

Research Article

The Decision-Making Process of Parents Choosing Home Care for Technology-Dependent Children and Related Factors

Kanaizumi S* and Ushikubo M

Department of Nursing, Gunma University Graduate School of Health Sciences, Japan

***Corresponding author:** Kanaizumi S, Department of Nursing, Gunma University Graduate School of Health Sciences, 3-39-22 Showa-machi, Maebashi, Gunma 371-8514, Japan**Received:** August 04, 2016; **Accepted:** November 08, 2016; **Published:** November 10, 2016**Abstract**

It is often challenging for parents to decide whether to provide care at home for a child with a chronic condition who requires life-support technology, and little is known about how parents make this difficult decision. This qualitative descriptive study aimed to explore the decision-making process of parents choosing home care for their technology-dependent child and the factors influencing this decision. Data were collected using semi-structured interviews with 11 parents whose children were technology-dependent and had been discharged from hospital. Throughout the decision-making process, conflicted or wavering feelings and various anxieties were present in the parents. Ultimately, accepting the child's state and/or feelings of affection toward the child led parents to decide to provide home care. This process was affected by various factors, including what other people said or did, and deciding to provide home care was represented by one or two of the following three categories: [feeling of "let us try"], [feeling of "it looks like it would work"], and ["being prepared for the possibility of the child's death"]. These findings demonstrate that the decision-making process is varied and complicated. Nurses and other medical professionals should assess parents' conflicted feelings, assist in clarifying the cause of their anxieties, promote parent-child attachment, and help facilitate the child's development to support parents during the decision-making process.

Keywords: Decision making; Parent; Technology-dependent children; Home care

Introduction

Advances in medical technology and health care now allow technology-dependent children with chronic diseases to receive care at home [1-3]. Technology-dependent children are defined as those who require both lifesaving medical devices to compensate for a loss of vital body functions and ongoing nursing care to avert death or further disability [4]. Types of technology dependency vary from procedures such as intermittent urinary catheterization to continuous mechanical ventilation. Home care brings normalization, a nurturing home environment, an enhanced quality of life, and improved development for such children [5-7]. Improved development for children receiving care at home and from the community has been reported in the literature [7-10]. However, providing home care to a child with a complicated condition who depends on technology is often challenging for parents, because in the home setting, medical care cannot always be provided by health professionals.

One of the prerequisites for successful home care is that the parents actually want the child to be at home [7]. Studies have shown that families sometimes have difficulty imagining life at home with the child and that they often fear caring for the child at home [11-14]. However, the decision-making process of parents regarding the transition of a child from the hospital to the home remains largely unexamined.

Carnevale et al. [15] explored the experiences of families with a

child who required assisted ventilation at home and found that many parents were ambivalent with regard to making life support-related decisions. They also found that parents sometimes asked themselves whether they made the right decision; this was commonly resolved by realizing that life without their child would be unthinkable. Although the experiences of families caring for children at home have been reported [4,6,15-18], to the best of our knowledge, no studies regarding the experiences of parents who decide to care for technology-dependent children at home have been conducted in the Western literature. In Japan, a small body of literature has examined the decision-making process of parents regarding the transition of their child from the hospital to the home. Suzuki [19] analyzed parents' perceptions of choosing home care for children dependent on mechanical ventilation and found a "gap" between the perceptions of parents and health care providers; this gap gradually altered parents' perceptions of health care providers from "professionals who keep our child alive and help raise them" to "professionals who merely keep our child alive when necessary", leading to the feeling that they needed to make a decision. Consequently, home care seemed to be the only viable choice. Suzuki also reported that awareness of the child's response, confidence in care, and care burden were associated with their struggle to gain sufficient information before making a decision [20].

Therefore, anxieties or fears among parents about caring for their child at home have been identified, and the experiences of parents

Table 1: Characteristics of the children in this study.

Diagnosis		A	B	C	D	E	F
		Congenital malformation syndrome	Hypoxic- ischemic encephalopathy	Hypoxic- ischemic encephalopathy	Primary alveolar hypoventilation syndrome	Holoprosencephaly Epilepsy	Hypoxic- ischemic encephalopathy
Age at discharge, months		56	24	20	3	14	11
Type of dependency	Mechanical ventilation			✓	✓		✓
	Tracheostomy		✓	✓	✓		✓
	Oxygen therapy	✓	✓				
	Suctioning	✓	✓	✓	✓		✓
	Tube feeding	✓	✓	✓		✓	✓
Family structure		Father Mother One sibling	Father Mother One sibling	Father Mother Two siblings	Father Mother One sibling	Father Mother One sibling	Father Mother One sibling

Table 2: Categories in the decision-making process of parents choosing to provide homecare for a technology-dependent child.

