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Japanese fathers' experience with children with profound intellectual and multiple disabilities

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ABSTRACT

Children with severe or profound intellectual and multiple disabilities (PIMD), who have high medical care needs, are under constant pressure of survival and their growth processes are difficult to predict. Although research has shown significant psychological and social burden on parents taking care of such children, research on Japanese fathers has been scarce. This study aimed to clarify the suffering and judgment of Japanese fathers following the birth of a PIMD child and describe their experiences living with a preschool PIMD child. We also discussed the effect of nursing support on maintaining the dignity of fathers by deeply understanding the nurture experience. Verbatim records of semi-structured interviews conducted with eight fathers were analyzed based on the Modified Grounded Theory Approach. Twenty-eight concepts were generated along with the following four categories: (i) fear for the child's life and a feeling of being left out of information sharing, (ii) struggle to continue home care, (iii) acquisition of nursing skills and collaboration with wife, and (iv) response to the child's precious growth. Despite challenges in caring for a child with PIMD, in-home medical and nursing care teaches fathers the significance of being a parent. These findings highlight the relationship between fathers of PIMD children and healthcare workers, who can provide support for fathers as dignified caregivers. *Ryukyu Med. J., 38 (1~4) 1~12, 2019*

Key words: Child with PIMD, Fathers' Experience with Living Child, In-home Medical care, Modified Grounded Theory Approach

INTRODUCTION

Recently, the survival of children with serious physical and mental disabilities is guaranteed by medical progress. Irrespective of the cause of disease, children can reside at home with the aid of various medical care devices, whereas in the past they required hospitalization. Therefore, parents have certain expectations from home medical doctors and visiting nurses who provide pediatric home care, and human resource development and education have become important issues[1].

In the study of parents of a child with a disability, physical and psychosocial stress associated with raising a child with a disability has been noted. For example, in the case of a child who has a sleep disorder and requires specialized medical care, the parents have psychogenic fatigue and night awakening produces poor health conditions[2, 3]. For parents of children with cerebral palsy and movement imperfections, assistance with getting the child in and out of the car is the greatest burden[4]. Parents of a child with profound intellectual and multiple disabilities (PIMD) must reduce their work hours to nurture the child and respond to changes to their

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lifestyles[5]. Similarly, parents of the PIMD child have to commit time to the management of the child's daily life activities and care, significantly reducing available free time for social and leisure activities[6].

Concerning the effect of the signposts program in parents of a child with an intellectual disability, a high effect was demonstrated for mothers who participated with partners[7]. Moreover, the participation of the father in the care of an autistic spectrum disorder child when the child was 9 months of age reduced the sense of burden of the mother when the child was 4 years of age[8].

Participation of the father in the care of a child with a brain lesion or mental disabilities, such as "interaction with the family," "guidance," "housekeeping activities," and "recognition, play, and leisure activities," has a significantly negative correlation with childcare stress of the mother[9]. These results show that participation of the father in child care is important in nurturing of the PIMD child, who has high medical care needs.

The father of a child with Down's syndrome who was delivered in the neonatal intensive care unit (NICU) experienced suffering by the crisis of the life just after birth and he held a strong feeling to protect the child, while the mother felt regret for having the child[10]. This observation indicates that fathers of children with severe disabilities can build a foundation for living with the child by limiting their personal work and leisure time[11]. Moreover, fathers who raised an 8—10-year-old child with a disability responded that they had to change the idealized image of the parent and child relationship because of the child's disability[12]. Because of the gradual growth of the child with a disability, fathers who raised both a healthy child and a disabled child tended to treat a disabled child like a baby more often than mothers[13]. Thus, parents of the PIMD child have varying experiences according to the child's birth order and condition.

According to the cultural norms in Japan, women mainly perform housework and provide child care. Thus, the roles of fathers and mothers in obtaining and providing child care and family function are different; mothers have more time for primarily providing child care[14-16]. Therefore, much previous research has focused on the burden to the mother of a child with a disability, and care not to sacrifice oneself is proposed for a mother bound by great nurture responsibility[17]. However, few studies have revealed the difficulty of a father to nurture and support his family during such situations. After birth, the early developmental growth of a PIMD child begins at home and is shaped by medical care by the family and relationships with the family before entering school. Therefore, it is necessary for healthcare professionals to provide family support to the father and mother during the preschool period. Thus, understanding the father's experience with receiving medical support and providing care to a child with a disability is critical.

