

## Original Article

# Characteristics of care for individuals with autism spectrum disorder and their families provided by psychiatric visiting nurses

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### Key words

autism spectrum disorder, psychiatric visiting nursing, consideration for disability characteristics, family care

### Abstract

**Aim:** The purpose of this study was to clarify the characteristics of nursing care provided by visiting nurses to individuals with Autism Spectrum Disorder (ASD) and their families, focusing on the characteristics of the disease and the difficulties faced by individuals with ASD, and to consider visiting nursing care for individuals with ASD and their families.

**Method:** Semistructured interviews were conducted with 16 psychiatric visiting nurses, and the results were qualitatively analyzed.

**Results:** Five categories were extracted as visiting nurses' care for individuals with ASD and their families: [providing experience of being understood], [focusing on interpersonal skill acquisition], [promoting family members' positive perceptions of individuals with ASD], [groundworking for relationship building between individuals with ASD and family members], [considering individual variations of RRBs.]

**Conclusion:** The results indicate that visiting nursing care for individuals with ASD and their families requires cyclical nursing care that focuses on the acquisition of experiences of being understood, which leads to a sense of self-worth, and interpersonal skills, nursing care that allows family members to view individuals with ASD in a positive light, and nursing care for building new relationships between family members.

## Introduction

ASD is a disorder characterized by persistent deficits in social communication and social interaction across a range of contexts, as well as patterns of behavior, interests, and activities that are Restricted and Repetitive Behaviors (RRBs). Persistent deficits in social communication and interaction include abnormalities in eye contact and body language or deficits in understanding and use of gestures, a total lack of facial expressions and nonverbal communication. RRBs refers to stereotyped or repetitive motor movements, highly restricted, fixated interests, and hyperactivity to sensory input (e.g., specific smells, textures, sounds.) Saito et al. reported an ASD prevalence of 3.22%<sup>1)</sup> whereas Shinoyama et al. reported a cumulative incidence of 2.75% in 5-year-old children in Japan<sup>2)</sup>. Meanwhile, the US Centers for Disease Control and Prevention reported an ASD prevalence of 3.42% from 2021 to 2022<sup>3)</sup>. It has also been reported that the prevalence of developmental disorders is on the rise<sup>4)</sup>. From the above reports, it is clear that society needs to support individuals with ASD, and nurses must play their role in providing that support.

Regarding nursing practice by visiting nurses for individuals with ASD, Nakajima et al.<sup>5)</sup> reported that the following support was provided based on “strength support” and “hope and decision-making support” including “support for understanding and accepting their characteristics” “lifestyle support according to the characteristics of ASD” “support for improving and maintaining interpersonal skills” “support for connecting with the local community” “stress management for individuals with ASD” “support for pharmacotherapy” “emergency support for socially deviant behavior” “support for psychological recovery and autonomy for families” “collaboration with multiple professions” and “structured visiting nursing support”. In addition, Nakajima et al.<sup>6)</sup> reported on a subsequent survey on the level of nursing practice by visiting nurses for individuals with ASD and listed “easy-to-understand communication” and “knowing a comfortable distance and building a relationship” as the types of support

provided each time. Ohashi et al.<sup>7)</sup> also focused on strengths of individuals with ASD and reported that accepting support from those around them and making use of their special skills are strengths. Furthermore, there have been reports overseas on the relationship between respite care and stress for caregivers of children with ASD<sup>8)</sup> stated that the use of respite care may reduce stress for caregivers, and reported that healthcare providers must recognize the importance of tailoring respite care services to the unique family needs. Danna also reported the importance of healthcare professionals understanding the characteristics of children with ASD and providing educational support tailored to the needs of patients and their families<sup>9)</sup>, and Daryl conducted a survey of parents of children with ASD and reported that these caregivers had healthy self-esteem, although they reported somewhat lower marital happiness, family cohesion and family adaptability than did norm groups, emphasizing the need for support programs that target not only family relationships but also children with ASD and their behavior<sup>10)</sup>. The above previous research has revealed that support utilizes the strengths of individuals with ASD, focuses on interpersonal relationships, and aims to reduce the caregiving and mental burden on families.

In order to find more effective and specific methods for nursing care provided by visiting nurses for individuals with ASD, we believe it is necessary to clarify nursing care that is specific to ASD. For the above reasons, this study targeted visiting nurses working at visiting nursing stations specializing in psychiatry, and investigated the visiting nursing care for individuals with ASD provided by highly specialized visiting nurses. The purpose of this study was to clarify the characteristics of nursing care provided by visiting nurses to individuals with ASD and their families, focusing on the characteristics of the disease and the difficulties faced by individuals with ASD, and to consider visiting nursing care for individuals with ASD and their families.

## Methods

### 1. Research design

This study followed a qualitative descriptive design.

### 2. Subjects

The subjects were psychiatric visiting nurses who were providing home nursing care to individuals with ASD by the time of the interview and who had experienced carrying out visiting nursing practice several times, and who the manager of the visiting nurse station judged to be able to speak adequately about providing visiting nursing care for individuals with ASD.

