified care worker, Child development support manager	40

^aYears of support for children with PIMD.

of support and play activities, all taking into account the individual characteristics of the children.

After all, there are many children who have a weak reaction—so by approaching [them] from various places, we make them notice or pay attention to us.

(No. 6, female, nurse)

For participants who had experience in supporting children with developmental disabilities, interventions were focused on sensory integration.

Overall, I really feel that the field of vision and tactile sensation are all integrated, yeah.

(No. 1, female, practical nurse)

Observing children's reactions

Additionally, the participants did not miss observing the results of the intervention, such as facial expressions and limb movements specific to each child. The participants sought to identify each child's expressions of joy or discomfort to understand the sensory stimuli that the children had difficulty with, ultimately striving to enhance their quality of life.

Of course, their faces express laughter, their muscles are relaxed, and their eyes are laughing. Of course, they also use their voices to express comfort.

(No. 7, female, child development support manager)

Direction underlying support

Participants felt that sensory hypersensitivity and blunting affected the difficulties in supporting children with PIMD in their daily lives. It was also mentioned that the sensory characteristics might be related to the children's lack of experience with sensory stimulation. The support discussed here is what the participants shared about their consideration of support, with a particular focus on sensory characteristics. This assumption for support emerged because the participants believed it was necessary to pay attention to sensory characteristics.

I think that I lack some experience with children with severe physical and mental disabilities, so I'm getting used to them by doing the same thing over and over again.

(No. 2, female, child instructor)

Well, when they dislike something, I don't force it on them anymore, and there are times when they are

okay with something besides disliking or liking something. I think it's a good thing to reflect on it every day and share information with everyone, such as, 'this child likes this kind of stimulus,' (...) disliking something is one reaction.

(No. 14, female, nurse)

The muscles to be moved are too specific, so they only move in the areas they are good at, so I think we should improve our approach by starting from the center of the body, the core muscles, and work on posture as much as possible, and then sensing the periphery of the body.

(No. 19, male, physiotherapist)

5.2.2 | Systematic support for children with PIMD

This theme consisted of four categories: (1) collaboration with others, (2) building trusting relationships, (3) responding to physical symptoms and (4) planning support.

Collaboration with others

In their support for the children, the participants collaborated with supporters in the same facility along with various other individuals, including family members, schools and therapists.

I talk a little with school teachers, kindergarten teachers, parents, etc. during transportation and share information about what happens during the day. I sometimes show parts that aren't shown at home or tell them about how the child actually likes something. I think that leads to the growth of the child.

(No. 2, female, child instructor)

Building trusting relationships

The participants also emphasised the importance of building trust between the supporter and the child through interpersonal contact. Even though the participants were not family members, as one of the people living with the children, they valued contact and creating relationships with each other.

Actually, interpersonal contact is the most important, so I think it's important to hold their hand.

(No. 4, female, nurse)

Responding to physical symptoms

Children with PIMD have epileptic seizures and scoliosis, and their physical symptoms require careful attention. Therefore, the participants had to pay attention to the physical symptoms along with the sensory characteristics.

Some children are more likely to have seizures due to strong sensory stimuli, so whenever that happened, I was careful when conducting a program or using sounds, loud sounds, and light.

(No. 14, female, nurse)

Planned support

Support was provided according to the individual support plan. The support plan was prepared by incorporating the wishes of family members and was reviewed regularly. This suggests that the support plan encompassed support and planning for the entirety of the children's lives, except for sensory characteristics.

Once every six months, well, there is a time to update the support plan. At that time, I have time to listen to mothers very carefully in the form of monitoring.

(No. 7, female, child development support manager)

5.2.3 | Challenges supporting children with PIMD in after-school daycare centres

This theme consisted of three categories: (1) challenges responding to sensory characteristics, (2) challenges for supporters and (3) challenges at the facility.

Challenges responding to sensory characteristics

In the limited space, the participants found it difficult to pay attention to sensory characteristics such as hearing. Moreover, the lack of opportunities to learn about the sensory characteristics in supporting children with PIMD was recognised as an issue.

Of course, if you live in a group, you can't eliminate all the sounds.

(No. 7, female, child development support manager)

I personally think that I haven't learned properly in a systematic way, so I think there's still a long way to go.

