

# Congruent Care for Children with Suspected Autism Spectrum Disorders and their Families in Japan: Qualitative Descriptive Research

Sugako TAMURA, Kimiko SUYAMA

Academic Assembly, Faculty of Medicine, University of Toyama

## Abstract

This study aimed to explore the nursing practices of public health nurses who provide home health nursing care for children with suspected Autism Spectrum Disorders and their parents, in order to clarify the characteristics of care that were congruent with family life. Six cases of nursing practices performed by six public health nurses were examined. Six nurses were interviewed about their intentions and actions in their home health nursing practice and other health support activities. In total, 302 “intentions” and 1,575 “actions” for children and their parents were recorded. Data analysis included 102 intentions and 492 actions to show four fields of care that were congruent with family life. The findings showed that the nurses aim to define the daily needs of children and their parents by gathering information about the surrounding neighborhood and child care providers, by assessing the external and internal household environment of parenting, and by assessing the capacity of parents for rearing children. Public health nurses were providing care congruent with the needs of children with suspected Autism Spectrum Disorders, their parents and families.

## Key Words

care congruent with family life, children with suspected Autism Spectrum Disorders (ASD), home health nursing practices, nurse actions, nurse intentions

## Introduction

During routine health examination and consultation, public health nurses (PHNs) may suspect and identify Autism Spectrum Disorders (ASD) when children display irritability, impulsivity, and poor eye contact. PHNs play an important role in providing care for children with suspected ASD and their parents, by encouraging early intervention, linking parents with childcare services and working to prevent child maltreatment<sup>1-3)</sup>. Home health nursing by PHN is a universal service and an appropriate vehicle for delivering effective and

efficient care for children with suspected ASD<sup>4,5)</sup>.

In nursing practice, the elements to facilitate a child's growth and development and the abilities of his or her family are determined, and then assistance suitable for that particular family and community is provided<sup>6)</sup>. In Japan, PHNs visit individual homes to provide assistance to populations at high risk for illness or disability, and to alleviate the burdens of people caring for children or sick or aged family members. PHNs strive to provide care that is congruent with the family's situation and the needs of family members, to respect the desired lifestyle of care receivers, and to promote the abili-

ty of family members to help them<sup>7)</sup>.

In my previous research, I used the methodology that described the actions of expert nurses in relation to their intentions<sup>8)</sup>, in order to clarify the characteristics of home health nursing and identify the following concerns home health nursing practices by PHNs who provided care for children with suspected ASD and their parents<sup>5)</sup>. PHNs aimed: 1) to establish relationships with parents and speak to them about their desires and feelings for rearing children with suspected ASD; 2) to encourage parents of children with suspected ASD to deal with developmental disabilities of children, and to take appropriate roles; and 3) to help parents to acknowledge developmental disabilities of children and respect their feelings. Characteristics of providing care that is congruent with the family's situation and the needs of family members has yet to be described in detail.

### Literature Review

There are several published studies indicating health care for children with ASD and their parents.

Regarding PHNs who provide care for children with ASD and their parents, Monsen et al. (2011) described family home visiting interventions by PHNs after creating a retrospective cohort. PHNs provided more visits and interventions to clients in the high-risk group with variations in problem, category, and specific client needs<sup>9)</sup>. Home visiting was an important component of the PHN's role in the early twentieth century<sup>10)</sup>.

Andrew (2016) described that ASD was a complex disorder that was becoming more prevalent. Primary care providers, including nurses and nurse practitioners, should become more knowledgeable about the disorder, and provide appropriate screening, evaluation, and treatment as part of an interdisciplinary team<sup>11-14)</sup>.

Bultas et al. (2016) indicated managing home and health care for children with ASD could be

challenging because of the range of symptoms and behaviors exhibited<sup>12)</sup>. Recommendations for primary care providers were provided to enhance the overall delivery of services; including understanding and managing a child's challenging behaviors, and supporting family management of common activities of daily living and behaviors. Home- and community-based services of Medicaid for children with ASD were respite, caregiver support and personal care, and evidence-based treatments. Stats and advocacy groups continued to develop these programs to improved access to care and clinical outcomes to maximize the benefits to individuals with ASD and their families<sup>13)</sup>.