### 3. Data collection method

In this study, subjects were recruited by having the manager of a visiting nurse station specializing in psychiatry, who had previously cooperated with the author's research, introduce them to other managers of visiting nurse stations specializing in psychiatry. The purpose and intent of the study were explained to the managers of the visiting nursing stations in writing and verbally. After giving their consent, they selected the subjects to be included. Subsequently, the selected subjects were given written and verbal explanations of the research. After obtaining their consent for study participation, a 1-h semistructured interview was conducted in a place where privacy could be maintained. The subjects were asked to recall the visiting nursing scenes for individuals with ASD that they had practiced up to the time of the interview, and interviews were conducted what kind of nursing care they provide, what they keep in mind when providing nursing care, and the difficulties they faced when providing nursing care. The interview was recorded with the consent of the subjects. Data collection and analysis were conducted, and the former was terminated when no new data was obtained. The data collection period was from August to December 2022.

### 4. Data analysis method

The verbatim transcripts were carefully read, and the parts related to the purpose of this study were extracted and coded using the words of the subjects. The similarities and differences of the codes were examined, and codes were

categorized and subcategorized while increasing the level of abstraction. We documented the relationships between the subcategories and categories, and we created a structure diagram.

The data analysis was supervised by a qualitative research expert, and while returning to the verbatim transcripts to reviewed and revised the analysis content and ensured the veracity of the results. In addition, at the end of the analysis, we checked the results with the subjects and made any corrections to the results that were pointed out in order to ensure rigor.

### 5. Ethical considerations

We explained to the subjects in writing that the study participation was voluntary, there would be no disadvantage in any case if they refused or discontinued participation, maximum consideration would be given to the human rights of the subjects and the protection of their privacy, the data would be anonymized, the data obtained would be securely stored, and the data would be destroyed immediately after the study completion. We obtained the subjects' signed consent. The interviews were conducted in a place within the facility where privacy could be maintained. The study protocol was approved by the ethics committee of the Ishikawa Prefectural Nursing University (approval number: 2022-130).

## Results

### 1. Overview of the study participants

The study cohort consisted of 16 visiting nurses, including 8 from Prefecture A and 4 each from Prefectures B and C.

Among the study participants, eight were men and eight were women, and they were aged between 30 and 50 years. Their average years of experience as psychiatric visiting nurse was 6.25 (range, 1–23), and their average years of experience in a psychiatric ward was 12.1 (range, 0–30).

2. Characteristics of care for individuals with autism spectrum disorder provided by psychiatric visiting nurses (Table 1)

Visiting nurse practice for individuals with ASD by psychiatric visiting nurses was divided into five categories and eighteen subcategories.

Table 1 Characteristics of care for individuals with Autism Spectrum Disorder and their families provided by psychiatric visiting nurses

Theme	Categories	Subcategories
Influencing the individual	Providing experience of being understood	Empathizing and accompaniment to the difficulties in life (due to the characteristics of the disability)
		Capturing the strengths of individuals with ASD hidden behind negative self-understanding
		Maintaining an objective perspective to achieve the set goals of visiting nursing care
		Demonstrating interest and concern with emphatic responses
	Focusing on interpersonal skill acquisition	Sharing the purpose of visiting nursing based on needs
		Building equal relationships using the situation in which care can be provided in the home of individuals with ASD
		Trying to elicit the needs and feeling of individuals with ASD by communicating with them in ways that are tailored to their characteristics
		Waiting for individuals with ASD to express their feelings and talk to them focusing on their emotions in order to verbalize them
		Encouraging awareness of the other person's perspective
		Attempting to solve problems collaboratively, not in a directive or educational way
		Waiting for a change in behavior and giving a push at the right time
		Being careful not to cause threats or discomfort while searching for the boundaries that would cause them to refuse contact
	Considering individual variations of RRBs	Visiting nurses try to become familiar with the usual atmosphere in the home of individuals with ASD
Influencing the family	Groundworking for relationship building between individuals with ASD and family	Relieving tense family relationships
		Appreciating the efforts and hardships of the family members
		Respecting the current state of the family
	Promoting family members' positive perceptions of individuals with ASD	Not missing small positive changes (in the individual with ASD) and communicating them to the family Explaining the characteristics of the disability and suggesting specific communication methods to the family

The relationships between categories and sub-categories are shown in the structural diagram (Figure1). Each category is explained below. Categories are indicated with [ ], subcategories with << >>, and representative stories with “ ”. The contents in the parentheses have been added to make the meaning easier to understand.