(No. 15, female, administrator and child development support manager)

Challenges for supporters

The supporters' quality of care varied, depending on their qualifications and experience in providing support. The nursery teachers were seeking a division of roles for care, including medical care that could not be performed by anyone other than nurses.

I'm not really a nurse, so I can't get involved in medical practice, so I always think that it's really important to get involved in play or massage.

(No. 13, female, nursery teacher)

The participants were also worried that they could not feel the same way as the children and were often confused about how best to provide support.

However, it's hard for me to feel the same way, so I'm not sure if I'm doing the right thing. Well, I am trying not to be too intense.

(No. 4, female, nurse)

Challenges at the facility

As supporters at an after-school daycare centre, participants were conflicted by the short amount of time they had to support the children from the end of school until the children returned home in the evening. Furthermore, participants considered it important to maintain safety in the hectic support environment, including during pick-up and drop-off. Even when working with physical therapists, the short time children spend in after-school daycare makes it challenging to achieve the outcomes.

When they come to the center, eat a snack, and take a bath, honestly, the time I can be involved with them is 5 min and 10 min per child if I want to do it in an efficient manner.

(No. 19, male, physiotherapist)

Furthermore, to ensure the safety of the children, the participants were alert to any unexpected movements due to sensory oversensitivity.

In terms of how to touch, I try to be as safe as possible, not to be a burden. Many children wear the apparatus, so I always try to hook the apparatus on at least one finger.

(No. 9, male, administrator)

6 | DISCUSSION

This study examined the experiences of supporters regarding the sensory characteristics of children with PIMD in three daycare centres. The strength of this study is that it was conducted in after-school daycare centres that support children living in the community and could integrate the experiences of multiple professionals involved in providing support. The short interview durations for some participants suggest that some supporters take care of children without being adequately aware of the child's sensory characteristics to be able to verbalise them. Furthermore, a subset of

participants encountered challenges when responding to interviews due to their perception of their real-time caregiving experiences as an insufficiently informed perspective on the children's sensory characteristics. At present, however, there is insufficient knowledge about the sensory characteristics and care practices of children with PIMD. The three themes identified in this study are useful for understanding the support necessary for children with PIMD in after-school daycare centres.

The first theme, understanding sensory characteristics and devising support, represents a series of steps in which supporters identify, support and evaluate the sensory characteristics. Although it is difficult to understand the sensory characteristics of children with PIMD who have difficulty expressing themselves while conversing or writing, the participants could interpret the children's reactions and respond to them, similar to the role of the support person in the decision-making process for children with PIMD (Watson et al., 2017). The key aspect of this role is the closeness between the child and the supporter. Research is underway to understand the preferences and emotions of children with PIMD using microswitches and other technologies (Roche et al., 2015). For the time being, it will be important for supporters who have established close relationships with children to understand their sensory characteristics. It is generally easy to ascertain a sensory characteristic when there is a hypersensitive response to a stimulus, but it becomes difficult to properly interpret a subdued response. In this study, the codes were characterised by both hypersensitivity and hyposensitivity, such as vision and hearing. In particular, objectively ascertaining whether the patient can see or hear is challenging. The children in this study may also have deficits in other sensory organs, but the difficulty of testing children with PIMD may prevent supporters and caregivers from properly identifying sensory characteristics. Therefore, the participants observed and cared for the children with PIMD by observing children's various reactions, such as facial expressions and voices, rather than relying on test results alone. It has been suggested that children with PIMD may indicate pleasure or discomfort through changes in head alignment, frowning and yawning (Petitpierre et al., 2022). Even in children with severe disabilities, supporters may be able to interpret responses to sensory stimuli from physiological indicators such as heart rate and behaviours (Lima et al., 2012, 2013). Therefore, supporters need to understand the sensory characteristics of children with PIMD and observe them from various perspectives to properly assess the changes caused by stimuli, which is likely to be the role of after-school daycare centres involving nurses, nursery teachers, physical therapists and other professionals.