Core category	Exemplars of categories	M	F
Initial impressions and feelings toward the child and home care	Wanting or not wanting the child to be at home	✓	✓
	Negative feelings toward the child's anomaly	✓	✓
	Recognition of the necessity of taking the child home to avoid family separation	✓	✓
	Wanting to live as a family	✓	✓
	Believing that it is natural for the child to stay at home	✓	✓
	Absence of the idea of taking the child home		✓
	Confusion about the option of home care	✓	✓
Perceptions arisen from anticipating home care	Thought that hospital is safer for the child than home	✓	✓
	Being aware of the possibility of losing the child's life at home	✓	
	Conflicted or wavering feelings	✓	
	Uncertainty about the decision		✓
	Vague anxieties	✓	✓
	Lack of an image of home care	✓	✓
	Emerging fears when anticipating life after discharge	✓	✓
	Fears about managing the child's physical condition after discharge	✓	✓
Perceptions in response to caring for the child	Feeling that bringing the child home is the only choice	✓	✓
	Justifying the choice of bringing the child home	✓	
	Acceptance of the child's state	✓	✓
	Feelings of affection toward the child	✓	✓
	Positive attitude for trying		✓
Choosing to provide home care	Feeling of "let us try"	✓	✓
	Feeling of "it looks like it would work"	✓	✓
	Being prepared for the possibility of the child's death	✓	
Influencing factors	Happiness from recognizing the child's reactions and development	✓	✓
	Positive responses from a sibling	✓	✓
	Harmony of views between the couple	✓	✓
	Medical assurance that home care is feasible	✓	✓
	Insistence of hospital medical staff	✓	✓
	Opportunity to observe the life of a similar child at home	✓	
	Presence and availability of a person with whom the mother can consult	✓	

providing home care to their child after discharge from hospital have been explored. However, few studies have been conducted on the parents' decision-making process and related factors in regard

to choosing to provide home care. Facilitating family strengths and supporting the decision-making process are considered essential roles of nurses [18], which suggests that support should be offered based on

a better understanding of parents' decision-making processes.

The objective of this study was to examine the decision-making processes and influencing factors of parents who chose home care for their technology-dependent child.

Materials and Methods

A qualitative descriptive design was used to explore the experiences of parents deciding to provide care for their technology-dependent child at home.

Selection of participants

The participants in this study were parents whose technology-dependent child had been discharged from hospital in less than three months. Participants were recruited from two tertiary hospitals in an urban region of Japan. The inclusion criteria were as follows: a) children with group I-III dependence on a life-sustaining mechanical device(s), such as mechanical ventilation, prolonged intravenous administration of nutritional substances or drugs, tracheostomy care, suctioning, oxygen support, or tube feedings, as defined by the Office of Technology Assessment [4]; b) children who had been hospitalized due to congenital anomalies, perinatal problems, or early neonatal illness; and c) children who had been discharged to their home for the first time.

Data collection

Semi-structured interviews were conducted from 2008 to 2010 at the participant's homes. The interview questions were composed of the following five parts concerning the parents' decision-making process and influencing factors: 1) course of hospitalization until the choice to provide home care was made; 2) factors that were thought to influence the decision to provide home care from the parents' perspectives; 3) what parents had imagined life at home with the child would be like; 4) parents' perceptions about technology dependency; and 5) the child's development. Finally, the participants were asked to comment freely about any other issues concerning the care of their child. All interviews were recorded.

Data regarding the child's age, diagnosis, duration of hospitalization, type of dependency, level of consciousness, and performance of activities of daily living were collected from medical charts.

Data analysis

In this exploratory study, data were analyzed using a qualitative descriptive method [21] that aimed to clarify the actual situation from the emic ("insider's") viewpoint. Analyses were carried out as follows. All interviews were transcribed verbatim and coded after careful review. In the coding process, the participants' own words were used as much as possible. Codes were classified through a comparison of differences or similarities and then divided into sub-categories, which were further abstracted to form categories and core categories. Next, the associations between categories were examined in consideration of cause, context, contingencies, consequences, covariance, and conditions [21,22], and schematized with respect to the flow of time.