Russell and McCloskey (2016) identified children with ASD experience significantly higher risk for unmet healthcare needs, and parents report less satisfaction with their care. Utilizing parent perceptions to highlight practice deficiencies could build a foundation for care models that were more comprehensive and family centered<sup>15)</sup>. Lee (2015) offered the development of improved policies for early intervention programs regarding family-centered practice, utilizing the perspectives of families<sup>16)</sup>. Sobotka et al. (2016) evaluated the receipt of core medical home components: accessible, comprehensive, coordinated, family-centered and compassionate and culturally sensitive care for children with ASD and their families. They insisted that care coordination activities were lacking for children with ASD. More resourced families were particularly likely to report unmet needs<sup>17)</sup>.

While a great deal has been written about providing care for children with ASD and their parents by some care providers after diagnosis, little is known about the health care for them by PHNs after routine health examination and/or health consultation.

### Study Purpose

The purpose of this study was to explore how nursing practices reflect the intentions and actions

of PHNs who provide care for children with suspected ASD and their parents, in order to clarify the characteristics of home health nursing. In this article, characteristics of providing care congruent with family life are identified and discussed.

### Definitions of Central Concepts

#### *Home health nursing practices*

The term “home health nursing practices” refers to the delivery of effective and efficient health care that meets the health needs of people and the community<sup>7)</sup>. For this study, home health nursing practices are defined as the vehicle used to identify the family’s issues related to a suspected developmental disability and the needs of family members, family self-care abilities, and the ability of family members to help themselves, and includes the actual home visit, the pre-visit, and the post-visit telephone consultations.

#### *PHNs’ intentions*

PHNs’ intentions are the professional goals and aims of PHNs<sup>18)</sup>, which are oriented towards philosophies of nursing and/or public health.

#### *PHNs’ actions*

PHNs’ actions are the behaviors employed by PHNs to fulfill their intentions<sup>19)</sup>. PHNs’ actions are observable and/or non-observable conscious behaviors founded in clearly held goals or motives, and implemented through a process of reflection, choice, and decision-making<sup>20)</sup>. The inner thoughts, choices, and decision-making of the PHNs also fall within this definition of “actions”.

#### *Congruent Care*

Congruent care refers to effective and efficient healthcare that meets the health needs of people and communities.

Table 1. Characteristics of participants

Characteristics	N
years of the PHN’s work experience	
5-10 years	2
10-20 years	1
20 years more over	2
2 years with her mentor for about 13 years	1
the activity area of the PHN	
Urban	2
Rural	4
types of home visit/ consultation	
home visit	12
kindergarten visit	6
hospital visit	1
consultation	2
telephone consultation	13
consultation at routine health examination	3
liaison with other childcare provider	13
others	27
Contributing risk factors	
ASD(suspected)	3
MR & ASD(suspected)	1
Asperger’s syndrome	1
ADHD(suspected)	1
Age of the child	
3-4 years	3
5 years more over	3

PHN: public health nurse, ASD: Autism Spectrum Disorder, ADHD: Attention Deficit Hyperactivity Disorder, MR: mental retardation

## Material and Methods

### Design

This study utilized a qualitative descriptive design in order to identify PHNs' nursing practices included inner thoughts, choices, and decision-making.

### Participants

The home health nursing practices of six PHNs involved in the care of six children and their parents were examined (Table 1). The characteristics of PHNs' nursing practices were identified and included inner thoughts, choices, and decision-making.

The PHNs involved in this study were selected for their ability to aptly describe their nursing practice in their own words, and for having five or more years of public health nursing experience.

Six PHNs were targeted as a convenience sample. PHNs received an explanation of the interview and a copy of the consent form. The directors of nursing in the public health office were confirmed their records reflected excellent detailed care, and asked to assist their involvement in the study. The PHN involved in Case 1 had less than five years of experience, but she had a mentor who had more than ten years of experience in public health nursing.

### Data Collection

Data were collected by investigating the intentions and actions of PHNs in relation to their home visits. PHNs' intentions were obtained from descriptive or narrative records of home visits. PHNs' intentions were the professional goals and aims of PHNs with the philosophies of nursing and/or public health. PHNs' actions were described along with nurses' intentions.

Six PHNs were contacted and interviewed about intentions and actions that demonstrated best practices in their home health nursing and other health

support activities (Table 1). Before the interviews, they were asked to document their behavior and their inner thoughts according to a provided format. Documentation was done after each home visit, telephone and/or e-mail consultation. After documentation, a time and place was determined for the individual interview to be conducted. All face-to-face interviews were conducted between January 2011 and March 2013.

The records of the PHNs were closely reviewed and the images and scenes of their nursing practice began to emerge. When the records were vague or unclear the PHNs were interviewed about their intentions and actions. All points were then itemized and the list of intentions and actions became more concrete. Their intentions and actions were described and revised by the author, and the PHNs were consulted again. The above process was repeated until all could agree that the data description was substantially more manageable and concrete.