In visiting nursing care for individuals with ASD, visiting nurses provided visiting care so that individuals with ASD could experience [providing experience of being understood], which is composed of <<empathizing and accompaniment to the difficulties in life (due to the characteristics of the disability)>>, <<capturing the strengths of individuals with ASD hidden behind negative self-understanding>>, <<maintaining an objective perspective to achieve the set goals of visiting nursing care>>, <<demonstrating interest and concern with emphatic responses>>. In addition, visiting nurses attempted to <<attempting to solve problems collaboratively, not in a directive or educational way>> through <<sharing the purpose of visiting nursing based on needs>>. This attempt was influenced by <<building equal relationships

using the situation in which care can be provided in the home of individuals with ASD>>, <<trying to elicit the needs and feeling of individuals with ASD by communicating with them in ways that are tailored to their characteristics>>, <<waiting for individuals with ASD to express their feelings and talk to them focusing on their emotions in order to verbalize them>>, <<encouraging awareness of the other person's perspective>>. And visiting nurses are <<waiting for a change in behavior and giving a push at the right time>> for individuals with ASD and then returning to <<sharing the purpose of visiting nursing based on needs>>, a cyclical visiting nursing care was practiced as [focusing on interpersonal skill acquisition]. In addition, visiting nursing provided [considering individual variations of (RRBs)], which consisted of <<being careful not to cause threats or discomfort while searching for the boundaries that would cause them to refuse contact>> and <<visiting nurses try to become familiar with the usual atmosphere in the home of individuals with ASD>> In providing home nursing care to the families of individuals with ASD, the

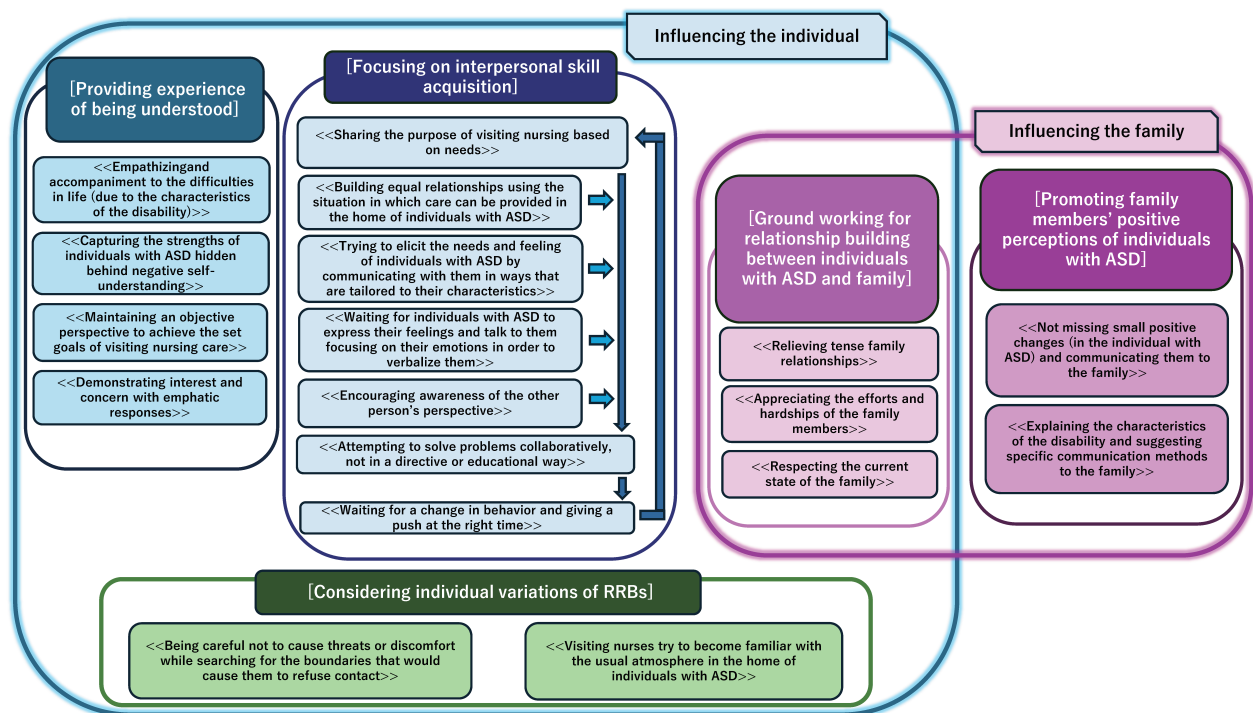


Figure 1 The structural diagram of nursing care provided by psychiatric visiting nurses for individuals with ASD and their family

visiting nurses provided feedback to the family about the changes in the individual with ASD by «not missing small positive changes (in the individual with ASD) and communicating them to the family», explained the characteristics of the ASD by «explaining the characteristics of the disability and suggesting specific communication methods to the family», and shifted family members' perceptions of individuals with ASD to a more positive one. In addition, the visiting nurses improved the relationships between individuals with ASD and their family members by «relieving tense family relationships», «appreciating the efforts and hardships of the family members», and «respecting the current state of the family», and practiced [groundworking for relationship building between individuals with ASD and family members].

1) [Providing experience of being understood]

This category focuses on the difficulties faced by individuals with ASD owing to their disability and the strengths that they have acquired despite such difficulties. The visiting nurses utilized an expert's objective perspective and active listening. These care are nursing care provided by visiting nurses that led to the experience of individuals with ASD being understood by others. The four subcategories are «empathizing and accompaniment to the difficulties in life (due to the characteristics of the disability)», «capturing the strengths of individuals with ASD hidden behind negative self-understanding», «maintaining an objective perspective to achieve the set goals of visiting nursing care», and «demonstrating interest and concern with emphatic responses».

