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Analysis of Challenging Issues Related to and an Accepting Attitude toward Habilitation from the Viewpoint of Mothers Living in an Underpopulated Community

Naoko Hibino¹, Nobuko Matsuda², Chizuko Noro³

Abstract

This study analyzed challenging issues related to habilitation and their management, as well as the development of an accepting attitude toward it through collaborative approaches using available resources, based on the narratives of 15 mothers of children requiring habilitation in an underpopulated community. Data were collected through 2 focus group interview sessions and qualitatively analyzed. The challenging issues recognized by the mothers were frequently due to the unavailability of sufficient resources for geographical reasons. The development of an accepting attitude toward habilitation depended on the mothers' thoughts, behavior, and relationships with doctors and center staff members engaged in habilitation. Such an attitude and maturation as a parent were observed more frequently when the mother and other family members actively participated in habilitation. On the other hand, some mothers had difficulty in accepting habilitation, highlighting the necessity of establishing equal relationships and collaborating with center staff members, in addition to community-based doctors and public health nurses, in order to maintain their daily support for habilitation. It may also be necessary for them to take active actions and improve their skills to access medical and welfare services at appropriate times through consultations and negotiations.

Key Words

Underpopulated community, Habilitation, Accepting attitude, Focus group interview

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INTRODUCTION

The southern part of A-Prefecture targeted for this study has been designated as an underpopulated community. With a total population of approximately 39,000 (2011), 28.7% to 37.4% of whom are aged 65 or over, and total fertility rate ranging from 1.59 to 1.69 (2007 to 2011)¹⁾, the community is facing markedly rapid aging. Furthermore, human resources are chronically insufficient. Despite the municipality's efforts, the unavailability of sufficient medical manpower has led to the sequential closure of medical facilities and wards in recent years. Since 2009, the author has conducted studies in cooperation with community-based specialists to examine challenging issues regarding child and maternal health²⁾, heavy financial burdens other than medical costs³⁾, and parenting experiences; such experiences may be considered positive or negative, depending on the parents' thoughts and views on management⁴⁾. In some previous studies on parenting in underpopulated communities, parenting under the community's control⁵⁾ and approaches to support parenting on islands⁶⁾ were reported. However, up to the present, there have been no studies examining children requiring habilitation and their mothers living in underpopulated communities. The term "children requiring habilitation" in this paper refers to those diagnosed with language or other developmental retardation by doctors or public health nurses. In underpopulated communities where appropriate diagnosis or consultation services are frequently unavailable, some mothers of children with disabilities or diseases cannot appropriately accept the reality regarding their children's conditions, which leads to daily parenting difficulties. The provision of early habilitation approaches during infancy has been examined in a large number of studies, reporting that early habilitation intervention for preschoolers is highly needed and effective^{7,8)}, and the main purpose of habilitation is to support parents⁹⁾. Other reports noted that: the child's and mother's behaviors mutually influence each other, and negative parenting behavior is frequently observed in mothers of children with developmental disabilities¹⁰⁾; the mother's depressive state influences the child's behavior¹¹⁾; and the child's problematic behavior is associated with the mother's depressive symptoms and stress¹²⁾. It has also been noted that neighbors' emotional support positively influences the mental health of mothers of children with autistic spectrum disorders (ASD)¹³⁾. These studies suggest that the effects of habilitation, background factors associated with problematic behavior, and support for mothers have been actively examined.

The present study aimed to clarify factors associated with challenging issues in an underpopulated community with insufficient medical, health, and welfare resources in consideration of the status of mothers of children requiring habilitation, as well as the

development of an accepting attitude toward habilitation through collaborative approaches using available resources in such mothers. Examination of the process of developing an accepting attitude toward habilitation may be useful to clarify mothers' needs and provide a basis for appropriate support.

METHODS

1. Study design

This is a focus group interview-based qualitative, descriptive, and exploratory study.

2. Definition of terms

Underpopulated communities: communities in underpopulated areas specified in the Act on Special Measures for Promotion for Independence for Underpopulated Areas (Act No. 15, 2000)

Habilitation centers: child development support centers providing day habilitation services for preschoolers

Habilitation: personalized approaches to help individual children develop self-management skills and abilities to perform daily life activities appropriately

Challenging issues: those faced by mothers in their daily lives as concerns, anxiety, and burdens

Accepting attitude: attitude to adjust, manage, and accept events occurring in a situation

Collaborative approaches: approaches for specific targets based on a certain view or for a certain purpose (Sugiman)¹⁴⁾

The present study encourages mothers, the staff of habilitation centers, and researchers to exert continuing efforts to discuss methods for improving habilitation in underpopulated areas, based on the results of the survey.