### Data Analysis

Data were analyzed using qualitative content analysis. Thus, the interviews were recorded, with participants' consent, using a digital voice recorder. Recordings were downloaded and transcribed. Transcripts were checked with the recordings to ensure accuracy. PHNs' intentions and actions were critically reviewed, and descriptive data from each participant were attached and then codes were assigned. The data were reviewed using an iterative process. Data were analyzed for themes and emerging concepts.

Credibility was also enhanced by member-checking and debriefing. In a final check after data-gathering, the author's interpretations were confirmed by the participants and two researchers with experience in public health nursing.

Relevant data were extracted by comprehensively referring to the context and combined PHNs' intentions and actions and by identifying similarities.

The characteristics of home health nursing practice were described through gathering summaries of relevant descriptive data extracted from PHNs' intentions and actions concerning congruent with family life.

### Protection of Participants

Protection of human subjects was ensured through approval by the Institutional Review Board of the Medical Ethics Center at the authors' university (No.22-7).

PHNs were provided with information regarding the purpose of the study. They were asked to write about their nursing practices prior to participating in the interview. The researcher met with PHNs for further details about their nursing practices. Before the interviews began, informed consent was obtained from each of the participants. Participants also received a written copy of the consent form.

Any information obtained from agency documents, such as patient records or referrals, was treated in a confidential manner. All interviews with the author were audio-recorded for later transcription and stored on a notebook computer dedicated to the study and without connection to the Internet. Codes were assigned to all data sets in order to maintain confidentiality. Children and their parents could not give informed consent because the data of this study was not gathered the information of children and their parent but PHNs' intentions and actions; however children with suspected ASD and their parents and all participating PHNs were assured of confidentiality and anonymity.

The author made an active effort to avoid interfering with the PHNs' schedules and time management. Therefore, the records were transcribed and written by the author using the recorded interview from each PHN. However, it was acknowledged that participation demanded a certain amount of time from each PHN.

## Results

Six PHNs were contacted and interviewed about their intentions and actions during their home health nursing practice. In total, 302 "intentions" and 1,575 "actions" regarding home health nursing practice with children with suspected ASD and their parents were recorded. Data analysis included 102 intentions and 492 actions to show four fields of care that were congruent with family life: 1) human relationships within the family, and family childcare, 2) interaction with resources in the community, 3) preserving the living environment, 4) child growth and development.

Combined instances for the intentions and actions are presented. A summary of relevant descriptive data was extracted from PHNs' intentions and actions during home health nursing practice. The summary of relevant descriptive data was used to describe the characteristics of providing care that was congruent with family life are presented in Table 2.

### Relevant Descriptive Data to Show 1) "Human Relationships within the Family and Family Childcare"

A summary of relevant descriptive data was extracted from 41 combined instances of nurses' intentions and actions to show: 1) "human relationships within the family and family childcare". Examples of relevant descriptive data are shown in Table 2: (1). From the summary, characteristics emerged: "PHNs identified the family's situation and human relationships within the family" (Table 2:1-1) ; "PHNs clarified care services required by parents, and predicted risk for inability or difficulties with child-rearing, and then helped the parents to make the most of their ability to cope with their children's disabilities" (Table 2:2)); and "PHNs facilitate parental coping, and involve parents in discussion" (Table 2:3)).

For example, in Case 3, the nurse's intention

**Table 2. Characteristics of home health nursing practices providing congruent care with family life, extracted from PHNs’ intentions and actions**