Because a PIMD child requires high medical care, and the child will face continuously changing physical and mental obstacles, the parent may find it difficult to be nurturing. Therefore, the purpose of this study was to clarify the suffering and judgment of Japanese fathers following the birth of a PIMD child and describe their experiences living with a PIMD child. We also discussed the effect of nursing support on maintaining the dignity of fathers by deeply understanding the nurture experience.

METHODS

Design

The analysis was conducted using the Modified Grounded Theory Approach (M-GTA). M-GTA differs from classical GTA in its strict coding procedure with explicit instructions for coding. It succeeds four basic characteristics from classical GTA: 1. theory generation, 2. use of grounded on data, 3. empirical proof characteristics, and 4. application of theoretical inspection. Furthermore, the analysis was controlled by investigating the issues of the classical version, not finely dividing text, emphasizing the perspective of researchers, setting analysis topics in the data range, and performing the analysis in recognition of the methodological limitations when judging the theoretical saturation[18]. M-GTA is uniquely suited for comprehensive explanations of concepts based on analysis closely attached to data, making it a good method for offering effective explanations and assumptions regarding human behaviors[18-20]. Research suitable for M-GTA must involve social interaction, be a domain about human service wherein inspection by the active application of findings is possible, and the phenomenon which is the object of the research has the character of the process[18]. We adopted the M-GTA in the present study because the methodology was reproducible

and the analysis could be adapted to these points.

Participant recruitment

The study participants were fathers of preschool children who have PIMD, require high medical care, and whose life support is dependent on the family. PIMD was defined as having both intellectual and physical behavior disorders[6, 21, 22]. High medical care was defined as requiring 24-hour nursing care at home and using multiple medical devices including a respirator[22, 23]. We excluded fathers with mental disease or communication difficulties.

To recruit the study participants, we sent an explanation of the study objectives to office administrators at Okinawa Home Visit Medical Nursing Consortium and requested candidate recommendations. Office administrators recommended fathers who expressed a willingness to contribute to the research. We then contacted the fathers and subsequently re-explained the study objectives as well as the voluntary nature of participation in the study. Dates and locations of interviews were then determined. We continuously screened participants from November 2016. We confirmed that further introduction was not provided by the temporary nursing staff at the home station of Okinawa Island and sufficient interview data were provided. Therefore, screening was concluded in April 2017. As a result, eight men met the eligibility criteria and were included in the study.

Data collection

Semi-structured interviews based on an interview guide were conducted to collect the data. The guide was structured in such a way that the participants, while recalling their experiences from when they found out about their child's disability to the present time, were able to freely talk about their feelings and lifestyle changes with an emphasis on episodes of their child's status changes, as well as relationships with family members and others.

Each subject participated in one interview that lasted approximately 60 minutes. Interviews were held at locations where privacy was secured, either at the university or locations designated by the participants. All interviews were recorded using an integrated circuit recorder, the contents of which were then transferred to verbatim transcripts. Both the interviews and subsequent analysis were conducted by the same group of researchers.

Data analysis

Based on the interview transcripts, the analytic theme emerged as the experience of fathers living with a child with PIMD, and the analytic target was set as the fathers of preschool children with PIMD. We extracted examples expressing the theme. Similarly, we extracted other specific examples and generated a definition and the concept that could explain the meaning of the set point and repeated examination until a resemblance example and opposing examples were not extracted. The series of concept generating processes was recorded in the analysis worksheet (Table 1). We kept a certain distance from the data while proceeding with the analysis. In addition, we conducted clustering