Specialists: professionals engaged in habilitation, such as doctors, public health nurses, childcare workers, school teachers, and physical or occupational therapists

3. Outline of participants

The target developmental consultation center was founded in the southern part of A-Prefecture in 2008 as a social welfare service corporation specializing in habilitation for children. Before its opening, it had been necessary for children requiring habilitation to commute to facilities in adjacent prefectures despite a number of difficulties related to transportation and consultation. Considering this situation, community residents and specialists insisted on the necessity of habilitation to found the study center as a unique day habilitation facility in this community. The center was capable of caring for up to 20

children.

The present study targeted the mothers of children enrolled in this center, based on the idea that it might be possible to clarify challenging issues in a community by examining these mothers as community residents living under similar environmental and habilitative conditions. In addition, with cooperation from the unique habilitation facility in the community, it was an important opportunity to collect data that might reveal habilitation-related challenging issues in an underpopulated community.

4. Inclusion criteria

At the author's request, staff members of the center (center staff members) selected mothers of children who currently or previously used day habilitation services, who consented to cooperate with the study after fully understanding its objective. To complement and confirm those obtained from these mothers, data were also collected from relevant center staff members, for whom data collection did not interfere with their work.

5. Data collection method and procedure

1) Data collection

Data were collected through focus group interviews (FGI)¹⁵⁾. FGI is a methodology to examine qualitatively data obtained from participants through group discussions based on semi-structured interview guides. In this study, each FGI session lasted approximately 90 minutes, during which the mothers and center staff members were divided into groups for discussions based on the same semi-structured interview guides that had been previously presented to them. The guide for the first session dealt with habilitation-related challenging issues in an underpopulated community in order to clarify the environmental status of habilitation and related issues. That for the second session dealt with an accepting attitude toward habilitation in order to examine approaches to addressing such issues.

The FGI technique was adopted in this study for the following reasons: it enables researchers to collect "real voices" through discussions among participants in similar situations and environments in terms of habilitation; it empowers both participants and researchers by allowing them to share settings for the former to express themselves and exchange opinions¹⁵⁾. Mothers in a similar position, living in underpopulated areas and having children who require habilitation, are able to share their opinions regarding lives centered on habilitation, and establish peer relationships by participating in discussions under this theme. It also allows analysis of issues commonly observed among those involved in habilitation and their intentions.

2) FGI procedure

Interview sessions took place in a quiet classroom within the center, during which 1

facilitator and 1 observer were present, and were recorded, with the participants' consent. Appropriate arrangements to create a relaxing atmosphere, such as offering tea and cakes, were also made during each session. As it is necessary to hold at least 2 FGI sessions in order to collect sufficient data¹⁶⁾, 2 sessions were held. On the basis of the author's experience, the first session aimed to determine roughly the characteristics of the participants, and the second one was focused on extracting their true intentions after the establishment of relationships among them. The facilitator gave careful consideration so that each participant was able to express themselves freely. In line with this, the second session was started by reviewing the outcomes of the previous one to help to confirm the course of discussions and to help new members participate smoothly in the discussions.

6. Study period

This study was conducted within the period between September 2013 and January 2014.

7. Data analysis

1) Data accuracy

To ensure sufficient data accuracy using this method, the collected data were initially shared among collaborative researchers to create narrative records and extract contracted semantics, and were subsequently encoded for abstraction. The data were classified through repeated discussions among the collaborative researchers, and analysis was performed under the supervision of a specialist who was well versed in pediatrics to ensure sufficient data accuracy. The contents of narrative records were confirmed for all participants.

2) Analysis method

The collected data were analyzed, adopting a qualitative data analysis method¹⁷⁾ that emphasizes case analysis and context-based interpretations, considering its appropriateness to determine accurately the semantic content and relationship of each context, with a view to appropriately interpreting extracted issues.

3) Procedure to classify and analyze FGI data

(1) Creating a narrative record for each FGI group

(2) Examining the created narrative record in detail and contracting the entire text based on its contextual semantics for encoding

(3) Extracting key phrases from the contracted semantics to create codes

(4) Categorizing the created codes based on similarities and associations for each FGI group and classifying and analyzing factors

(5) Data of mothers were analyzed with a focus on the thoughts and behaviors of mothers and their families who live in underpopulated areas and receive habilitation, and data of

the staff were analyzed from the viewpoint of the thoughts and behaviors of professionals who provide habilitation.