The aspects focused PHNs’ actions	Example of relevant descriptive data extracted from PHNs’ intentions and actions to focus of data analysis “care congruent with family life”	Summary of relevant descriptive data
(1) human relationships within the family, and family childcare (41 instances)	<p><b>[case1]</b>PHN encourages the mother in order to maintain the situation of child-rearing and dwelling in daily life from themselves, and then respects the mother’s perception and the relationship with her, the grandmother and other family members. [other:2]</p> <p><b>[case2]</b>PHN clarifies the direction for providing care services to the mother, and predicts that she may give up rearing her children. [other:2]</p> <p><b>[case3]</b>PHN helps the mother make the most of her ability to cope well with her child, and identifies her way of coping with the limitation of her child. [other:13]</p> <p><b>[case4]</b>PHN helps the father cooperate with coping with developmental issues of his child, and involves him in the settings for discussions with PHNs. [other:6]</p> <p><b>[case5]</b>PHN identifies that the mother gets appropriate coping out from the educational classes of the child care services for mothers and her children, and then considers the more appropriate childcare services. [other:9]</p> <p><b>[case6]</b>PHN helps the mother identify her perception for her child and coping, and then have the direction for bringing up her child. [other:3]</p>	<p>1)-1 PHNs identified the family’s situation and human relationships within the family.</p> <p>2) PHNs clarified care services required by parents, and predicted risk for inability or difficulties with child-rearing, and then helped the parents to make the most of their ability to cope with their children’s disabilities.</p> <p>3) PHNs facilitate parental coping, and involve parents in discussion.</p>
(2) interaction with resources in the community (7 instances)	<p><b>[case1]</b>PHN makes it the significant occasion for modifying the relationship between the mother and PHNs in the nursery school, and identifying the developmental disabilities of her child, to participate the conference in the nursery school. [other:4]</p> <p><b>[case2]</b>PHN identifies the meanings of the mother’s expression that she is reluctant to go to the place with the crowd.</p> <p><b>[case3]</b><b>[case4]</b><b>[case6]</b>(none description)</p> <p><b>[case5]</b>PHN identifies the friend of the parents who play with their child and drive the mother and her child to and from the health examination, and then considers whether he will meet the same expectation of the child’s parents in future.</p>	<p>1)-2 PHNs identified human relationships with friends or at nursery school, and identified childcare support situations and environments.</p> <p>4) PHNs consider whether friends or the kindergarten environment could meet parental expectations for providing future childcare.</p>
(3) preserving the living environment (23 instances)	<p><b>[case1]</b>PHN identifies the part-time working condition, and recognizes it is a good result for the mother to take time off to do herself. [other:2]</p> <p><b>[case2]</b>PHN identifies the mother’s concerns to participate the childcare services, such as health examinations.</p> <p><b>[case3]</b>PHN identifies the surroundings of child life and human relationships within the family, and then considers whether the family has the capacity for taking appropriate childcare.</p> <p><b>[case4]</b>PHN avoid to miss an opportunity for intruding herself on home, such as the home visit service for newborn baby. [other:9]</p> <p><b>[case5]</b>PHN identifies the mother’s life situation and the capacity of housekeeping, and then helps the mother strike a balance between work and rest in order to live in a way like pregnant woman. [other:6]</p> <p><b>[case6]</b>PHN identifies the mother’s feeling of fatigue, and considers the more appropriate childcare services.</p>	<p>1)-3 PHNs identified the living situation, poverty level, and the capacity for housekeeping.</p> <p>5) PHNs evaluated if childcare at home was provided in a suitable environment, whether the mother was feeling troubled, or whether the mother was having difficulty with child-rearing.</p>
(4) child growth and development (23 instances)	<p><b>[case1]</b>PHN identifies the situation of the child in an elementary school. [other:1]</p> <p><b>[case2]</b>PHN predicts that the child need to receive the support for entering an elementary school without the correct diagnosis of the doctor, and clarifies the direction for the more appropriate childcare services. [other:2]</p> <p><b>[case3]</b>PHN identifies the behavior of the child in her home, and considers the degree of her development and her difficulties. [other:5]</p> <p><b>[case4]</b>PHN identifies the issue of the child’s development in one year 6 months health examination, and considers the more appropriate childcare services. [other:6]</p> <p><b>[case5]</b>(none description)</p> <p><b>[case6]</b>PHN identifies the child’s feeling of the difficulties to make friends with other children in the nursery school, and considers the more appropriate childcare services. [other:4]</p>	<p>1)-4 PHNs identified the behavior of the children in their homes, nursery schools and elementary schools.</p> <p>6) PHNs aimed to identify the most appropriate childcare services that were congruent with the individual child’s development, their behavior during the health examination, and with behaviors seen in nursery school and elementary school.</p>

The number within () is combination instances of intentions and actions from Table 2.  
 PHNs: public health nurses

was: “PHN helps the mother to make the most of her ability to cope with her child, and identifies coping with the limitations of her child.” To fulfill this intention, the PHN performed the following action. “The PHN listened to the mother explain her concerns that her child could not independently skip rope, so she had checked on a web site for alternative ways to skip rope, but she could not teach her child how to independently perform the exercise. The PHN guessed that the mother had positive attitude towards child rearing, because every night she encouraged her child to practice the rope skipping, even though she also had to prepare supper as soon as she got home. The PHN decided to support the mother’s effort.”