Furthermore, the participants believed that these sensory characteristics involved the inexperience of children with PIMD. Infants with PIMD often present with symptoms in the nervous and digestive systems and are managed in the NICU (van Timmeren et al., 2016). Current NICUs are striving to have as little light and sound as possible to reduce stressful stimuli for infants, although it has been noted that less stimulation of language and contact may negatively impact children's development (Jobe, 2014). The participants speculated that children with PIMD who had been hospitalised for a long

period after birth lacked the experience of touching objects with their hands and feet or hearing loud noises, which they attributed to sensory sensitivity. Therefore, repeated stimulation is expected to help such children become accustomed to the stimulation and eliminate any irritability-causing stressors that interfere with their daily functioning. This important insight may help provide better support for children with PIMD.

The second theme, systematic support for children with PIMD, is an important component of support to preserve the life of children with PIMD and maintain the quality of care. This theme is unique in that, along with addressing individualised sensory characteristics parallelly, the necessary support for caring for children with PIMD is implemented as an institutional system. Collaboration among supporters and therapists is important in providing care to support children with PIMD. Qualitative research on adults with PIMD suggests that although complex, collaboration among supporters can improve the quality of health care (Matérne & Holmefur, 2022). For example, parents of children with PIMD may benefit if supporters share their in-depth knowledge, which may further enhance the quality of care (Kruithof et al., 2020). School and nursery teachers are also involved in supporting children living in the community, and after-school daycare centres serve as a link between them and their families. A trusting relationship between the supporters and the children with PIMD is the foundation for providing quality care.

Additionally, paying attention to physical symptoms and complications in supporting children with PIMD is critical. Children with PIMD experience various physical symptoms, including epileptic seizures, scoliosis and gastrointestinal disorders (van Timmeren et al., 2016). As a precondition for observing and responding to sensory characteristics, the participants emphasised the importance of a stable physical condition. The participants were particularly concerned with postural stability with an awareness of the core muscles. Postural management can contribute to the stability of respiratory function and ease of hand and foot activity. It is also a prerequisite for efforts to enhance experiences with sensory stimulation. Head and neck postural management is also associated with dysphagia in children with PIMD (Nakamura et al., 2021). Interventions for improving the physical condition of children with PIMD are complex, but they are needed to help stabilise children's physical condition to address sensory characteristics.

The direction of this type of support was based on an individualised plan, including not only the content of care and prevention of physical symptoms but also the cooperation of the family and school. It is useful to develop individualised support plans to meet the complex needs of children with PIMD (Vlaskamp & van der Putten, 2009). Incorporating sensory sensitivity precautions into the plan will ensure that care is implemented with consistent awareness among supporters. Program managers should be prepared to provide group activities, play and seasonal experiences to reduce their lack of experience. Goals must be determined for the short and long term, and the results should be evaluated (Vlaskamp & van der Putten, 2009). Since Japanese after-school daycare centres for children with PIMD target those aged 0–18 years, they can provide

continued support over a long period. Sensory characteristics do not change abruptly, and continued observation and support are likely to make life easier for children with PIMD.

The last theme was challenges supporting children with PIMD in after-school daycare centres. The participants were aware of the inadequate response to their respective sensory characteristics. Particularly, paying attention to sensory stimuli in the surrounding environment, such as hearing and smell, is difficult. It has been reported that children with PIMD can distinguish between odours (Petitpierre et al., 2022). Therefore, it is important to consider the effect of the smell of other children's stools and vomit in a limited space.

The participants also perceived challenges due to differences in experience and qualifications as supporters. It has been suggested that nurses with more than 10 years of experience in supporting children with PIMD are able to notice minor abnormalities and develop trusting relationships with parents and children, leading to quality care (Sato, 2022). However, supporters with little experience supporting children with PIMD may find it difficult to establish a trusting relationship with children and observe minor changes. Currently, inadequate comprehensive education for supporters of children with PIMD in Japan is available. Guidelines for their respective roles and collaboration in daycare centres, where multiple professionals, including nurses, work together to provide support, need to be developed. Furthermore, one challenge the participants perceived was that the supporters and children perceive stimuli differently. Similarly, it has been suggested that the physiological signals of children with PIMD and the assessments of supporters may differ (Blain-Moraes & Chau, 2012). Obtaining information from multiple indicators and improving awareness among fellow supporters is critical to evaluating the responses of children with difficulty expressing themselves verbally.

