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Abstract
This qualitative descriptive study explored the challenges faced by Japanese Public Health Nurses in supporting pre-school-aged children with Autism Spectrum Disorder and their families. Nine Public Health Nurses volunteered to participate in the study. Data was collected through nine in-depth interviews with data collection and analysis continuing until all themes was saturated. Six main themes were identified: 1) expertise in child development; 2) reviewing clients’ needs, acquiring new resources and developing existing resources; 3) collaborating with Allied Health Professionals of relevant organizations; 4) core role of the Public Health Nurse; 5) developing rapport with the family; and 6) being a partner in family support. The findings indicated the need for improved training for Public Health Nurses in supporting children with Autism Spectrum Disorder, in order to reduce the challenges they encounter. Training is also required to improve the practical skills for creating appropriate resources in the community, and to promote collaboration with Allied Health Professionals. Improving the skills of Public Health Nurses will provide them with confidence in overcoming many challenges they face when delivering appropriate support to clients.

Key Words
Autism Spectrum Disorders, Challenges, Japanese, Public Health Nurses, Qualitative

INTRODUCTION

Japanese Registered Nurses who also hold a National Public Health Nursing License can work as a Public Health Nurse (PHN) undertaking a range of activities to assisting clients in the community. Their role share similarities with those of the PHN in other countries such as in Europe and America. However, in Japan most Public Health Nurses (PHNs) are employed in municipal or prefectural governments, assisting in preventing illness and promoting citizens’ health. Having the dual nursing license and being employed by municipal or prefectural governments is unique to Japan 1).

The importance of the role of PHN in Japan is well documented in the guidelines about the health activities of PHNs in the community 2). The content and methods of the PHN activities in municipalities includes the responsibility of both supporting the individual/family and providing community-focused practice 3). The extent of the PHNs responsibilities is acknowledged by Saeki 5) and Okamoto 4) who reported that central to the PHNs performing their role is the requirement to possess interpersonal health support competencies in addition to administrative and management competencies.

Recently in a global context, there has been increasing concern about the increase in the prevalence of Autism Spectrum Disorders (ASD) 5)-8). Several studies have underlined the importance of early identification of ASD and the need to tailor individual intervention programs to improve the management and outcomes of ASD 9)-11). To improve the detection rate of ASD, the American Academy of Pediatrics 12) recommends screening tests be performed regularly at 9, 18, 24, or 30 month visits. In Japan children have a health check at 18 months and 3 years of age at their local health center, in accordance with the Maternal and Child Health Law 13). The attendance rate at these health checks is higher than 90% 14). These health checks are thought to function effectively as

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a place to screen children for ASD. And the screening tests enable PHNs and other Allied Health Professionals (AHPs) to detect children with suspected ASD systematically.\textsuperscript{15, 16}

Several researches have commented on the important role PHNs play in assisting children with ASD and providing support to the family. Begley\textsuperscript{17} asserts PHNs have a key role in assisting children at risk in the community. Her claim is supported by Chakrabarti\textsuperscript{18} who found PHNs are a major source of referrals requesting the assessment for ASD. Equally, the research of Halpin\textsuperscript{19} gives added weight to the importance of the role of the PHN by reporting that interactive activities between the PHN and families are important in providing holistic quality care.

Though procedures are in place for detecting cases of ASD and providing family support, various challenges exist for PHNs in undertaking these activities. To address this situation there have been discussions centered on improving the systems in place allowing PHNs to provide support for families who have a child with ASD\textsuperscript{20, 21}.

Despite the research highlights the important contribution made by PHNs in supporting children with ASD and their family, an exhaustive literature review failed to uncover studies focusing on the “challenges” PHNs face in performing their role. However, anecdotal evidence highlights some of the challenges PHNs encounter in assisting in the identification of children with ASD and providing ongoing support for the family.

To address the lack of research aimed at identifying the challenges PHNs encounter, a qualitative descriptive approach was selected for this study, to shed light on challenges facing PHNs in Japan.

This qualitative study aimed to explore the challenges faced by Japanese PHNs supporting pre-school-aged children with ASD and their families.

**METHODS**

**Design**

To best interpret the Japanese PHNs perspective concerning their challenges in supporting pre-school-aged children with ASD and their families, a qualitative descriptive approach underpinned by the naturalistic inquiry\textsuperscript{22} was adopted for this study.

**Participants**

After gaining ethical approval, information about the study was forwarded to all PHNs in one city, by a gatekeeper nominated by the director of public health nursing. Nine female PHNs who indicated an interest in participating in the study contacted the principal researcher. The criterion for inclusion was to be directly involved in providing ongoing support to pre-school-aged children suspected of having ASD and their families at the time of the study.