#### **Relevant Descriptive Data to Show 2) “Interaction with Resources in the Community”**

A summary of relevant descriptive data was extracted from 7 combined instances of nurses’ intentions and actions to show 2) “interaction with resources in the community”. Examples of relevant descriptive data are shown in Table 2:(2). Characteristics that emerged included: “PHNs identified human relationships with friends or at nursery school, and identified childcare support situations and environments” (Table 2: 1)-2) and “PHNs consider whether friends or the kindergarten environment could meet parental expectations for providing future childcare” (Table 2:4)).

For example, in Case 2, the nurse’s intention was: “PHN identifies meaning in the mother’s reluctance to go to crowded places.” To fulfill this intention, the PHN performed the following action. “The PHN remembered that the mother was receptive to home visits and talking on the phone. The PHN decided that it was best to stay in touch with the mother, because the mother would not take the child in for examination or to attend nursery seminars.”

#### **Relevant Descriptive Data to Show 3) “Pre-**

#### **serving the Living Environment”**

A summary of relevant descriptive data was extracted from 23 combined instances of nurses’ intentions and actions to show 3) “preserving the living environment”. Examples of relevant descriptive data are included in Table 2:(3). Characteristics that emerged were: “PHNs identified the living situation, poverty level, and the capacity for housekeeping” (Table 2:1)-3) . “PHNs evaluated if childcare at home was provided in a suitable environment, whether the mother was feeling troubled, or whether the mother was having difficulty with child-rearing” (Table 2:5)).

For example, in Case 5, the PHN performed the following action. “PHN identified the mother’s living situation and capacity for housekeeping, and then the nurse helped the pregnant mother to strike a balance between work and rest.” To fulfill this intention, the PHN performed the following action. “The PHN suspected that the mother was young, and not very good at housekeeping, when the mother disclosed that she worked until midnight without regard to being six months pregnant. The PHN decided that the mother had to make adjustments to her work schedule.”

#### **Relevant Descriptive Data to Show 4) “Child Growth and Development”**

A summary of relevant descriptive data was extracted from 23 combined instances of nurses’ intentions and actions, using the focus of data analysis to show 4) “child growth and development”. An example of relevant descriptive data is shown in Table 2:(4). Characteristics that emerged included: “PHNs identified the behavior of the children in their homes, nursery schools and elementary schools” (Table 2:1)-4) ; “PHNs aimed to identify the most appropriate childcare services that were congruent with the individual child’s development, their behavior during the health examination, and with behaviors seen in nursery school and elementary school” (Table 2:6)).

For example, in Case 6, the nurse's intention was: "PHN identified the child was having difficulties in making friends with the other children in the nursery school, and considered more appropriate childcare services." To fulfill this intention, the PHN performed the following action. "The PHN watched the child's behavior with the director of the kindergarten. The PHN guessed that the child could stay calm but was not good at making friends with other children. The PHN decided that she had to support the child and consider living conditions and developmental disorders."

## Discussion

Findings suggested that PHNs were providing care that was congruent with the family situation, the needs of children with suspected ASD, and their parents throughout the home health nursing care. These allowed the PHNs to identify the needs of children with suspected ASD and the needs of their parents, and to provide care that was congruent with family life in the community

### Identifying the needs of children with suspected ASD and the needs of their parents

PHNs identified the needs of children with suspected ASD and the needs of their parents in order to provide effective and efficient care. The areas of need included the family's situation, human relationships and the behavior of the children within the family. Family's situations included poverty level or capacity for housekeeping. Human relationships included the childcare support situations and environments such as friendships formed in nursery school.

PHNs identified children with suspected ASD. Observations were based on realities of daily family life at home, behaviors displayed at nursery school and elementary school. Observations were also made during home visits.

When children are suspected of ASD, their par-

ents have special needs because of the daily pressure related to keeping house, raising children, providing special training for children and supporting the child's educational needs. They struggled to find the optimal way to raise the child, and they worry about the child's school experience<sup>21</sup>. Other researchers reported that the families had financial problems and needed additional income for the child's medical care because they had to reduce or quit work because of the child's condition<sup>22</sup>. In addition, they had unmet needs for specific health care services, adequate medical services, family support services, and special education at home. Also, care was less comprehensive, less coordinated, and less family-centered and family-focused than desirable<sup>21-25</sup>.

PHNs recognized that these special health care needs could be met through partnership, trust, and mutual respect between families and professionals<sup>26,27</sup>.

### Providing care congruent with family life in the community

PHNs in this study helped the parents to make the most of their ability to cope with their children's disabilities (Table 2:2), and facilitated parental coping, and involved parents in discussion (Table 2:3). In order to make the most of the families' ability to maintain their lives<sup>28</sup>, PHNs should consider needs in the context of the parents' wishes and desires for their children and for family life. PHNs should also encourage the involvement of the mother, father and other family members in dealing with the issues of children with suspected ASD.