«Empathizing and accompaniment to the difficulties in life (due to the characteristics of the disability)»

The visiting nurses listened to the individuals with ASD talk about their past failures and their current difficulties in life, empathized with their difficulties in life, and supported them rather than criticizing or intervening.

“I can somehow tell that the clients have not had many successful experiences. The clients of-

ten have negative experiences in their daily lives, so they lack confidence.” “I wonder why we have to give guidance to people who are struggling with life. I think visiting nurses should be there to accompany people who have had difficult experiences and have done things up until now. When something happens, we solve it together.”

«Capturing the strengths of individuals with ASD hidden behind negative self-understanding»

The visiting nurses focused on the fact that individuals with ASD have come to have a negative self-understanding as a result of their repeated failures. The visiting nurses said that it is important to try to discover the small positive aspects of individuals with ASD that have not been focused on before and that the individuals themselves have not noticed, and to incorporate these small positive aspects into support for individuals with ASD as their strengths.

“I believe that individuals with ASD have had experiences of failure in relationships with others in various places such as hospitals and schools, and that the focus has been on what they can't do, without their good points being recognized. Therefore, I try to find the good points of individuals with ASD as much as possible. I think it is important to have the perspective of looking for their strengths.”

“I always try to find something positive to praise about the individuals with ASD, and praise them for everything.”

«Maintaining an objective perspective to achieve the set goals of visiting nursing care»

The visiting nurses wanted to provide nursing care that met the needs of individuals with ASD, by resolving the difficulties individuals with ASD feel in their daily lives and fulfilling their hopes for the future, as people who understand individuals with ASD. However, the visiting nurses said that in order to achieve the goals of visiting nursing care, it is necessary to objectively assess the symptoms of individuals with ASD and the environment in which they live.

“I try to have the attitude of understanding (towards the individual with ASD), but I also try to be conscious of keeping that (objective) per-



spective somewhere.”

“The more I empathize with the users, the more I tend to neglect to be objective and narrow my perspective on symptoms and environmental factors, so I try to be careful not to do that.”

《Demonstrating interest and concern with emphatic responses》

The visiting nurse listened carefully to what the individuals with ASD were trying hard to speak and responded in a way that seemed excessive. The visiting nurse said that his intention in doing so was to convey that the individuals with ASD was different from the reactions they had received from people around them, and to clearly convey his interest and concern for them.

“When I listen to individuals with ASD talk about their hobbies, if I have 100% energy, I listen to them with the intention of using up all 100% of it. If I don't do that, individuals with ASD will notice that I'm not putting in enough effort. If I responds with “Oh, I see”, individuals with ASD will think that visiting nurses are not interested in them. So I respond with all my might, like “Wow, that awesome!”

2) [Focusing on interpersonal skill acquisition]

This category involves visiting nurses grasping the characteristics of communication with individuals with ASD and, within an equal relationship, sharing the purpose of visiting nursing based on the needs of such individuals, encouraging awareness, helping them verbalize their thoughts, and working together to solve problems. This nursing care was provided to individuals with ASD as circulatory nursing care. It consists of seven subcategories: 《sharing the purpose of visiting nursing based on needs》, 《building equal relationships using the situation in which care can be provided in the home of individuals with ASD》, 《trying to elicit the needs and feeling of individuals with ASD by communicating with them in ways that are tailored to their characteristics》, 《waiting for individuals with ASD to express their feelings and talk to them focusing on their emotions in order to verbalize them》, 《encouraging awareness

of the other person's perspective》, 《attempting to solve problems collaboratively, not in a directive or educational way》, and 《waiting for a change in behavior and giving a push at the right time》.

《Sharing the purpose of visiting nursing based on needs》

Visiting nurses inform individuals with ASD of the purpose of visiting nursing by discussing what they want to achieve in the future and the circumstances under which they are unable to achieve their goals.

“Rather than suddenly asking individuals with ASD, “What is the difficulty in living?”, I ask questions like, “How do you want to design your life from now on?” I try to ask questions like, “Is there anything you want to do?” or listen to stories of individuals with ASD such as, “Even if there is something I (individuals with ASD) want to do, it's hard to do it.” Then I try to align that with the purpose of the visit nurse.”

《Building equal relationships using the situation in which care can be provided in the home of individuals with ASD》

Visiting nurses try to build an equal relationship with individuals with ASD, not one in which they provide guidance or education but in the home environment where these individuals can relax and talk.

“In a hospital, it's hard to speak ASD's true feelings, but in their living environment, it's their home. In the home, surprisingly, people talk about all sorts of things, like, ‘Is it okay to say this?’ Rather than a relationship between medical professional and client, we can talk as truly equals.”

“I always try to build a relationship with individuals with ASD so that they do not feel constrained. I think that the most important thing in visiting nursing is to be on an equal footing. That means seeing things from the same perspective as people with autism spectrum disorder.”