Table 1 **Example of the analysis worksheet**

Concept name	Information regarding the child provided mainly to wife
Definition	During hospitalization, medical personnel explain the crisis and medical information regarding the child only to the wife, who is with their child at all times. There is no scope for the father to directly hear from the child's attending physician because he visits the hospital after work.
Examples (Variation)	Mothers, but not fathers, can enter the NICU. My wife was always with our baby, but for a long time I could not be with him (C1). I was not allowed to touch my baby, who was in the PICU; however, my wife could do everything (C2). It was necessary to attend the child; therefore, my wife always stayed with her (C3). I frequently visited my baby, but I was not able to directly meet with the attending physician (C5). Although medical personnel say they provide full nursing care, a parent has to attend the child during hospitalization, which is quite demanding (C6) I had to take care of the hospitalization process in the beginning. I had no information about my baby's symptoms, and I had to wait alone until everything about my baby's urgent care and hospitalization settled down (C7).
Theoretic note	Although fathers want to be informed regarding any crisis, such as sudden medical changes or potential disabilities, directly from medical personnel, no such explanation is offered at night. This concept was generated according to data indicating that such explanation is provided to mothers only, giving fathers a sense of alienation from information sharing.

relationship analyses between the concepts and continued comparative analyses until categories and subcategories were identified. We decided that theoretical saturation was reached because new concepts were not generated any more, the concepts and categories were interrelated and the overall integrity was confirmed. Finally, we created a chart of the results and organized the entire analytic process as a storyline.

Rigor

For qualitative studies, the criteria for determining rigor in order to ensure reliability and validity include authenticity, credibility, integrity, and applicability[24, 25]. To ensure authenticity, credibility, and integrity, this study followed the analysis method of M-GTA and clarified the data analysis process using worksheets. We also maintained consistency by checking the analysis contents. Throughout the process, from study design to analysis, the study was supervised and constantly reviewed by a professional who specializes in home nursing and M-GTA. In addition, we confirmed with home visit nursing care office administrators the applicability of the results to other fathers who also had a PIMD child.

Ethical considerations

This study was approved by the Ryukyus University Ethics Committee for Clinical Studies (Authorization No. 850). In the interviews, the researchers explained the study objectives both orally and in writing and obtained written informed consent from all participants. The written forms provided the names of the researchers, their contact information, and the study objectives. They also explained that participation in the research was voluntary and the participants were allowed to withdraw at any time. The forms further described the advantages and disadvantages of participating in the study, privacy protection, intent to publish the study outcomes, and data management/disposal during and after the study, along with the contact information for inquiries. The obtained data were separated from networks and managed on a personal computer with access restricted by a password.

RESULTS

Participant characteristics

Researchers conducted interviews with eight participants. The general characteristics of the participants are presented in Table 2. The interview durations were between approximately 40 and 75 minutes (average 61.5 minutes). As a result of having judged that interview data were sufficient, we did

Table 2 **General characteristics of the participants**

			Child			
Case	Age (years)	Work	Age (years)	Sex	Diagnosis Care needs	Position of the child in family
1	28	Independent business	1	Male	Laryngomalacia, growth retardation BIPAP, frequent suction	2/2
2	36	Public service employee	5	Female	Nuclear DNA metabolic disorders respirator, gastrostomy	1/2
3	36	Office worker	3	Female	CNS disease respirator, tracheal aspiration, gastrostomy	2/2
4	50	Public service employee	5	Male	Chromosome aberration syndrome respirator, frequent suction, gastrostomy	4/4
5	30	Office worker	1	Female	Paroxysmal intractable epilepsy, CPAP, frequent suction, cuff assist, tube feeding	3/3
6	45	Public service employee	2	Male	Congenital myopathy, chronic respiratory failure CPAP, cuff assist, gastrostomy	2/2
7	24	Office worker	0.6	Male	Severe asphyxia sequelae respirator, tube feeding, management of body temperature	1/1
8	50	Public service employee	3	Male	Congenital anomaly syndrome tube feeding	3/3

not carry out additional participant screening or interviews.

Storyline

The analysis generated 28 concepts, nine subcategories, and four categories. A chart was prepared to show the overall relationships among them (Fig. 1), and all analysis results were organized into a storyline. Hereafter, concepts are shown in quotation marks (“ ”), subcategories are shown in angle brackets (< >), and categories in square brackets ([ ]).