Previous research suggested that support from another family member increased family function<sup>29</sup>. PHNs aimed to encourage and contribute to support systems that fostered a positive experience for caregivers of the children with suspected ASD<sup>30</sup>. PHNs aimed to respect family decisions and consider human relationships for parents and



children with suspected ASD

PHNs in this study clarified care services required by parents, and predicted risk for inability or difficulties with child-rearing (Table 2:2)). Furthermore, PHNs evaluated whether the mother was feeling troubled, or was having difficulty with child-rearing (Table 2:5)). PHNs aimed to enhance the self-care ability of the children and their families<sup>4)</sup>.

PHNs must practice preventive nursing care for children with suspected ASD and their parents while they predict risk in order to facilitate self-care abilities. PHNs should consider risks in order to prevent child abuse or abandonment of child-rearing responsibilities<sup>31)</sup>.

PHNs fostered the families' ability to bear responsibility for family life, and to make better choices for healthy behavior. Even if PHNs identified that the parents needed to make improvements in their life style or rearing their children, PHNs strived to accept the family life style and situation and to foster strengths to encourage independence<sup>32)</sup>.

The families in this study seemed to accept their children behaviors. They positively revised their relationships with their children, and applied new policies and attitudes towards life in the nursery school and elementary school. It appeared that parents could increase self-care abilities when they became positively engaged in rearing children with suspected ASD. It was very important for PHNs to respect parents' own methods to sustain daily life.

PHNs can incorporate the community resources to increase satisfaction with family life for children with suspected ASD and their parents<sup>32,33)</sup>. PHNs in this study considered and evaluated whether child-care was provided in a suitable environment at home, the kindergarten, the nursery school and elementary school (Table 2:4), 5) and 6)). PHNs aimed to expand and maintain relationships within the neighborhood and with child care providers. PHNs should strive to help families to maintain dai-

ly life at home and in the community<sup>4)</sup>. It is important for PHNs to identify how families related and interacted with the community.

Previous researchers suggested that effective and efficient nursing care for children with suspected ASD included having medical care at home<sup>24, 25, 34, 35)</sup>, how-to-parent training for parents<sup>36)</sup>, family-centered music therapy<sup>37)</sup>, home-based intervention conducted by occupational therapists<sup>38)</sup> and individualized school health care plans<sup>39)</sup>.

The exchange of information among the parents of children with suspected ASD was effective and contributed to efficient nursing care for children with suspected ASD<sup>40)</sup>. PHNs should evaluate whether formal or informal service providers can meet parental expectations for providing future childcare.

#### Limitations

The method of this study was selected as the most appropriate to describe the practices and the competencies of PHNs. The PHNs' intentions and actions were critically reviewed, and relevant data was extracted to examine the characteristics of home health nursing using focused data analysis, however, the study had several limitations.

The results typified the Japanese PHN context, which might limit transferability to other international contexts, or regions. Furthermore, while the study was an in-depth study with few participants, not all types of PHNs were represented. The demographic information collected was also limited; therefore, homogeneity of the PHNs was not completely transparent. As PHNs participated for this study, they might have been more interested in nursing practices than others.

Further research should be conducted to clarify the characteristics of home health nursing in order to provide better support for children with suspected developmental disabilities and their parents.

## Conclusion

The study illuminated nurses' intentions associated with characteristics of home health nursing that resulted in care that was congruent with the needs of children with suspected ASD, and their parents.

Nurses defined the needs of daily living by gathering information about relationships to the neighborhood, the external and internal household environment as related to parenting, and the capacity of parents to care for a child with suspected ASD. Nurses aimed: 1) to respect family decisions and consider human relationships for parents and children with suspected ASD, 2) to respect parents' own methods to sustain daily life, and 3) to expand and maintain relationships within the neighborhood and with child care providers.

## The implications for practice

PHNs in this study aimed to establish relationships with parents and families, and to share the problems and the problem-solving and the families' wishes and hopes. PHNs should design interventions that engaged parents and families in order to improve child-rearing. In addition, when PHNs were seeking the best solutions with parents and families they should identify possible lifetime disabilities that were based on specific behaviors of the children with suspected ASD. Furthermore, PHNs should recognize the importance of community-based services including social services for children with suspected ASD and their parents, and encourage involvement and cooperation between multidisciplinary professional childcare providers.

## Acknowledgments

The author would like to acknowledge the PHNs for participating in this study. A part of this work was supported by JSPS KAKENHI Grant Number

JP24593432.