《Trying to elicit the needs and feeling of individuals with ASD by communicating with them in ways that are tailored to their characteristics》

Despite the communication disorders in indi-

viduals with ASD, visiting nurses try to get them to express their needs and feelings, and while trying multiple approaches, they seek for communication methods that suit their characteristics.

“We find clues about how to interact with them to get a sense of warmth, to make interactions easier, and to get them to talk.”

《Waiting for individuals with ASD to express their feelings and talk to them focusing on their emotions in order to verbalize them》

Visiting nurses understand that individuals with ASD have communication disorders and are not good at appropriately conveying their thoughts and feelings. They also understand the pain and frustration felt by these individuals owing to their inability to communicate and help them express their thoughts in words.

“I think that asking individuals with ASD to express their thoughts is like forcing them to do so. I don't think visiting nurses need to force them to express their thoughts too much. If individuals with ASD want to talk, they will talk about their thoughts.”

“I would speak on their behalf, asking questions like ‘What do you think if we do it like this?’ or ‘Isn't it what you were feeling?’ or ‘You're doing it this way because you feel this way, right?’”

《Encouraging awareness of the other person's perspective》

Visiting nurses recognize the gap in awareness of problems between individuals with ASD and those around them. Rather than directly pointing out the problem to the person with ASD, they encourage awareness through discussion and try to reduce the difficulties these people face in their daily lives.

“I think there is a gap between what the person thinks and what those around them think. By visiting nurses, they can pick up on things that the person might not notice on their own and make suggestions, little by little, and think together about ways to deal with the situation, in order to make life even a little less difficult.”

《Attempting to solve problems collaboratively, not in a directive or educational way》

Visiting nurses practice providing care to individuals with ASD who have difficulty living rather than taking a directive approach. In the process of providing care, they discuss how they would solve problems caused by the disability together.

“Even if I just tell them what is supposed to be correct, such as being instructional or educational, individuals with ASD will not be convinced. So I think it's like thinking about it together.”

《Waiting for changes in behavior and giving a push at the right time》

Visiting nurses understood that simply proceeding with nursing practice unilaterally would not lead to a good relationship with individuals with ASD or to adaptive behavior in them, and waited for individuals with ASD to change, even if it took more time. In addition, if the individuals with ASD seemed confused by the change, visiting nurses did nursing practices that would encourage the individuals with ASD at the right time.

“When visiting nurses visit individuals with ASD with the intention of intervening about this, this, and that, they are unable to take time to interact with them. This does not work.”

“Some users just want a nudge to meet their needs, without forcing them to do so.”

3) [Promoting family members' positive perceptions of individuals with ASD]

This category focuses on nursing care in which visiting nurses communicate small improvements in the individual with ASD to their family and explain the characteristics of the disability, helping the family view the individual in a positive light. It has two subcategories: 《not missing small positive changes (in the individual with ASD) and communicating them to the family》 and 《explaining the characteristics of the disability and suggesting specific communication to the family》

《Not missing small positive changes (in the individual with ASD) and communicating them to the family》

Visiting nurses care family member's impatience by informing them of the time it takes for



the individuals with ASD to change and by informing them of the small changes in the individuals with ASD that the family members may not notice.

“Family members are often impatient because the results of interventions for individuals with ASD are not immediately apparent or because the individual with ASD does not change right away. In response to the families' concerns, visiting nurses explain that it takes time for the characteristics and behavior of individuals with ASD to change. In addition, we (visiting nurse) believe it is important to provide detailed explanations of the changes in the individual with ASD.”

《Explaining the characteristics of the disability and suggesting specific communication methods to the family》

Visiting nurses explained that they would support family members understand the behavior of individuals with ASD by explaining the characteristics of ASD from a medical perspective, and if asked for advice from the family members, visiting nurses would provide specific ways to deal with individuals with ASD.

“For those who have a distance between individuals with ASD and their family members, I think there is a misunderstanding or miscommunication. In such cases, the visiting nurse will explain the characteristics of individuals with ASD from a medical perspective to the family members. By doing so, the misunderstanding can be corrected.”

“I try to give specific advice based on specific complaints. For example, I might say, ‘When this happens, how about you (individual with ASD) phrase it this way?’”

4) [Groundworking for relationship building between individuals with ASD and family members]

This category unraveled the tangled family relationships due to the disability characteristics of people with ASD and encouraged the families by praising their efforts. The nursing care also respected the current family relationships and sought to use it as a foundation for building new relationships. This category has three subcategories:

《relieving tense family relationships》, 《appreciating the efforts and hardships of the family members》, and 《respecting the current state of the family》.

《Relieving tense family relationships》

Visiting nurses observe the relationships between the person with ASD and their family members and mediate communication between them.

“Sometimes the mother cannot accept the characteristics of the disorder and becomes too emotional, which causes individuals with ASD to not talk. In such cases, the visiting nurse intervenes with the family first.”