8. Ethical considerations

Before the initiation of the study, the participants were provided with oral and written explanations regarding unconditional withdrawal or refusal and voluntary participation to obtain their consent. Their statements were recorded using an IC recorder, with their consent after explanations regarding appropriate data destruction after termination of the study. Their consent for the publication of study outcomes was also obtained after explaining methods to maintain anonymity. This study was conducted with the approval of the Ethics Committee of Gifu College of Nursing (approval number: 0070).

RESULTS

1. Outline of participants

Fifteen mothers participated in the study, the majority of whom were in their thirties or forties, and 2 were working part-time. Their children were enrolled in the habilitation center at the age of approximately 2, and the duration of its use ranged from 1 to 4 years, with a mean of 2 years. Reasons for enrolment were frequently based on public health nurses' advice. Complementary data were obtained from 12 center staff members in their thirties or forties, who had been working in the center for from 1 month to 10 years, with a mean of 6.5 years. They included 4 childcare workers, 1 social worker, and 2 instructors.

2. Results of FGI data analysis

In the following sections, various symbols are used to describe: factors: “”, categories: ◇, and codes: [].

1) Analysis of the mother group (Tables 1 and 2)

Seven and 8 mothers participated in the first and second FGI sessions, respectively, which lasted 70 and 90 minutes. Participants varied between the sessions, except for 2 who participated in both. On data encoding, the following 3 factors were extracted: “geographical conditions”, “the mother’s thoughts and behavior”, and “secure life”.

(1) First FGI session (Table 1)

Forty-two contracted semantics were obtained, and 13 codes were classified into 5 categories: “geographical conditions”: <living environments> and <the unavailability of sufficient resources>; “the mother’s thoughts and behavior”: <medical consultation-seeking behavior and its influences> and <information and judgments>; and “secure life”: <the sense

of security and stability>. The codes and categories are explained as follows:

(1)-1: “Geographical conditions”

This factor represented <living environments>, such as [an underpopulated community] and [partially comfortable rural life]. The category <the unavailability of sufficient resources> summarized the influences of [chronically insufficient medical resources], resulting in [limited pediatric service options] and [limited community-based medical services for the child], as well as difficulty in resolving problems.

(1)-2: “The mother’s thoughts and behavior”

This factor represented the mothers’ <medical consultation-seeking behavior and its influences>, such as [the necessity of periodically visiting a remote hospital with all family members]. While facing such necessity, they made efforts to take a positive perspective on their situations. After taking several hours to access the hospital, they were only provided with [unsatisfactory pediatric services] on some occasions. Regarding hospital visits, they showed [minimum necessary medical consultation-seeking behavior]. On the other hand, they addressed [difficulty in accurately recognizing the child’s health condition]. There were also concerns over [a delay in learning activities due to hospital visits for rehabilitation]. Regarding <information and judgments>, they obtained [information and advice from specialists and experienced mothers], and considered the child’s developmental stage as one of the [developmental family members] the entire family should address.

(1)-3: “Secure life”

The category <the sense of security and stability> summarized [secure and stable habilitation service use], explaining that the mothers maintained a stable mental condition by consulting habilitation-related issues with peers.

Table 1: First FGI Session
 {Habilitation-related Challenging Issues from the Viewpoint of Mothers Living in an Underpopulated Community}

Factor	Category	Code
Geographical conditions	Living environments	Underpopulated communities Partially comfortable rural life
	Unavailability of sufficient resources	Chronically insufficient medical resources Limited pediatric service options Limited community-based medical services for the child
The mother's thoughts and behavior	Medical consultation-seeking behavior and its influences	Necessity of periodically visiting a remote hospital with all family members Unsatisfactory pediatric services Minimum necessary medical consultation-seeking behavior Delay in learning activities due to hospital visits for rehabilitation
	Information and judgments	Difficulty in accurately recognizing the child's health condition Information and advice from specialists and experienced mothers Development of family members
Secure life	Sense of security and stability	Secure and stable habilitation service use

(2) Second FGI session (Table 2)

Sixty-three contracted semantics were obtained, and 13 codes were classified into 4 categories: “geographical conditions”: <the unavailability of sufficient resources>; “the mother’s thoughts and behavior”: <the mother’s thoughts on habilitation> and <views on parenting and dilemmas>; and “secure life”: <requirements of habilitation>. The codes and categories are explained as follows:

(2)-1: “Geographical conditions”

This factor represented <the unavailability of sufficient resources>, resulting in [an isolated mother and child] and [unsatisfactory pediatric services]. The mothers were unsatisfied with limited resources, and such dissatisfaction led to difficulty in accepting their “geographical conditions”.