**Data collection**

The chief nurse of each public health center identified potential participants (referred to as PHNs) for this study. With the permission of each PHN, the chief nurse provided their names to the principal researcher who explained the study to each of them before obtaining their written consent. In-depth interviews were conducted as the primary method of data collection. All interviews were conducted individually and in the privacy of the PHN’s office. Each interview lasted approximately 110 minutes with the following questions asked from a semi-structured interview guide; “Would you tell me in as much detail as possible the support you provided for the pre-school-aged child with ASD and his/her family that has had the greatest impression on you?” and “What were the challenges you faced in your role as a PHN in providing support for the case?” The PHNs were then asked to address each question by describing the challenges they had experienced, how they managed them, and what kind of support they had received/lacked from colleagues, families and AHPs. Probing questions such as: “Can you give me more information about that?” and “How did this make you feel?” were asked in order to extract the maximum amount of detail from the PHNs’ experiences.
Data analysis
Following the completion of each interview, data was processed and transcribed verbatim by the principal researcher. To enhance the researchers’ understanding of the PHNs’ situation from their point of view, memos and field notes of the principal researcher were read and compared with the transcripts.

A qualitative descriptive method was used to process all interview data. To allow the principal researcher to become familiar with all of the text describing the experiences of each PHN, the audiotapes were listened through, and transcribed text was read and reread. As meaning units were condensed, they were labeled with a code. The differences and similarities between the codes were then compared. Codes were sorted into categories according to the similarities between them. Interactive analysis was undertaken between the whole texts, codes, and categories. An interpretation of the underlying meaning which was identified in the categories was formulated into various themes.

To ensure the trustworthiness of the data, the following tenets established by Lincoln 22) were adhered to. To affirm credibility, the principal researcher along with the co-researchers checked with the nine PHNs during debriefing sessions. To establish dependability, the identified themes, along with categories, were compared and then discussed with the co-researchers. The raw data, memos, field notes and products of the data analysis increased the trustworthiness and confirmability of the data.

Ethical considerations
Approval for this study was given by the Research Ethics Review Committee of Kobe University School of Medicine. Before signing the consent form, participants were verbally informed about the study by the principal researcher and assured all information provided would be kept confidential and anonymous.

RESULTS
Demographic characteristics
The ages of the PHNs ranged from 26 to 52 years. Two had worked as a PHN for more than 20 years, four between 15 - 20 years, one 10 - 15 years, one 5 - 10 years, and one 0 - 5 years. Seven were employed at the Maternal and Child Health division and two at the Welfare division for persons with disabilities. Seven were staff members in the work place, one was the subsection chief and one the section chief. Six graduated from vocational school, one from junior college and two from university.

Challenges faced by Public Health Nurses
Six themes and thirty categories emerged from the data analysis. Themes are discussed below with the categories shown in quotation marks.

Expertise in child development
PHNs expressed concern about the challenges they encountered as childhood development ‘experts.’ Concerns included the challenge of “providing appropriate information to the family concerning the child’s situation and their growth/development” based on the need for the family “to accurately grasp the child’s growth/development.” Also, “to determine the most appropriate services suitable to meet the child’s needs”, “to judge the appropriate intervention time required for utilizing the services” and “to connect the child with the services.”

There are times I find the developmental variations in children with ASD difficult to assess accurately. My knowledge of the development of such children needs to be continually updated due to changes in treatment modalities and for me to accurately determine the developmental changes. However, ongoing training is rarely available. The lack of training leaves
me feeling confused as to whether the advice I provide to the family about the level of their child’s development is appropriate, accurate or sufficient (PHN 1).

One of the greatest challenges I am faced with in my work, is how best determine the necessary services appropriate for children and families, and when should families commence using the services. This situation results from the lack of guidelines outlining procedures to assist PHNs in determining what services are appropriate, and at what stage during contact with the client should treatment commence (PHN 2).

Reviewing clients’ needs, acquiring new resources and developing existing resources

PHNs responsible for reviewing the progress and level of support provided to clients, expressed concerns about the lack of resources and poor administration systems. The PHNs saw as their greatest challenge, acquiring additional resources and developing workable systems so as to provide quality service to their community. Other challenges included “making appropriate support plans for the children and their families,” “recognizing whether the needs of children and their families were adequately met,” “deciding when to complete the following-up of the children and their families” and “reviewing the progress of support void of supervision.” Also, “creating new social resources to provide support for the family,” “constructing/reconstructing the system to foster improved collaboration with related organizations” and “developing rapport amongst AHPs involved in providing support:”

Reviewing the progress of support is often difficult ... and we lack clear procedures and criteria of when or how to terminate services after successful intervention is completed (PHN 3).