Initially, the fathers experienced a sense of crisis about their children’s lives and a feeling of alienation caused by not being able to obtain information about their children’s health at the hospital: [Fear for the child’s life and a feeling of being left out of information sharing]. Furthermore, the fathers strove to continue living with their child’s medical care given at home: [Struggle to continue home care]. Through experience, they gained nursing care skills and built collaborative care systems with their wives: [Acquisition of nursing care skills and collaboration with wife]. They also recognized the precious nature of interacting with their child and witnessing their gradual development and discovered the significance of growing as parents together with their child: [Response to the child’s precious growth].

Elements of a configured process

The following paragraphs explain the categories, or components, of the fathers’ experience using subcategories and concepts according to the generation process (Fig. 1). Characteristic sections of interviews

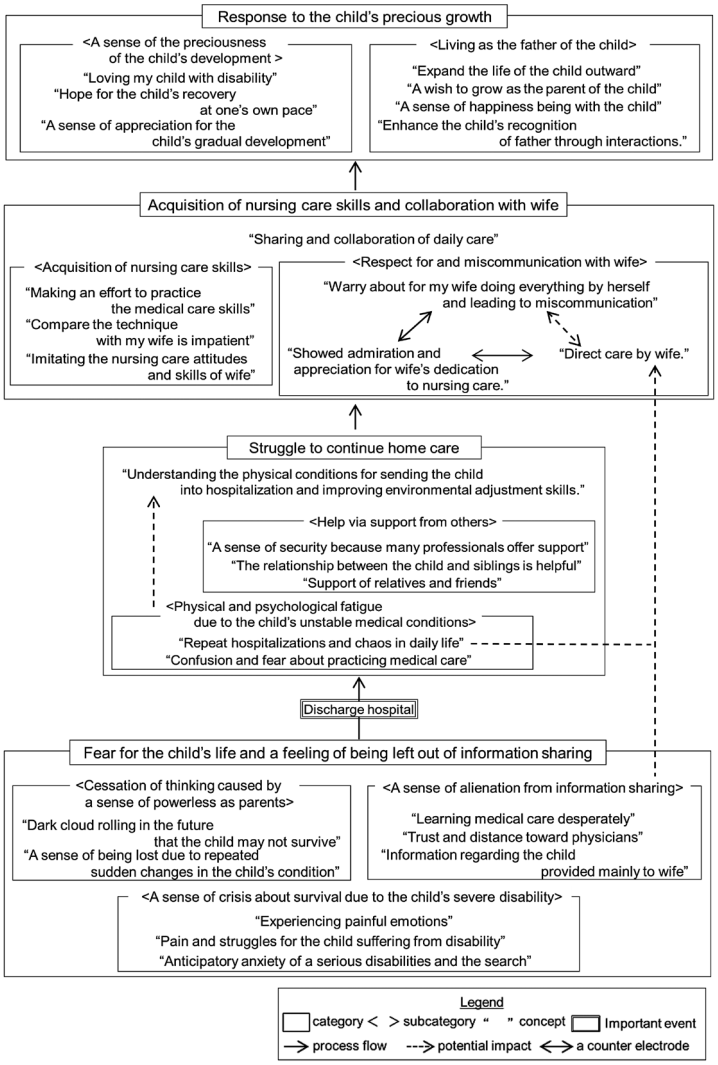

Fig.1 **Japanese fathers’ experience with children with PIMD**

that provided a basis for the concept generation are excerpted from the data.

Fear for the child's life and a feeling of being left out of information sharing

This category indicates a situation in which the fathers were surprised by the severity of the child's disability and, while experiencing a strong sense of danger about the child's survival, felt alienated during the child's hospitalization as information regarding the child's condition was only given to their wives, who stayed with the child all the time.

> Well, I did not think that the baby would have a very short life; however, there was no diagnosis, the conditions were not good, and no one knew whether he would live or die (C6).

As implied above, the fathers experienced "Pain and struggle for the child suffering from disability" and had <A sense of crisis about survival due to the child's severe disability> as they worried whether their child would live.

> It is more like getting on a roller coaster than talking and discussing. Many things happen every day, and I have my hands full just to keep up with things or maybe I am not able to keep up with them… The situation is like this, and no one knows the future either (C6).