(2)-2: “The mother’s thoughts and behavior”

This factor represented <the mother’s thoughts on habilitation> and <views on parenting and dilemmas>. <The mother’s thoughts on habilitation> summarized each of their thoughts and behavior immediately before and after enrolment. [The child’s unpredictable acts] indicated that the mothers faced their children’s abnormal behavior, while [support from specialists] suggested that specialists’ advice enhanced their sense of security. [Reasons for enrolment in a habilitation center] explained the mothers’ positive or negative views on habilitation. [Concerns and anxiety over the child’s academic career] revealed the presence of concerns and anxiety when considering the child’s next stage of education. [Appreciating positive habilitation effects] confirmed that both the mothers and the children realized positive habilitation effects. <Views on parenting and dilemmas>

summarized the mothers' views on and prejudice regarding parenting. [Reviewing the mother's own view on parenting] clarified each of their views on parenting not only for the child, but also for his/her siblings in the process of making habilitation-related decisions. [Other family members' and relatives' understanding of the necessity of enrolment] revealed that, while obtaining understanding from other family members, the mothers faced difficulty in obtaining it from relatives, as represented by [the presence of those lacking understanding]. On the other hand, [the mother's own prejudice] revealed the presence of her own underlying prejudice.

(2)-3: "Secure life"

This factor represented <the requirements of habilitation>, such as [restoring the mother's personal life] and [the importance of mutual support among family members]. [Restoring the mother's personal life] explained that the mothers' mental conditions stabilized after their children's enrolment in the center, while [the importance of mutual support among family members] suggested their situations, in which they needed support from other family members. In such cases, they developed an accepting attitude as a "secure life".

Table 2: Second FGI Session:

{Accepting Attitude toward Habilitation from the Viewpoint of Mothers Living in an Underpopulated Community}

Factor	Category	Code
Geographical conditions	Unavailability of sufficient resources	Isolated mother and child Unsatisfactory pediatric services
The mother's thoughts and behavior	The mother's thoughts on habilitation Views on parenting and dilemmas	The child's unpredictable acts Support from specialists Reasons for enrolment in a habilitation center Concerns and anxiety over the child's academic career Appreciating positive habilitation effects Reviewing the mother's own view on parenting Other family members' and relatives' understanding of the necessity of enrolment Presence of those lacking understanding The mother's own prejudice
Secure life	Requirements of habilitation	Restoring the mother's personal life Importance of mutual support among family members

2) Analysis of the center staff group (Tables 3 and 4)

Five and 7 center staff members participated in the first and second FGI sessions, respectively, 5 of whom participated in both. Both sessions lasted for 75 minutes to clarify the actual status of environments for habilitation and mothers' lives from the viewpoint of center staff members. On data encoding, the following 3 factors were extracted: "environments for habilitation", "the characteristics of roles", and "present life".

(1) First FGI session (Table 3)

Forty-one contracted semantics were obtained, and 17 codes were classified into 7 categories: “environments for habilitation”: <living environments>, <available resources>, and <the center>; “the characteristics of roles”: <center staff members>, <parents and other family members>, and <community residents>; and “present life”: <community life>. The codes and categories are explained as follows:

(1)-1 “Environments for habilitation”

This factor represented <living environments> as a category summarizing the characteristics of the community, such as [undeveloped public transportation systems], [abundant nature in the community], and [living environments comprising tourist destinations]. [Environments for parenting] highlighted the sense of security of the center staff members and mothers who lived close to their families and relatives as neighbors in the community. <Available resources> clarified the influences of the unavailability of a sufficient number of non-substitutable medical professionals, such as [chronically insufficient medical resources], while [insufficient social resources] indicated inconvenient physical environments. The center staff members also recognized [the availability of resources in adjacent prefectures]. <The center> where they worked mainly targeted [children aged approximately 2 requiring support], and acted [as a unique day habilitation facility in the community]. For its staff, [limited training methods] was a challenge.