A constant comparative method [21,23] was utilized to ensure trustworthiness. First, comparisons were carried out within the cases, and then across interviews, going back and forth between codes,

sub-categories, and categories. The categorization was discussed with researchers experienced in home care nursing. Transferability was secured by intense description, including direct quotations of the participants in the codes, sub-categories, and categories. Data analysis was supervised by an expert in home care nursing research.

Ethical considerations

All parents were informed of the purpose of the study, the study methods, and the content of the data to be collected, and that the confidentiality of all participants would be maintained and the study results would be submitted for publication in an academic journal. The parents were also informed that their participation in the study was strictly voluntary. This information was explained orally and accompanied by an explanatory handout that was then given to each parent. Participants signed a consent form if they agreed to participate. All interview data were anonymized and reviewed repeatedly to exclude any data that could identify individuals. This study was approved by the ethics review committee of the authors' university.

Results

Finally, 11 parents (six mothers and five fathers) of six technology-dependent children participated in the study. Interviews took place from the 7th to 75th day after the child's discharge from hospital. The characteristics of the children are shown in (Table 1). Four children were receiving tube feedings, four required tracheostomy care, and three were dependent on mechanical ventilation. The age of children at discharge ranged from 3-56 months.

As a result of the qualitative descriptive analysis, 306 sub-categories were extracted and 64 categories were generated in relation to the parents' decision-making processes for providing home care for their child. The 64 categories were further abstracted into the following five core categories: initial impressions and feelings toward the child and home care; perceptions arisen from anticipating home care; perceptions in response to caring for the child; influencing factors; and choosing to provide home care (Table 2, Appendix).

Relationships between the categories were examined according to the flow of time in consideration of cause, context, contingencies, consequences, covariance, and conditions, and then the decision-making process was schematized (Figure 1).

Each core category is explained in detail as follows, with brackets denoting categories and quotation marks indicating verbatim responses from the parent interviews.

Initial impressions and feelings toward the child and home care

Seven parents expressed that they wanted the child to be at home in the early period of the child's hospitalization: "I wanted to take her home from the beginning, no matter what condition she is." "When the doctor asked me, there was no hesitation; I just wanted to take her home." One mother did not want her child to be at home in the beginning: "I didn't want him at home" "I wanted him to be institutionalized." Perceptions such as [recognition of the necessity of taking the child home to avoid family separation], [wanting to live as a family], and [believing that it is natural for a child to stay at home] laid the foundation of their willingness to have the child at