As the narrative indicates, the fathers felt "A sense of being lost due to repeated sudden changes in the child's condition" and experienced a <Cessation of thinking caused by a sense of powerlessness as parents>.

> Ever since the child was born, mothers could go inside the NICU but not fathers… My wife stayed with our baby all the time, but I was not able to be with him for a long time (C1).

> I frequently visited my baby, but, well, I was not able to directly meet with his attending physician (C5).

In addition to the feelings of both "Trust and distance toward physicians," fathers increasingly experienced <A sense of alienation from information sharing> because "Information regarding the child provided mainly to wife."

Struggle to continue home care

This category applies to a situation in which the child recovered from a critical condition and began medical care at home, but re-hospitalization occurred repeatedly due to sudden changes in the child's health, resulting in the father's feeling frustrated while struggling to maintain a stable home life.

> I thought that I knew the procedure when I practiced it a few times at the hospital, but I was not able to hear this airborne sound with our stethoscope at home. But I cannot say that to my wife and physicians. So I do not want to touch those tube-type things as much as possible (C8).

> At times, I would go to the hospital to take care of my baby and go to work without getting much sleep at home, and days like that continued… I had to bear a big burden (C4).

The fathers felt "Confusion and fear about practicing medical care" after their child came home and experienced <Physical and psychological fatigue due to the child's unstable medical condition> because of "Repeated hospitalizations and chaos in daily life."

> When I want to go any such places with my baby, I can go now. I gradually learned the support system or contacts of people who can give us support because I had experienced (C2).

When family members were confused by the transition from the hospital to home care, the fathers felt the "Support of relatives and friends" who stood with them and who supported their efforts to raise the child in the family. They also felt "A sense of security because many professionals offered support" and received <Help via support from others>.

> After my baby left the hospital, I started to learn how to care for her at home as I gained experience… I would say that I am now used to it (C2).

As fathers and other family members repeatedly

experienced the child's hospitalization, they became capable of maintaining medical care at home and advancing the skills of prevention of pathologic aggravation by "Understanding the physical conditions for sending the child into hospitalization and improving environmental adjustment skills."

Acquisition of nursing care skills and collaboration with wife

This category describes the process of fathers learning daily nursing care skills and managing relationships with their wives who support medical care at home together.

> My wife is used to playing with him or maybe I think that she is an absolute presence for him. When she is cradling him, he often plays and smiles, but if I do the same thing, he looks at me as if to say, "Who are you?" You know, you can tell from his expressions. He has this expression of relief as if to say, "Oh, this is my mom" (C1).

While feeling confused about how to interact with their children with contracture, flaccidity, or deformation, the fathers learned by "Imitating the nursing care attitudes and skills of wife" and also engaged in the <Acquisition of nursing care skills>.

> Recently, I took the older sibling, baby, and my wife for a walk visiting the town park… I just want to reduce situations where only my wife carries physical and psychological burdens… (C4).

> I have been leaving the care of my baby to my wife altogether… I play, interact, or bathe him, but my wife has been in charge of regularly feeding once every 3 hours during the night, and I do not change diapers at all (C1).

The fathers were impressed that their wives cared for their child attentively for 24 hours a day. They thought about what they could do for their wives and "Showed admiration and appreciation for wife's dedication to nursing care." Conversely, due to fears about medical care practices, the fathers considered that taking care of the child was the role of their wives and tended to describe the child's nursing care as "Direct care by wife."

> When we talk about other measures/services for taking care of our child, the conclusion always leads us to the same phrase, "I'm doing my best!"… I only want to reduce my wife's care burden (C3).

> My wife does not have to do something with our baby all the time during the day and she can take breaks here and there… Sometimes she seems frustrated because she has to constantly do things with him (C5).

Although the fathers were worried about their wives doing everything by themselves and intended to give suggestions for easing the burdens on their wives, they tended to hear objections from their wives, leading to miscommunication. These contradictory situations were named <Respect for and miscommunication with wife>.

> For example, my wife bathes with our baby. I then dry and clothe our baby. In addition, after I am done with my work, I help with housekeeping chores, take a bath, and calm myself down. Then I lie down next to my baby and talk to her until she sleeps. I sometimes hold her hands, too (C3).