(1)-2 “The characteristics of roles”

The role of <center staff members> was providing [individualized and specialized support for parents]. Among these <parents and other family members>, there were some [families choosing to move] in search of a more convenient life. As described as [fathers’ more active commitment] and [parents’ abilities to collect information and make appropriate judgments], the center staff members regarded such families as making efforts for their children. <Community residents> revealed that they were also aware of [community residents’ prejudice], while maintaining [communication with community residents] through their daily activities.

(1)-3 “Present life”

This factor represented <community life>, such as [life in an underpopulated community], reflecting the participants’ sense of familiarity with their community.

Table 3: First FGI Session
{Habilitation-related Challenging Issues from the Viewpoint of Center Staff Members}

Factor	Category	Code
Environments for habilitation	Living environments	Undeveloped public transportation systems Abundant nature in the community Living environments comprising tourist destinations Environments for parenting
	Available Resources	Chronically insufficient medical resources Insufficient social resources Availability of resources in adjacent prefectures
	The center	Children aged approximately 2 requiring support As a unique day habilitation facility in the community Limited learning methods
Characteristics of roles	Center staff members	Individualized and specialized support for parents
	Parents and other family members	Families choosing to move Fathers' more active commitment Parents' abilities to collect information and make appropriate judgments
	Community residents	Community residents' prejudice Communication with community residents
Present life	Community life	Life in an underpopulated community

(2) Second FGI session (Table 4)

Sixty-three contracted semantics were obtained, and 16 codes were classified into 4 categories: “environments for habilitation”: <living environments>; “the characteristics of roles”: <specialists> and <parents and other family members>; and “present life”: <the requirements of habilitation>. The codes and categories are explained as follows:

(2)-1 “Environments for habilitation”

This factor represented <living environments>, such as [parenting with cooperation from the child's grandparents], indicating that cooperation from the child's grandparents was indispensable for parenting. [Surrounding environments] highlighted the mothers' necessity of supporters and, on some occasions, development of an accepting attitude.

(2)-2 “The characteristics of roles”

This factor regarded <specialists> engaged in habilitation in the community, such as childcare workers, doctors, public health nurses, and school teachers, while the mothers were represented by <parents and other family members>. The former category highlighted the center staff members' focus on [the provision of individualized and specialized habilitation approaches] and [emotional support for families]. Their goal was providing habilitation approaches to help children develop [abilities necessary for their ages] in collaboration with public health nurses engaged in [activities to support families]. [Community-based childcare workers' advice] revealed that some childcare workers' statements regarding the child's development negatively affected the mother, occasionally

leading to the necessity of [support for mothers without available consultants] from center staff. [The necessity of learning about the latest treatment methods and diseases] explained that it was necessary for the center staff members to prevent underpopulated environments from interfering with their obtainment of necessary knowledge. <Parents and other family members> clarified that enrolment in a habilitation center was not desirable for a large number of parents, as represented by [undesired enrolment in a habilitation center]. In most cases, habilitation was initiated when it was still difficult for parents to address their own insufficient understanding of and prejudice against the child's disability and develop an accepting attitude toward habilitation. However, their attitudes changed with time, as explained by [parents' active attitude toward habilitation]. On the other hand, [mothers not expressing their true intentions to center staff] revealed a lack of mutual understanding between the mothers and center staff members, highlighting the difficulty of establishing trust-based relationships between them. Families gave priority to treatment and education for their children, as represented by [families choosing to move], and occasionally needed [support for families with religious dependence]. This factor, "the characteristics of roles", demonstrated that it was difficult for the center staff members to establish appropriate relationships with the mothers, and for the latter to develop an accepting attitude toward childcare worker-related issues. In contrast, the relationship between the mothers and public health nurses was well established through continuously active communication.

(2)-3 "Present life"

This factor represented <the requirements of habilitation>, such as an [accepting attitude in daily life] and [mature parents]. The latter indicated positive changes in parents from the center staff members' viewpoint.

Table 4: Second FGI 2 Session
{Accepting Attitude toward Habilitation from the Viewpoint of Center Staff Members}

Factor	Category	Code
Environments for habilitation	Living environments	Parenting with cooperation from the child's grandparents Surrounding environments
Characteristics of roles	Specialists	Provision of individualized and specialized habilitation approaches Emotional support for families Abilities necessary for their ages Support for mothers without available consultants Public health nurses' activities to support families Community-based childcare workers' advice Necessity of learning about the latest treatment methods and diseases
	Parents and other family members	Undesired enrolment in a habilitation center Mothers not expressing their true intentions to center staff Parents' active attitude toward habilitation Support for families with religious dependence Families choosing to move
Present life	Requirements of habilitation	Accepting attitude in daily life Mature parents