《Appreciating the efforts and hardships of the family members》

Visiting nurses acknowledge that the family members care the person with ASD and express an empathetic attitude to be close to the family members.

“We need to be close to the family members as well. We may not be able to empathize with them, but we listen to their stories and say that it must have been difficult.”

《Respecting the current state of the family》

Visiting nurses understand that the relationship between the person with ASD and the family members was built as they lived together, and they respect and accept the relationship rather than denying it or asking for change.

“There are some parts where the mother's thoughts are reflected directly in the son, so it is undeniable that she may think, ‘Huh?’ I can't point out the values of this family, so I'll just accept it for now.”

5) [Considering individual variations of RRBs]

This category involves nursing care that blends into the atmosphere of the home where individuals with ASD live while considering the characteristics of individuals with ASD, such as sensitivity to smell and aversion to change, so that they would not refuse home visits. It consists of two subcategories: 《being careful not to cause threats or discomfort while searching for the boundaries that would cause them to refuse contact》 and 《visiting nurses try to become

familiar with the usual atmosphere in the home of individuals with ASD》.

《Being careful not to cause threats or discomfort while searching for the boundaries that would cause them to refuse contact》

Visiting nurses understand that individuals with ASD may refuse to accept visiting nurse care due to their highly individualized disability characteristics, and they carefully observe where the boundaries are when communicating with them and try not to cross these boundaries.

“There are definitely things that are okay and not okay in the relationship between visiting nurse and the user at this point in time, so I'm thinking about what the things are that are not okay. I want to quickly find out what the user doesn't like, and what are the things that I don't want to be touched on in the current relationship between the visiting nurse and the user.”

《Visiting nurses try to become familiar with the usual atmosphere in the home of individuals with ASD》

Individuals with ASD take longer to get used to nursing care in the private space of their own homes than persons with other mental illness. The visiting nurses talked about how they tried to blend in the home atmosphere that individuals with ASD and their family had created so that individuals with ASD would not feel uncomfortable with the visiting nurses' presence in the home.

“Keeping in mind that it will take longer than you think (to get people to accept visiting nurses), the first thing to do is to get used to the environment. I think the first thing to do is to get used to the atmosphere, that atmosphere.”

## Discussion

1. Acquisition of new experiences for individuals with ASD through nursing care by visiting nurses

ASD is characterized by a limited and repetitive pattern of behavior, interests, or activities. This includes strong distress over small changes and hypersensitivity to sensory stimuli, which affect their daily lives. 《empathizing and accompaniment for the difficulty of living (due to the

characteristics of the disability)》 allows individuals with ASD, who have difficulty living and understanding the people around them, to connect with others. We believe that this would lead to the healing of their wounded hearts through interaction with visiting nurses. Nakajima et al.<sup>8)</sup> reported that there are understanding and acceptance of ASD as a visiting nursing care for individuals with ASD. But this study revealed that visiting nurse care focused on the hard to live individuals with ASD face. This provides a new method of visiting nurse care. The experience of healing the difficulties that individuals with ASD have builds a relationship between the visiting nurse and the individual with ASD, which is thought to lead to better nursing practice. Meanwhile, 《demonstrating interest and concern with emphatic responses》 to individuals with ASD allows them to feel a sense of acceptance and understanding. As reported by Honda<sup>11)</sup> and Takiyoshi et al.<sup>12)</sup>, these individuals are prone to self-denial due to the failures they experience because of their disability. Active listening practiced by visiting nurses may help alleviate the feeling of self-denial that these individuals are prone to. Visiting nurses should 《capturing the strengths of individuals with ASD hidden behind negative self-understanding》 of individuals with ASD. As there have been several reports on the strength of individuals with ASD<sup>13-15)</sup>, strength is an important perspective for caring individuals with ASD. Understanding and using the strengths of these individuals are believed to increase their sense of self-worth and reduce their sense of self-denial. An increase in their sense of self-worth can be expected to have a positive impact on their social skills and motivate them to participate in activities. We believe that 《capturing the strengths of individuals with ASD hidden behind negative self-understanding》 is an important nursing practice as reported in previous studies. Furthermore, the perception of individuals with ASD as professionals, namely, 《maintaining an objective perspective to achieve the set goals of visiting nursing care》 leads to effective nursing care.