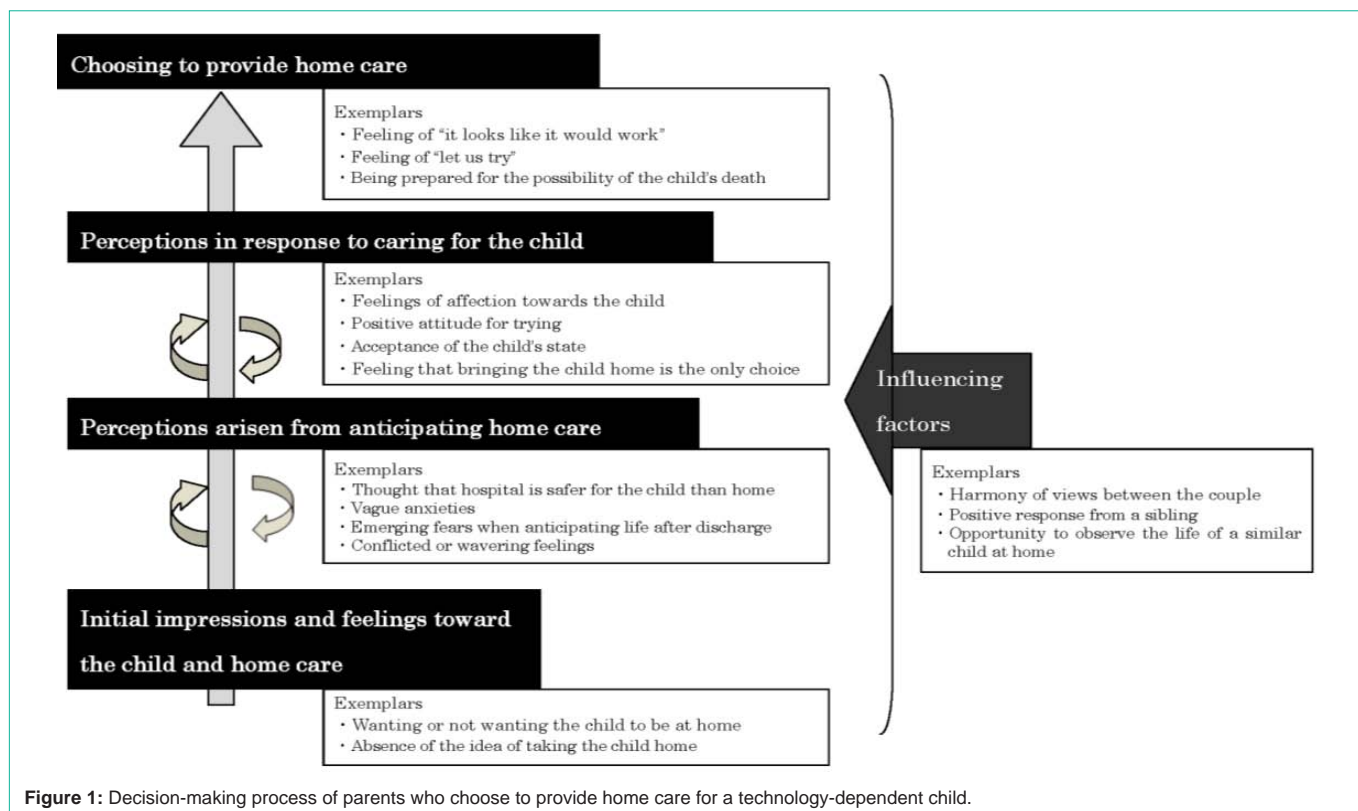


Figure 1: Decision-making process of parents who choose to provide home care for a technology-dependent child.

home. The mother who did not want her child to be at home could hardly accept the reality of her child’s anomaly: “It was about the sixth month of gestation, and the doctor told me the diagnosis, and I could not accept it at all. I wanted to terminate the pregnancy, but it was too late. I asked him if I should institutionalize my baby and he said no, but I just could not accept it.”

In the beginning, the idea of bringing the child home was absent in some parents: “I could not conceive of the idea of bringing him home at first. I thought that he could not be discharged to home.” Some of them then expressed that they want the child to be at home, while others showed [confusion about the option of home care].

Perceptions arisen from anticipating home care

Conflicted or wavering feelings and anxieties were arisen when parents anticipated taking care of their child at home. Perceptions among parents such as [belief that staying at the hospital is safer for the child] evoked conflict, and contrasted with their feelings that they wanted the child to be at home. One of the mothers stated, “I was ‘fifty-fifty’ for hospital stay and home care”. Another mother’s child was particularly vulnerable to infection, so she felt conflicted because while wanting the child to be at home, she was also [aware of possibility of losing the child’s life at home]: “Discharge meant to us that once he catches cold it would directly lead him to death.” Nine parents had [vague anxieties]; in other words, that they felt anxious but could not identify the cause. The category [lack of an image of home care] comprised a number of codes: “I didn’t know how to prepare; I didn’t know what to do.” “I couldn’t imagine what was going to happen.” “It was after we brought her home that I realized how home health nurses could help us.” “I didn’t even know what to ask.” “I couldn’t imagine how big space we needed at home.” “There

were a lot of things I couldn’t figure out.” Parents felt [emerging fears when anticipating life after discharge]. One mother said, “I thought that I would always have to keep my eyes on her (the child) at home and that I would hardly have time to do household tasks.”

Perceptions in response to caring for the child

Representing the category [feeling that bringing the child home is the only choice], three participants stated the following: “He (the child) cannot stay at the hospital forever. There were no other options except bringing him home.” The category [justifying the choice of bringing the child home] was derived from one mother whose child was particularly vulnerable to infection: “The long-term facility refused to take him, and that meant options were limited to either the NICU (Neonatal Intensive Care Unit) or home. So now I can take him directly home. Since there is no option of a long-term care facility, it’s not my egotism, there is no choice but to take him home.”