As the fathers were repeatedly involved in the child's nursing care, they created a flow of sharing daily care and collaborating with their wives to establish a family lifestyle that included the child with a disability.

Response to the child's precious growth

This category represents the various feelings of the fathers who, after seeing their child undergo a life-threatening crisis or after feeling frustration during the time before medical care was established at home, gained a strong sense of their child's development and discovered deeper meanings of being the father of their child.

> My baby is not worried when she is with me… Her mother is out shopping and not around her, but she is fine staying with me. Since I was able to feel that she started to recognize me, I started to feel something like attachment (C3).

In the course of spending time with their children, the fathers strengthened their feeling of "Loving my child with disability" as they realized that the child's responses toward them were

different from the child's responses to others.

> The baby's condition is becoming stable… when she was in the hospital, her weight did not increase at all and she did not grow. She suddenly grew when the current lifestyle at home started to stabilize. Now she is included in the upper range of the growth curve. She is growing big… (C2).

> Well, I do think that I have a hope for a cure… but it is not certain. I take the reality into consideration while maintaining hope (C5).

The fathers felt <A sense of the preciousness of the child's development>, including "A sense of appreciation for the child's gradual development" and "Hope for the child's recovery at his or her own pace."

> Of course, I used to have various hobbies… Now I take a walk with my family or spend holidays together. It is nothing special but my happy time spent with my family (C4).

> It is a matter of fact that the presence of the mother is significant for A, but I want A to recognize my existence too. So, I voluntarily take a bath with A and I always carry him when we go shopping… (C1).

> I am working on myself too, such as the way I think about people with disabilities. So, I feel that I also have had to grow up since my child was born… (C7).

The fathers were impressed with the children's gradual development and trying hard to "Enhance the child's recognition of the father through interactions." The fathers then experienced "A sense of happiness being with the child" and "A wish to grow as the parent of the child," and they felt a sense of <Living as the father of the child> through actions to "Expand the life of the child outward."

DISCUSSION

Features of the fathers' experience

In this study, [Fear for the child's life and a feeling of being left out of information sharing] was generated as a part of the fathers' experience. Some fathers described frustration with obtaining information indirectly from their wives since they were not able to interact with the medical care personnel in charge of their child after staying with their child at night after work.

Kawai et al.[26] indicated that NICU staff did not interact with fathers because fathers had less time to meet due to work schedules, which also made follow-up contact with fathers more difficult. Takahashi[27] pointed out that mothers and outpatient nurses have different opinions about the involvement of professionals. For example, outpatient nurses thought that about relationship with mothers, "we will watch without intervening in mothers", because of there were not have appeals from mothers and did not show that mothers were in trouble. On the other hand mothers thought that "we couldn't talk with nurses deeply. we gave up." Research conducted in Italy and Poland, Nepal, and document review in foreign countries showed similar findings[28-31]. Thus, this gap appears to be a common problem in the healthcare setting in various cultures.

As captured in [Struggle to continue home care], the fathers in this study experienced greater physical and psychological fatigue due to inconsistent lifestyle patterns after their child returned home, as they had to adjust their work and private time to align with their child's medical schedule. The difficulty of balancing work and child care for fathers of children with disabilities is representative of the current social situation in Japan. In a survey about child care awareness of fathers who had infants, most fathers expressed an increased desire to be involved with child care, but setting protected time to spend on child care and housework without drastically changing work hours was considered difficult32-34). In a time-budget survey, differences in the amount of child care time between the father and mother decreased but were remarkable in families that had a child younger than 6 years of age at the time when the mother spent it on child care[35].

According to current cultural norms in Japan, the mother is responsible for child care and sociocultural labor circumstances dictate that the father keeps regular office hours regardless of the situation of a family member. Furthermore, the father feels a sense of alienation from information sharing because he cannot interact with medical personnel at night after work. In addition, it was

thought that these experiences worsen the mental and physical state of a father who continues working while coping with the sudden change in the child's condition.