2. Circulatory nursing care for acquiring in-

terpersonal skills

Due to persistent deficits in social communication and interpersonal interactions, individuals with ASD have difficulty initiating and responding to social interactions. This leads to difficulties in establishing relationships with others and behaving appropriately in situations. Furthermore, this can lead to individuals with ASD having little understanding of their own situation and not noticing issues occurring between them and the people around them. In this study, «sharing the purpose of visiting nursing based on needs» was conducted. Regarding home nursing care for people with mental disabilities living in the community, Endo<sup>16)</sup> reported that confirming the client's wishes regarding home nursing care and elucidating the purpose and role of home nursing care are important to respect the client's autonomy and care their self-determination. Nakajima et al.<sup>5)</sup> also reported that visiting nursing care for individuals with ASD included support for decision-making and the improvement and maintenance of interpersonal skills. What was newly discovered in this study was that the nursing practice of [focusing on interpersonal skill acquisition], which began with «sharing the purpose of visiting nursing based on needs» was carried out in a cyclical manner. As mentioned above, a characteristic of ASD is the persistent deficiency in social communication and interpersonal interactions. Therefore, nursing care should not be limited to one-way nursing care for the issues faced by individuals with ASD, but rather individuals with ASD need to learn interpersonal skills through various situations. Repeated nursing care for individuals with ASD will be more effective. This cyclical nursing care was influenced by «building equal relationships using the situation in which care can be provided in the home of individuals with ASD». This is a feature that has not been reported in previous studies, and we believe that the fact that nursing care was provided in the privacy of the home for individuals with ASD who have difficulty building relationships with others is an important perspective. We believe that this prevented nursing care from becoming unreasonable,

with medical professionals taking the lead, and led to nursing support that emphasized the relationship between individuals with ASD and nurses. In addition, owing to the characteristics of the disorder, individuals with ASD have difficulty communicating smoothly with others in their daily lives. Nakajima et al.<sup>5)</sup> reported that visiting nurses provide care that considers the communication and individuality of individuals with ASD and that it is important to consider communication when supporting them. We believe that the subjects of this study were able to provide effective nursing care by «trying to elicit the needs and feeling of individuals with ASD by communicating with them in ways that are tailored to their characteristics».

As the focus of attention shifts to interpersonal skills between visiting nurses and individuals with ASD, the visiting nurses in this study «waiting for individuals with ASD to express their feelings and talk to them focusing on their emotions in order to verbalize them» was a feature not found in previous studies. Individuals with ASD have difficulty expressing their thoughts to others owing to their communication disorders, but as they said, they themselves are troubled by their inability to express themselves. If visiting nurses do not wait for verbal expressions from patients with ASD, do not support their verbal expressions, and instead suggest the patient to express themselves or provide visiting nurses' predictive care, the patient with ASD may feel uncomfortable in the interpersonal relationship and may lose trust in the visiting nurse. Based on these findings, we believe that the nursing care taken by the visiting nurses in this study, «waiting for individuals with ASD to express their feelings and talk to them focusing on their emotions in order to verbalize them» was effective nursing care that provided a sense of security to individuals with ASD. The visiting nurse also «encourages awareness of the other person's perspective». This encourages awareness among individuals with ASD who are unable to imagine the feelings of others owing to the aforementioned difficulty in developing relationships with others. Nevertheless, they have

the potential to establish relationships with others by being able to communicate their feelings clearly and being aware of their feelings. Visiting nurses expect these individuals to realize their lack of interpersonal skills and recognize it as their own issue. We believe that nursing care that supports individuals with ASD to gain perspective on interpersonal skills and suggests them to pay attention to their own thoughts is the nursing practice that makes individuals with ASD aware of the gaps that exist between individuals with ASD and the people they interact with.

We believe that visiting nurses provide nursing care by eliminating any gaps that may have arisen between the patient and the people in their care, «attempting to solve problems collaboratively, not in a directive or educational way» and then «waiting for a change in behavior and giving a push at the right time». Visiting nurses do not provide one-sided care for the problems that become clear by filling the gaps but instead think of solutions together with the individual. This care is not aimed solely at solving problems but also at improving the problem-solving abilities of individuals with ASD. It is also believed that waiting for changes in individuals with ASD and slowly interacting with them provides them with a sense of security. With this sense of security as a background, timely care leads to successful experiences for these individuals, and even if they failed, they did not increase self-denial, but leading to cyclical nursing care from the visiting nurses aimed at acquiring interpersonal skills.

3. Adjustment of the environment, which is the basis of family nursing and all interactions by visiting nurses

The visiting nurses are «not missing small positive changes (in the individual with ASD) and communicating them to the family not missing small positive changes in the ASD person and communicating them to the family» for family members. Kawada<sup>17)</sup> reported that support for the families of the person receiving psychiatric visiting nursing includes disease education, education on how to interact with the

family, and acceptance of their suffering. This study clarified a new perspective on family support in psychiatric home nursing care, which differs from previous home nursing care in terms of educational support for families and acceptance of family suffering. Because they live with individuals with ASD, family members are unable to see the casual efforts and small improvements made by these individuals and may become impatient with the lack of improvement and demand more effort from them. We believe that the visiting nurses were putting into practice [promoting family members' positive perceptions of individuals with ASD] by informing families of small changes in individuals with ASD and contributed to obtaining ongoing support for individuals with ASD from their families. «Explaining the characteristics of the disability and suggesting specific communication methods to the family» increase understanding of the characteristics of the disability, making it easier to notice small positive changes in the ASD individual, and nursing care that led to the practice of appropriate communication methods for families that can promote change in the ASD individual. In this way, the visiting nurse does not simply advise the family members to view the ASD individual in a positive light but rather provide active nursing care that enables the family members themselves to do such. We believe that this nursing practice also contributed to [promoting family members' positive perceptions of individuals with ASD]. The visiting nurse also lays the foundation for building trusting relationships between individuals with ASD and their family members. In the field of psychiatry, as reported by Nakai et al.<sup>18)</sup>, there is an increasing number of cases in which emphasis is placed on family care. Specific examples of family care include empowering the family<sup>19)</sup> and supporting and coordinating with the family<sup>20)</sup>. The types of family care that families seek include psychological support, educational support, health management for the family, adjustment of family relationships, and collaboration with multiple professions<sup>21)</sup>. The care for family relationships reported in previous studies include «relieving

tense family relationships》 and 《appreciating the efforts and hardships of the family members》, which are mental care and empowerment for the family. These are home nursing practices common not only to ASD but also to the psychiatric field in general.