3. Habilitation-related issues extracted from the mother and center staff groups

1) Habilitation-related challenging issues in an underpopulated community

The mothers regarded “geographical conditions” as a major factor associated with challenging issues, and considered <the unavailability of sufficient resources> to influence habilitation activities for their children negatively. Such activities included: making arrangements among family members when visiting a remote hospital for medical consultation; and maintaining the health and learning activity of the child undergoing outpatient rehabilitation. To adapt to life supporting habilitation, the mothers made judgments based on the information collected from specialists. However, as represented by [chronically insufficient medical resources], the unavailability of specialists for consultation and [limited pediatric service options] led to a sense of dissatisfaction with medical services, and prevented them from establishing trust-based relationships with doctors. Similarly to the mothers, the center staff members also realized [chronically insufficient medical resources] due to <the unavailability of sufficient resources>, including full-time doctors, who are able to diagnose children’s developmental problems accurately, and substitute medical professionals.

2) Accepting attitude toward habilitation

The mothers were unsatisfied with “geographical conditions” while leading their daily lives. From the center staff members’ viewpoint, mothers showed an accepting attitude toward habilitation even in the case of [undesired enrolment in a habilitation center], if they could realize its positive effects. In fact, the mothers sought specialists’ advice on the child’s daily activities, and took actions for habilitation daily, while other family members showed an active attitude toward habilitation as [mature parents]. On the other hand, they had [concerns and anxiety over the child’s academic career], and expected their children’s early graduation from the center. The center staff members faced the difficulty of appropriately determining the child’s ability to perform daily life activities for the age of approximately 2 as a requirement of enrolment as [abilities necessary for their ages], particularly when there were differences between the actual time of enrolment and those desired by mothers. In short, the center staff members recognized the presence of [mothers not expressing their true intentions to center staff], revealing the difference in views on habilitation between the two parties. In the case of children admitted to schools, school teachers asked the mothers to confirm their children’s health conditions with doctors, in order to ensure safe group activities. However, [difficulty in accurately recognizing the child’s health condition] demonstrated that, when confirming this with doctors, some mothers faced difficulty in

sharing the recognition of their children's health conditions with them due to the difference in the level of medical knowledge, revealing insufficient communication between mothers and schools. [The presence of those lacking understanding] and [the mother's own prejudice] also revealed that it was difficult for the mothers to develop an accepting attitude due to dilemmas, which prevented them from resolving their concerns and anxiety. The center staff members noted unfavorable relationships between some mothers and childcare workers in the case of children simultaneously belonging to a public nursery school in the community and the habilitation center, as [community-based childcare workers' advice] negatively affected mothers' emotions on some occasions.

DISCUSSION

1. Factors associated with habilitation-related challenging issues from the viewpoint of mothers

The majority of habilitation-related challenging issues were due to <the unavailability of sufficient resources> as a “geographical condition”; therefore, this factor may be responsible for the mothers' dissatisfaction and anxiety. As medical resources for specific purposes are non-substitutable, their unavailability forced the mothers to give up on their use or visit remote medical facilities. In fact, [chronically insufficient medical resources] and [limited pediatric service options] confirmed that the unavailability of full-time specialists and the lack of established trust-based relationships with doctors frequently prevented the mothers from addressing their problems by themselves. “The mother's thoughts and behavior” were affected by <the unavailability of sufficient resources> as a “geographical condition”, and this may be mainly explained by [the necessity of periodically visiting a remote hospital with all family members] and [a delay in learning activities due to hospital visits for rehabilitation]. In such a situation, difficulty levels may depend on adjustment and dealings among family members, while, as the mothers pointed out, challenging issues may negatively influence their daily lives, and, consequently, the entire family³⁾. Furthermore, in addition to the necessity of using long-term medical services due to the characteristics of the child's disability or disease, it was also necessary for them to prepare themselves for crisis management, as such management more frequently depends on individuals in underpopulated communities, and this may explain their dissatisfaction with and anxiety over public support systems¹⁸⁾, indicating the difficulty of independently resolving these issues as a challenge.