Furthermore, the participants felt that the environment of the after-school daycare facility presented some challenges. Environmental challenges for the facility included limited space and support hours. In Japan, after-school daycare services limit the number of daily users to five. Many facilities operate on a small scale, which creates barriers to conducting activities and attending to the sensory characteristics of children with PIMD. Auditory problems and sleep problems in children with PIMD are associated with self-injurious and stereotypical behaviours (Poppes et al., 2016). Therefore, it is important to collaborate with caregivers, school teachers and others involved outside of daycare to obtain information about sensory characteristics and sleeping conditions and create an appropriate environment. It is presumed that the ability to understand and support children's sensory characteristics will strengthen the services provided by the facility and contribute to its stable management.

The participants of this study were recruited from three facilities, each with its unique characteristics and limitations. It is worth acknowledging that conducting interviews within homogeneous groups might introduce bias into the results. Conversely, the study's strength is its comprehensive exploration of the specifics of support from various sources. However, it is imperative that future research

expand its scope to investigate whether these findings hold for heterogeneous groups.

6.1 | Limitations of the work

This study exclusively centred on urban facilities dedicated to children with PIMD and, therefore, could not consider practices in rural settings or facilities that do not specialise in children with PIMD. The study comprised a sample size of 20 participants, with the longest interview lasting only 1 h. Given the small number of physiotherapists working in daycare facilities currently, only two physiotherapists could be recruited. Although there are no clear criteria for determining the sample size in qualitative research (Morse, 2015), the richness of the data in the present study was considered sufficient to clarify the topic of focus. In addition, participants were recruited through a snowball sampling method, which may have limited the diversity of the results (Kirchherr & Charles, 2018). Owing to these limitations, it should be noted that although the results of this study may be useful in future practice, they only serve as preliminary findings in terms of transferability. In particular, the range of participants' years of experience in supporting children with PIMD was wide. While the experience of paediatric nurses and other individuals may have influenced the results, it also reflects the current situation of supporters with different levels of experience since it targets after-school daycare.

An additional challenge was the brevity of interview sessions, which could have been mitigated by allocating ample interview time for richer information exchange. However, the participants' occupation and years of experience also limited what they could talk about. Some participants had never verbalised or found it difficult to verbalise the sensory characteristics of the children. These issues can be addressed in the future by providing preparatory information to participants and employing participatory observation techniques.

Furthermore, ensuring data saturation posed challenges. While two additional participants were interviewed after the data analysis to confirm the absence of new categories, these additional interviews did not account for the influence of participants' facilities and occupations. Future investigations should ensure the rigour of the results by focusing the research on specific occupations.

6.2 | Recommendations for further research

This study is the first step in examining the level of support for the sensory characteristics of children with PIMD in after-school daycare services. The findings may be used to educate supporters and provide opportunities for new support personnel working in after-school daycare services to become more cognizant of children's sensory characteristics when providing care. Further research is needed to evaluate the outcomes of responding to each sensory characteristic. In addition, examining the differences in parents' and supporters' perceptions of children's senses is essential.

7 | CONCLUSION

The study identified the experiences of supporters who provided support for the sensory characteristics of children with PIMD at after-school daycare centres. To understand and respond to children's sensory characteristics, the supporters dealt with physical complications and collaborated with other caregivers. Furthermore, the difficulties in supporting children with sensory characteristics, challenges due to the supporters' characteristics and challenges with the facility's infrastructure were identified. These findings provide an important perspective for supporting children with PIMD.

AUTHOR CONTRIBUTIONS

Yuta Koto: Conceptualisation, Data curation, Formal analysis, Funding acquisition, Investigation, Project administration, Writing – original draft. Machiko Tomozawa: Data curation, Formal analysis, Writing – review & editing. Toshiaki Sato: Formal analysis, Resources, Writing – review & editing. Kazuteru Niinomi: Formal analysis, Methodology, Writing – review & editing. Norio Sakai: Supervision, Writing – review & editing. Toshisaburo Nagai: Supervision, Writing – review & editing.

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CONFLICT OF INTEREST STATEMENT

None of the authors have any conflicts of interest to declare.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

This research was conducted with the approval of the research ethics committee of the Osaka Aoyama University.

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