What was newly discovered in this study was that the nursing practice of 《respecting the current state of the family》. This means that visiting nurses choose to build a new relationship based on the relationship that was formed as the individual with ASD and their family overcame various obstacles rather than correcting an objectively inappropriate relationship into an appropriate one. As reported by Kuzushima et al.<sup>22)</sup>, dealing with family is a difficulty faced by psychiatric visiting nurses; thus, family care is a nursing practice that involves difficulties. Nurses want to improve the condition of the subject, but this may lead to difficulties in providing family care. Moreover, the perspective of first accepting the current family relationships that may be distorted, such as 《respecting the current state of the family》 is thought to be new and important when providing visiting nursing care to individuals with ASD.

Visiting nurses provided nursing care to individuals with ASD taking into [considering individual variations of RRBs]. There have been reports of refusals of visits in the psychiatric field owing to incompatibility with the visiting nurse or not feeling the need for visiting care<sup>23-25)</sup>. As visiting care is provided at the client's home, nursing practice cannot be carried out if the visit is refused. There are similar refusals for visiting care for individuals with ASD. However, the strong distress caused by small changes due to the limited and repetitive patterns of behavior, interests, or activities, which are among the characteristics of ASD, may cause the client to refuse the visit to their home. In this study, we believed that the visiting nurses tried to 《visiting nurses try to become familiar with the usual atmosphere in the home of individuals with ASD》 so as not to make individuals with ASD feel uncomfortable about having a visiting nurse in their home. In addition, visiting nurses carefully

work to prevent the individuals with ASD from refusing visiting care once they have accepted, by 《being careful not to cause threats or discomfort while searching for the boundaries that would cause them to refuse contact》. It is thought that this relationship led to the implementation of continuous visiting care.

#### 4. Limitations and challenges of the study

This study focuses on the nursing practice of visiting nurses for individuals with ASD. The results were obtained from a survey conducted on 16 visiting nurses in three facilities in three prefectures. The nursing practices may differ due to regional characteristics and the variations in the experience of the visiting nurses. However, given the lack of previous research, we believe that the results of this study can provide certain suggestions for home nursing practice for individuals with ASD. In the future, it will be necessary to conduct more detailed research on visiting nursing practice for individuals with ASD through surveys that take into account regional characteristics as well as large-scale quantitative surveys.

### Conclusions

The visiting nursing care for individuals with ASD and their families newly obtained in this study was visiting nursing care that focused on the difficulties of living with ASD, cyclical visiting nursing care aimed at acquiring interpersonal skills, visiting nursing care guided the family to a positive perception by conveying small changes in the individual and respecting the current state of the family before intervening in the relationship between the individual with ASD and their family. In addition, it is said to be difficult to provide visiting nursing care to relationships between individuals with ASD and their families, but it is expected that the respecting the current state of the family approach revealed in this study will become an important perspective for intervening in difficult family relationships.

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### Conflict of interest

There are no conflicts of interest to disclose in this study.

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# 精神科に特化した訪問看護ステーションで勤務する訪問看護師が行う 自閉スペクトラム症者とその家族への看護支援の特徴

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## キーワード

自閉スペクトラム症, 精神科訪問看護, 障害特性への配慮, 家族支援

## 要 旨

- 【目的】 本研究は、自閉スペクトラム症（ASD）の疾患特性と当事者が抱える困難に焦点を当て、訪問看護師によるASD当事者とその家族への看護の特徴を明らかにし、ASD当事者とその家族への訪問看護のあり方を考えることを目的とした。
- 【方法】 精神科訪問看護師16名を対象に半構造化面接を実施し、質的に分析した。
- 【結果】 ASDの人とその家族に対する訪問看護ケアとして、「理解されているという体験を提供する」「対人スキルの獲得に重点を置く」「家族のASDの人に対する肯定的な認識を促す」「ASDの人と家族との関係構築の土台作り」「反復的・限定的な行動の個別性を考慮する」の5つのカテゴリーが抽出された。
- 【結論】 ASDの人とその家族に対する訪問看護ケアには、「理解されているという体験の獲得とそれに伴う自己価値感や対人スキルの獲得に重点を置いた循環的な看護ケア」「家族がASDの人を肯定的に捉えられるような看護ケア」「家族間の新たな関係構築のための看護ケア」が必要であることが示唆された。