As a PHN, it is necessary to review the services we provide despite the challenges in doing so. Reviewing services is necessary to draw attention to the degree of lack of resources and the need to provide additional services to support the child and family. In many rural regions such as our own, few resources are available to support children and families. It is necessary that we develop new resources in collaboration with AHPs and administrators. However, due to the complex administrative nature that exists between our service and the local municipality, it is difficult to acquire and engage in developing existing services in part due to financial constraints (PHN4).

Collaborating with Allied Health Professionals of relevant organizations

PHNs expressed concerns about the lack of collaboration with AHPs and relevant organizations in the community. They spoke about the challenge of wanting to be involved in the discussions and “sharing the policy about supporting clients with other AHPs and relevant organizations” and “having AHPs acknowledge and understand the role of the PHN.” The lack of “cooperation with AHPs and relevant organizations” has made it difficult for PHNs “to introduce the child and his/her family to the services provided by relevant organizations” and “to be familiar with the existing services in the community to support the child and his/her family:”

Collaboration between PHNs and colleagues is necessary to provide appropriate quality of care and support for the client. However, achieving a workable support strategy in collaboration with AHPs always seems elusive. Despite tireless efforts, I continue to struggle with the challenges involved to have AHPs acknowledge the need for improved collaboration (PHN 5).
Core role of the Public Health Nurse

PHNs spoke about the challenges faced in attempting to explain to AHPs and families their responsibilities and role. Specifically, they expressed a degree of frustration stemming from the challenges they encountered in attempting to “communicate the role of PHNs to the families” by “explaining the differences and similarities that existed between the roles of PHNs and other AHPs” and “discussing the treatment plans and intervention strategies provided by them to assist families:”

Many AHPs representing different professions and organizations are involved directly or indirectly with ASD cases. This leads to confusion and gaps in the treatment and support of families hence, the need for families to understand the role of the PHNs. Though I attempt to educate families about the role of PHNs’, doing so is quite difficult and at times frustrating. It is important to ensure families understand the role of PHNs’ and other AHPs. Equally trying to gather and organize information from the AHPs and organizations involved so as to provide continuity of services for the families is extremely challenging. I am often left feeling uncertain in how I should go about securing relevant information that is not always made readily available to me (PHN 6).

Developing rapport with the family

PHNs described many challenges faced in developing rapport with families. Some of the challenges mentioned included “developing and maintaining treatment and support between the PHN and families” by “developing rapport between families and PHNs” based on “encouraging families to share their concerns with PHNs” and “convincing families of the benefits of evaluating and or accepting proposals and advice offered by the PHN.”

In my efforts to support families, there are times I find I am confronted by a number of challenges in trying to have them consider or accept my professional advice. When I do receive a consultation phone call from a mother who had previously ignored my advice, I feel that the psychological gap between us no longer exists and I think, “Yes, I have achieved success in developing the trust of the mother!” This can only lead to improved quality of care for the child with ASD and the family (PHN 1).

Being a partner in family support

From this theme emerged how PHNs struggled with the daily challenges associated with the need to be considered as partners in providing family support and quality client-centered care. They emphasized the need “to accurately grasp the child’s and family’s living situation,” “to understand dynamics of the family’s troubles” and “to encourage families to focus on their strengths in order to reach desired outcomes:”

From my perspective and experience as a PHN, I firmly believe that having the family and child’s support are absolutely necessary for providing efficient and effective quality client-centered care. Though it is often a challenge to grasp the true reality of each family’s life style and difficulties, I try doing this where possible, as it is central to the overall success of any intervention. Also, supporting the family by helping them to identify, fully understand and take advantage of their strengths is an ongoing challenge. My efforts are made even more challenging because I am fully aware of the enormous benefits for the family when they focuses on their strengths, in order to succeed in reaching their desired intervention goals (PHN 7).
DISCUSSION

In this study six themes were identified, highlighting various challenges faced by PHNs in their efforts of supporting children with ASD and their families. The challenges impact on how PHNs perceive their role as health providers, and influence the way they perform their clinical and administrative responsibilities. While the six themes are able to stand alone, they also overlap each other.

Our findings indicate that PHNs in this study challenge their level of expertise. Expertise is defined as having specialized knowledge gained by acquiring and updating knowledge and skills \(^{24}\). The need for ongoing professional development to improve one’s skill level is supported by Saeki \(^{1}\) and Okamoto \(^{4}\) who suggest that to perform as an expert, PHNs must possess competencies in skills. We contend that the lack of opportunities for PHNs to participate in professional development to improve their competencies results in a degree of confusion and affects the levels of care provided to clients.