## References

- 1) Ministry of Health Labor and Welfare: The Early Interventions and the Screening of Autism Spectrum Disorder at Routine Health Examination. Tokyo, 2009.
- 2) Masuzawa T, Ookawa H, Minamiyama K, et al: The Review focused the relationship between Child maltreatment and Autism Spectrum Disorder. Children's Rainbow Center, Tokyo, 2009.
- 3) Kamio Y, Honda H, Uno H, et al: The Guideline of the Intervention for Persons with Autism Spectrum Disorder according to their life stages. National Institute of Mental Health, Tokyo, 2010.
- 4) Tamura S: Home Health Nursing. In "The Newest Community Health Nursing General (2nd ed), Miyazaki et al eds, pp208-248, Jap Nurs Assoc publishing company, Tokyo, 2010.
- 5) Tamura S: Characteristics of Home Health Nursing in Areas near the Mountains for Children with Suspected Autism Spectrum Disorders and Their Parents. Jap J Rural and Remote Area Nurs 9: 11-26, 2014.
- 6) Tamura S: Nursing for Children with Disability. In "The Newest Community Health Nursing Particular 1 (2nd ed), Miyazaki et al eds, pp66-85, Jap Nurs Assoc publishing company, Tokyo, 2010.
- 7) Tamura S: The Characteristics of Home Health Nursing Provided Congruent Care with the Family/Neighborhood Living at Home Manifested to Illuminate Nurses' Intentions and Actions. Jap Assoc Re Family Nurs 15: 30-40, 2009.
- 8) Tamura S: The Characteristic of Nursing Care in Home Health Nursing Centered Client-Nurse Interaction. J Jap Soc Nurs 15: 78-87, 2006.
- 9) Monsen KA, Radosevich DM, Kerr MJ, Fulkerson JA: Public Health Nurses Tailor Interventions for Families at Risk. Public Health Nurs 28: 119-128, 2011.

- 10) Foley EL: The Nurse's First Visit. *Public Health Nurs* 30: 177-180, 2013.
- 11) Andrew Y: Autism Spectrum/Pervasive Developmental Disorder. *Prim Care* 43: 285-300, 2016.
- 12) Bultas MW, Johnson NL, Burkett K, Reinhold J: Translating Research to Practice for Children With Autism Spectrum Disorder Part 2, Behavior Management in Home and Health Care Settings. *J Pediatr Health Care* 30: 27-37, 2016.
- 13) Velott DL, Agbese E, Mandell D, et al: Medicaid 1915(c) Home- and Community-Based Services waivers for children with autism spectrum disorder. *Autism* 20: 473-482, 2016.
- 14) McGuire K, Fung LK, Hagopian L, et al: Irritability and Problem Behavior in Autism Spectrum Disorder, A Practice Pathway for Pediatric Primary Care. *Pediatrics* 137: 136, 2016.
- 15) Russell S, McCloskey CR: Parent Perceptions of Care Received by Children With an Autism Spectrum Disorder. *J Pediatr Nurs* 31: 21-31, 2016.
- 16) Lee YH: The meaning of early intervention, A parent's experience and reflection on interactions with professionals using a phenomenological ethnographic approach. *Int J Qual Stud Health Well-being* 10: 1-10, 2015.
- 17) Sobotka SA, Francis A, Vander PBK: Associations of family characteristics with perceptions of care among parents of children with autism. *Child Care Health Dev* 42: 135-140, 2016.
- 18) Tatematu H: intentionality. In "Phenomenology, Kida et al eds, pp177-181, Jap Kobundo, Tokyo: 2003.
- 19) Kadowaki S: action. In "Phenomenology, Kida et al eds, pp142-143, Jap Kobundo, Tokyo: 2003.
- 20) Shinmura I: action. In "Kojien (6th ed), Shinmura et al eds, 924, Jap Iwanam, Tokyo: 2008.
- 21) Matuoka S, Tamaki A, Hatsuda M, Nishiike E: Difficulties Experienced by Mothers of Children with Pervasive Developmental Disorders and Their Psychological Support. *J Jpn Acad Nurs Sci* 33: 12-20, 2013.
- 22) Kogan MD, Strickland BB, Blumberg SJ, Singh GK, Perrin JM, van Dyck PC: A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics* 122: 1149-1158, 2008.
- 23) Preece D, Jordan R: Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support. *Br J Learn Disabil* 38: 10-20, 2010.
- 24) Carbone P, Behl D, Azor V, Murphy A: The medical home for children with autism spectrum disorders, parent and pediatrician perspectives. *J Autism Dev Disord* 40: 317-324, 2010.
- 25) Hyman S, Johnson J: Autism and Pediatric Practice, Toward a Medical Home. *J Autism Dev Disord* 42: 1156-1164, 2012.
- 26) Byrd EM: Social Exchange as a Framework for Client-Nurse Interaction during Public Health Nursing Maternal-Child Home Visits. *Public Health Nurs* 23: 271-276, 2006.
- 27) Family Voices Inc: Family-Centered Care Self-Assessment Tool User's Guide. 2008.
- 28) Tamura S: The Characteristic of Nursing Care in Home Health Nursing Manifested to Illuminate Nurse's Intentions. *J Chiba Acad Nurs Sci* 8: 61-66, 2002.
- 29) Imai A, Asano M, Kobayashi K: Family Function and Support of the Families who are raising a Preschooler with Autism. *Soc Nurs Health Care* 8: 17-25, 2006.
- 30) Markoulakis R, Fletcher P, Bryden P: Seeing the glass half full, benefits to the lived experiences of female primary caregivers of children with autism. *Clin Nurse Spec* 26: 48-56, 2012.
- 31) Yamamoto N, Okamoto Y, Suzuki I, Okada S, Ishigaki K: Development of the Quality Indicators on Family Support in Home Care Nursing for Older Adults. *Jap J Res Family Nurs* 13: 19-28, 2007.
- 32) Zerwekh JV: Laying the Groundwork for Fam-