2. Development of an accepting attitude toward habilitation

While [the necessity of periodically visiting a remote hospital with all family members] illustrated mothers addressing difficult situations through certain approaches, such as enjoying the trip to the hospital with the child as an excursion, [minimum necessary medical consultation-seeking behavior] suggested that the medical consultation-seeking behavior of mothers with a realistic view on medical consultation may have been based on their own thoughts and sense of values. These efforts to take a positive perspective on their situations and actions based on their own sense of values may also have helped the mothers develop an accepting attitude toward habilitation. Such mothers may be regarded as able to use their skills appropriately to accept their situations, while their skills may be influenced by the relationships between habilitation resources or specialists and mothers and among the latter, in addition to personal factors, such as mothers' own thoughts and actions, understanding of habilitation, and sense of values. For example, mothers for whom peer consultations are available are influenced by mutual support more frequently¹⁹⁾. In this respect, the influence of non-specialists on mothers may be more marked than that of specialists and their development of an accepting attitude toward habilitation in an underpopulated community. As the population of those areas is small, efforts should be implemented to help mothers establish relationships. Although parent-child classes are available for mothers with children who require habilitation, some mothers feel anxiety over child-raising and burdened with participation in such classes. Those parent-child schools should be improved so that mothers and their children view them as an opportunity to receive necessary support. As <information and judgments> suggested, the mothers developed an accepting attitude to maintain their daily lives supporting habilitation in an underpopulated community as family members by addressing issues related to the development of their children with disabilities. Although developmental challenges during infancy²⁰⁾ increase mothers' and other family members' distress and anxiety in daily habilitation activities, efforts to address them lead to their mental growth. Therefore, for mothers living in underpopulated communities, it may be important to recognize their challenges accurately, and to address them by taking actions with other family members. As a characteristic of families living in underpopulated areas, grandfathers and grandmothers are very important. With the aim of maintaining an environment in which all members of a family accept their lives based on habilitation, it is necessary to provide them with support to help them receive information from, or share it with, public health nurses and the staff of centers to consider and make decisions with the help of professionals on a daily basis, so that they can enhance their ability to address problems in each of their developmental stages.

3. Challenges of developing an accepting attitude

In this study, determining an appropriate time for enrolment in a nursery school was one of the most difficult issues for mothers. They expressed vague anxiety about it; in fact, if children are regarded as lacking skills to perform daily life activities sufficiently for the age of 2 and a half years during academic career guidance provided by center staff, the opportunity to enter a nursery school will be shelved. While strongly desiring the most beneficial choices for their children's lives, the mothers expected early termination of habilitation. Such a tendency may have been associated with the relationship between mothers as habilitation service users and center staff members as providers. In such a service-based relationship, it is possible for service users to obtain support, but not to provide it to others¹⁹⁾; in short, the mothers may not have been in an equal relationship with center staff members. Basically, as revealed by [undesired enrolment in a habilitation center], parents of children requiring habilitation do not desire their children's enrolment in a habilitation center. The center staff members stated that they invited mothers 1 month after enrolment to demonstrate improvements in their children, suggesting that such arrangements may increase mothers' excessive expectations for habilitation; observing early improvements, they may expect that their children will complete habilitation programs early. However, from the center staff members' viewpoint, habilitation was only part of available resources in the community, and mothers' excessive expectations for it might have increased their sense of burden. Such a difference in views on habilitation between them may be due to their relationship, indicating that they may not necessarily share the identical direction of habilitation. What is required for mothers and the staff to proceed in the same direction to promote habilitation, then? Mothers' awareness of habilitation should be improved, and all family members are required to acquire accurate knowledge and overcome prejudices. Efforts by the community as a whole are also essential to allow family members to actively promote it. The staff should not only cooperate with community events, but also actively become involved in activities associated with the community. Therefore, the intermediation of public health nurses, who have been promoting community-based activities, is essential, and it is necessary to encourage the nurses to interact with community residents and staff members of habilitation centers as well as maintain these relationships. The mothers also expressed their dissatisfaction with available medical services. In current medical systems, pediatricians dispatched from university medical offices provide pediatric services for a limited period of time. It is not necessary for them to consider the provision of long-term general medical services, as they leave communities before fully understanding community residents' living conditions. In such a situation, mothers' efforts to educate pediatricians

dispatched to underpopulated communities may be important even for a limited period of time. In this study, the majority of mothers simply expressed their dissatisfaction with pediatricians, rather than making such efforts. Their behavior may also be explained by the above-mentioned service-based relationship. Although the number of children targeted for habilitation is limited, doctors who treat such patients in underpopulated communities should recognize that they themselves are also community residents, in addition to the importance of collaborating with mothers. In order to maintain children's health in underpopulated communities, efforts to access specialists and services despite the chronic insufficiency of medical resources and difficulty in developing an accepting attitude toward habilitation are crucial. Therefore, it may be necessary for mothers to enhance their awareness of the necessity of collaboration with center staff members, as well as community-based specialists, such as doctors, public health nurses, childcare workers, and school teachers, take active actions based on appropriate information and knowledge, and improve their skills to access appropriate medical services for their children through consultations and negotiations.