Another important finding in this study was the challenge PHNs face in accessing appropriate resources. Sasamori \(^{21}\) spoke about there being discussions centered on improving systems that are in place to assist PHNs in undertaking their activities. Despite such discussions, our research shows reviewing clients’ needs, acquiring new resources and developing existing resources still remains a challenge for PHNs.

The disappointment in the level of collaboration with AHPs and relevant organizations expressed by PHNs is another key finding of this study. In addressing the lack of effective collaboration, PHNs openly spoke about the challenge they experience when referring clients to the appropriate organizations. The challenge results from poor communication exchanges, lack of feedback and from often being excluded from discussions central to treatment modalities’ involving their clients. The need for effective collaboration is acknowledged by Chakrabarti \(^{18}\) who found that PHNs are the major source of referrals, and by Banner \(^{25}\) who asserts that the lack of information sharing creates a degree of uncertainty. Together, these findings draw attention to the reason collaboration is central to having an effective community health care system. Failure to engage in appropriate collaboration impacts negatively on the level of care, and often leads to duplication, fragmentation and un-coordinated services.

PHNs in this study also expressed concern about how they perceive and perform their role within their community. The lack of information sharing and feedback makes it a difficult challenge for PHNs to adequately perform their role. Results from the interviews demonstrate that the PHNs often feel professionally isolated from other AHPs, and perceive their role to be undervalued. This prevents the sharing of vital information about the client and creates confusion about the role of the PHN in supporting families. Begley \(^{17}\) reported that PHNs play a key role in providing for children at risk in the community. Despite this finding, PHNs in this study believe that the absence of acknowledgement of the importance of their role in the community remains a challenge for them to overcome. This lack of acknowledgement leads to gaps in developing intervention strategies and to securing and organizing relevant client information. It also creates challenges for PHNs in trying to explain their role to clients. By being aware of the challenges expressed by PHNs in this study, interested stake-holders have the opportunity to address the findings. To do so will go a long way to promoting the role of the PHN among AHPs and the families they support.

PHNs spoke about the challenges they face in establishing rapport and encouraging families to accept the role of the PHN as a necessary partner in family support. The importance of this was addressed by Dawson \(^{9}\), Eikeseth \(^{10}\) and Magiati \(^{11}\) who found that it was necessary to tailor individual intervention programs to produce the best outcomes relating to ASD. For this to occur, rapport between the PHN and the family is central in allowing the PHN to closely engage with the family to more effectively identify their needs. This would also allow the PHN to evaluate the family’s social environment more closely and assist them in providing holistic client centered intervention programs. This is supported by Halpin \(^{19}\) who reported a close relationship between client and health provider is important in providing holistic quality care. Additional research is required to fully identify the complex nature of the causes that create challenges for PHN in establishing rapport and building interactive partnerships.
Limitations of the study

The findings of this study may not represent the experiences of all health providers or have identified all the challenges that exist in the public health system. However, this does not lessen the need to further research the challenges raised by the PHNs in this study. The small number of PHNs from the same city who participated may not be an accurate representation of other health organizations in Japan. Therefore, the findings must be interpreted cautiously while at the same time acknowledging the contributions made by the PHNs in this study.

Implications for health providers and administrators

The findings highlighted in the six themes of this study have far reaching clinical and administrative implications for health providers and administrators. First, health care providers can use the information from this study to promote and provide a collaborative team approach to holistic health care and to assist in breaking down barriers that impede collaboration between health providers and organizations. Second, being made aware of the challenges provides administrative health personnel with knowledge of the need to provide ongoing professional development training, and update appropriate health systems. In doing so, the focus must be on developing systems that are designed to improve health outcomes. Finally, additional research is warranted to examine the impact the challenges outlined in the six themes have on assessment procedures, treatment interventions, and support for clients.

CONCLUSION

This study highlights the challenges faced by Japanese PHNs in supporting children with ASD and their families. The challenges identified provide information that can be used to improve the management of public health care. It provides the opportunity for PHNs and administrators to use the information gained to put forward programs and interventions specific to the clients’ needs. Participation in developing programs should be based on first-hand clinical experience, and understanding of what is required to effect changes to the public health system. Significantly, the findings of this study can contribute to the efforts of promoting improved inter agency collaboration in addition to professional development opportunities. Also, in developing systems that promote the role of the PHN, and to support the interactive interventions by PHNs to allow them to provide the best possible outcome for children with ASD and their families.

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