- ily Self-Help, Locating Families, Building Trust, and Building Strength. *Public Health Nurs* 9: 15-21, 1992.
- 33) Sato N: A Study on Nursing Care to Expand Family Self-Care. *J Chiba Acad Nurs Sci* 10: 1-9, 2004.
- 34) Golnik A, Scal P, Wey A, Gaillard P: Autism-Specific Primary Care Medical Home Intervention, *J Autism Dev Disord* 42: 1087-1093, 2012.
- 35) Farmer J, Clark M, Mayfield W, et al: The Relationship Between the Medical Home and Unmet Needs for Children with Autism Spectrum Disorders. *Matern Child Health J* 18: 672-680, 2014.
- 36) Tuda Y, Tanaka M, Takahara M, Hashimoto T: The Effects of Parent Training for the Parents Having Preschool Children with High Functioning Pervasive Developmental Disorders. *J Child Health* 71: 17-23, 2012.
- 37) Thompson GA, McFerran KS, Gold C: Family-centered music therapy to promote social engagement in young children with severe autism spectrum disorder, a randomized controlled study. *Child Care Health Dev* 40: 840-852, 2012.
- 38) Liao S, Hwang Y, Chen Y, Lee P, Chen S, Lin L: Home-based DIR/Floortime™ Intervention Program for Preschool Children with Autism Spectrum Disorders, Preliminary Findings. *Phys Occup Ther Pediatr* 34: 356-367, 2014.
- 39) Gardner R: Understanding and caring for the child with Asperger syndrome. *J Sch Nurs* 17: 178-184, 2001.
- 40) Yamamoto M, Kadoma A, Furusawa A, Oohashi Y, Mori A, Asano M: Mutual Support in the Narratives of Mothers of Children with Autism Spectrum Disorder, The Lesson of Encouraging Other People. *J Jap Soc Nurs Res* 35: 35-43, 2012.

# 発達障害を危惧された児と家族の家庭生活に見合った支援

田村須賀子, 陶山 公子

富山大学学術研究部医学系地域看護学講座

## 要 旨

本研究は、家庭生活に見合った支援の特徴を明確にするために、発達障害を危惧された児とその養育者に対して、家庭訪問援助を提供した保健師の看護実践について調べた。保健師による6事例の看護実践から情報収集した。6人の保健師から、家庭訪問援助とそれに関連する支援活動についてインタビューした。保健師の意図と行為の記述総件数は、意図302件、行為1,575件で、本稿での分析対象「家庭・地域生活を含めた援助提供」に関するものは、意図102件、行為492件であった。保健師は、対象本人・家族の家庭・地域生活状況について、療育・就園・就学・人間関係等から把握していた。家庭・地域生活を含めた援助とは、養育者の育児を放棄する可能性とそこに潜む困難を想定しつつ、発達障害を危惧された児への対応能力を引出し、良好な家族内人間関係のもと、療育生活を継続できるようにするよう援助提供するものと考えられた。

## キーワード

家庭生活に見合った支援, 発達障害を危惧された児, 家庭訪問看護援助,  
看護師の行為, 看護師の意図