Concerning the medical care of the PIMD child, fathers had different senses to provide care at the hospital under medical personnel and to carry out care only at home. Fathers also expressed strong uneasiness for practicing medical care at home and expressed embarrassment and fear of carrying out care. Thus, fathers became motivated to leave nurturing of the child to their wife and not participate in medical care so as to avoid embarrassment and fear conveyed by their wife.

This was characteristic of fathers of children who require medical care, and the possibility that instability of medical care technology caused difficulty to their PIMD child. Home visiting nurses and rehabilitation personnel generally visit the home during daylight hours on weekdays. Therefore, there are few opportunities for the fathers to interact with a service provider. In this study, the fathers had strong concerns about practicing medical care at home, resulting in confusion and fear about such care, an inducing factor in leaving nursing care to their wives. The fathers reported feeling fear about practicing medical care at home by themselves, as it felt different from providing medical care at the hospital with the help of medical personnel.

In this study, we could not identify the actual feeling from fathers when they were directly supported by medical personals. However, the father made an effort and acquired an understanding of medical care technology so that [Acquisition of nursing care skills and collaboration with wife] was identified as a category. Thus, professional health care providers should also identify fathers as the main caregiver and expand training of medical care technology and provide support to fathers so that fathers can perform tasks independently.

Fathers who faced various nurture experiences, including confusion about a crisis and the family life of the child, ultimately developed a sense of appreciation for the child's development. This is similar to what fathers who are highly interested in child care feel, such as daily fulfillment, happiness, and gratefulness, through participating in various activities with their child36). In document examination about a father who had a child who was admitted to the NICU, we showed the joy of many documents associated with the child[28]. In addition, fatherhood is reported to improve the work environment, and concern about the child's development and care of the wife forms through coming in contact with a child[37]. First-time fathers may be unsure of their feelings but their awareness increases through repeated experiences[38]. Fathers of PIMD children who have high medical care needs during the preschool period acquire the ability to realize the growth of their children by understanding the children's reactions to others, including themselves.

Fathers realized the preciousness of the child's growth through facing the child's disability and medical care. In addition, the fathers themselves grew up and their desire to expand their child's world became clear.

Applications for clinical practice

Based on the findings of this study, two points regarding potential nursing care support for fathers raising children with disabilities can be discussed. First, support is needed to enhance the interaction between mothers and fathers as equal bearers of responsibility in caring for the PIMD child. Most past studies evaluated the father as a supporter of the mother. However, we found that fathers experienced difficulty living with a PIMD child and required nursing support. We recommend direct communication between the father and the physician and nurses to avoid alienating the father from information sharing. Second, maintenance of the hospitalized technical guidance system and continuous support system for technique acquisition is necessary once the PIMD child is released to home care. Fathers need to receive continued education to increase their ability to obtain nursing care skills. However, various feelings may appear if they compare the child with a disability to their ideal child, such as shock, sorrow, or a sense of guilt. Fathers must come to terms with the idea of their child and the reality after having accepted the obstacle(s) faced by the child, regardless of age and child care period39). Thus, it is necessary for fathers to receive ongoing psychological support from medical or educational personnel.

Study limitations

Seven of the eight participants had other children; for six of these fathers, the disabled child

was the second or younger child in the family. Therefore, it is presumed that this study's results reflect the perspective of fathers who had experienced raising healthy children before their disabled child was born. It is necessary to study fathers whose first child was born with a disability, since nursing care support is presumably more important for such fathers. In addition, this study was conducted in Okinawa, Japan. Therefore, further investigation of the model in other populations is necessary.

CONCLUSION

We applied M-GTA to analyze the stories of eight fathers regarding the nursing care of their preschool children with PIMD who require high medical care needs and identified four main categories: [Fear for the child's life and a feeling of being left out of information sharing], [Struggle to continue home care], [Acquisition of nursing care skills and collaboration with wife], and [Response to the child's precious growth].

The fathers' experience in taking care of children with PIMD at home was as follows. While experiencing a sense of crisis about the child's life and a sense of alienation caused by not being able to obtain information about the child's health directly, the fathers strove to continue life with their child's medical care given at home, gained nursing care skills, built collaborative care systems with their wives, recognized the precious nature of interaction with their child as well as witnessing their gradual development, and discovered the significance of growing as parents together with their child.

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