4. Specialists' efforts to improve the quality of habilitation in underpopulated communities

It has been reported that families' sense of relief is enhanced by developing an appropriate understanding of their children with diseases after diagnosis²¹⁾. In line with this, it may be necessary for specialists to reduce mothers' and other families' dilemmas due to enrolment in a habilitation center by helping them mentally stabilize and appropriately understand the necessity of habilitation. In underpopulated communities, interpersonal relationships are close¹⁹⁾ in the presence of persistent exclusivity and prejudice. The necessity of maintaining family life, including the child's grandparents, under such conditions may be a factor increasing mothers' stress and concerns over other residents' views and prejudice. Therefore, specialists should devise appropriate methods to support mothers in consideration of their stressful environments and the relationship between long-term resource insufficiency and chronic stressors²²⁾. Donenberg²³⁾ emphasized the necessity of support from public health nurses, in addition to considering environmental factors, when parents suffer from severe stress due to their children's communication-related problems. In the studied community, reasons for enrolment in the habilitation center were mostly based on advice from public health nurses who noted developmental problems, such as language retardation. On this basis, public health nurses may play an important role in establishing an appropriate relationship between mothers and community-based specialists to achieve mutual understanding and empowerment from enrolment to graduation. When habilitation is needed during infancy in an underpopulated

community, parents generally suffer from stress due to anxiety over the disease or disability, in addition to typical parenting stress^{24, 25)}. Halpin²⁶⁾ reported that the role of health visitors for children with suspected autism and their families is to help parents clarify the characteristics of the children's development, rather than providing a diagnosis. It has also been reported that, in the case of children with autism, mothers frequently suffer from a higher level of stress than fathers, and the level of stress depends on the availability of support²⁷⁾. On the basis of these findings, it may be center staff members' duty to support them from a professional viewpoint, while placing importance on their living conditions and interpersonal relationships in consideration of community residents' common sense of values. Furthermore, as information is actively shared and accumulated during daily habilitation activities in underpopulated communities, appropriate environmental arrangements to enable mothers to share such activities may also be essential. The study center is a unique habilitation facility in the community, and its users live in its vicinity. As the community is extensive, comprising rural households, habilitation services provided by the center did not cover the entire community. In recent years, a number of novel attempts for underpopulated communities have been made in- and outside Japan, such as remote medical consultation services via television²⁸⁾ and improved systems to consult physicians using digital technologies²⁹⁾, respectively. These systems are characterized by communication using monitors. Now that advanced Internet environments are accessible, it may also be useful for the study community to establish systems to access specialized consultation services effectively using IT equipment in consideration of cost performance.

CONCLUSIONS

In the studied underpopulated community, collaboration among mothers or with specialists was highly necessary due to the unavailability of sufficient resources. The following results may provide a basis for habilitation approaches considered appropriate by mothers and specialists: From the viewpoint of mothers, difficulties in accessing daily medical consultation services and independently addressing situations due to the chronic insufficiency of medical resources as a geographical condition and its influences were challenges. In order to maintain daily life supporting habilitation in an underpopulated community, the mothers developed an accepting attitude based on their own thoughts, actions, and sense of values, as well as information-based judgments. Such a tendency was marked when accessing medical services in remote facilities, and less frequently observed when making decisions regarding the child's academic career, communicating with doctors

or schools, and establishing relationships with childcare workers. In order to help mothers develop an accepting attitude, it may be necessary for specialists to empower them, and for the latter to become aware of such empowerment. It may also be important for specialists to maintain an equal relationship with mothers from their professional standpoint, while mothers should improve their skills to discuss, consult, and negotiate sufficiently with specialists in search of appropriate medical and welfare services.

Since mothers living in underpopulated areas are considered to be stressed due to prejudices and a shortage of medical resources in the community, public health nurses, as persons who deeply understand mothers, should start to provide them with support even before their children are admitted to habilitation centers while respecting the backgrounds of their community lives and relationships. Nurses should also implement various approaches such as activities to increase community residents' awareness of habilitation and health activities to enhance the ability of family members, including grandfathers and grandmothers, to solve problems.

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