All of the parents showed [acceptance of the child’s state] and/or [feelings of affection toward the child]. Representative quotations for [acceptance of the child’s state] included; “Gradually, I became convinced of the situation, and anyway, he is nothing but him.” “Now it is a matter of course that he requires oxygen therapy.” “Tracheostomy is just a part of her daily existence.” For [feelings of affection toward the child]; “At first, I was only allowed to touch my daughter, and then gradually, I could hold her. I could feed her milk. It made me feel to take her home, and every time I visited her, that feeling grew stronger.”

The category [positive attitude for trying] was specific to fathers. Although the fathers had anxiety, they mentioned “There is nothing to worry because we won’t know what is really going to happen until we try.”

Choosing to provide home care

The categories [feeling of “let us try”] and [feeling of “it looks like it would work] were extracted from most of the parents. One mother stated, “I frequently practiced how to take care of her (the child) in the hospital, and I have to do the same at home. Anyway, that’s why I practiced,” which demonstrated that the mother came to feel “let us try.”

One child was particularly vulnerable to infection so that a single incident of infection could result in death. For the mother of this child, [being prepared for the possibility of child’s death] meant that she chose to bring him home: “The situation was unchanged; something could happen and he could die.”

Influencing factors

Various factors influencing the decision-making process were derived. Parents’ [happiness from recognizing the child’s reactions and development] was evidenced by quotations such as: “I saw him smile for the first time, and I cannot forget that day.”; and “Occasionally, I can hear her voice, and I’m happy to see her react when I play music, even though I don’t know if it’s a direct result or only a coincidence.” [Positive responses from a sibling] was also an influencing factor: “Her older sister was also at home waiting for her.” [Harmony of views between the couple] indicated that the views of the father and mother were similar: “The views of me and my husband were similar, so it’s okay”; and “Basically, our goal is home care, and we were both thinking in the same direction.”

The other influencing factor was [Medical assurance that home care is feasible]: “I asked the doctor’ which would be better for him (the child), home care or remaining in the hospital.’ I thought that remaining in the hospital would be, you know, like that. But then we were told that home care would also be all right. We cannot judge whether home care is feasible because we are only laypeople.” On the other hand, [insistence of hospital medical staff] was also experienced: “We only followed what the people around us said, and found that it was time for discharge.” “Home care became a reality thanks to the push from the doctors and nurses.”

The [opportunity to observe the life of a similar child at home] was derived from most of the mothers: “Our nurse referred me to another mother of a child dependent on medical devices at home. When I visited her home, I could see how things were arranged in the room, I thought, oh, so it’s like this.”

Regarding the [presence and availability of a person with whom the mother could consult], one mother cited that the district public health nurse was supportive: “She cared about me, and I could talk about anything with her.”

Discussion

Parents decision-making process

The results of qualitative analysis of the 11 parents showed that their decision-making process regarding the choice to provide home care for their technology-dependent child was varied and complicated.

Parents felt that they want the child to be at home at varying points. Some expressed this willingness in the early period of the child’s hospitalization, while the idea of bringing the child home was absent

in some fathers in the beginning. In the literature on parenthood, mothers have been shown to be more inclined to feel as if their child is a part of them, while fathers need time before they feel like they are a father [24]. Mothers usually spend much more time with their children than fathers, and can therefore appreciate the conditions and changes in their children, whereas fathers do not have the same kind of close relationship. These factors might have contributed to the differences seen between mothers’ and fathers’ perceptions in the early stage. However, fathers gradually seemed to become more aware of their child’s situation and consider that they want the child to be at home. Therefore, a key role of nurses is to provide fathers with proper information about their child at appropriate times.

Although most of the parents wanted the child to be at home, conflicted or wavering feelings and various anxieties were present throughout the decision-making process. Conflicts were likely to arise between their desire to live with the child and concerns regarding the child’s safety. Especially for the mother whose child was vulnerable to infection, she wanted her child to be at home, but was also aware that he could die there. Conflicts also arose about whether to admit the child to a long-term care facility. Therefore, the mother was seeking the best place for her child in consideration of the quality and length of his life. Decision making is a process of synthesizing choices with rational deliberation [22], and models of decision making are delineated as a process of solving conflicts [25-28]. O’Connor et al. [25,26] identified “support, knowledge, values, and certainty” as decision-making needs. In order to support these decision-making needs, nurses should assess parents’ conflicts, clarify their decision-making needs, provide information about resources, and monitor the consequences.

Parents had vague anxieties and said that they could hardly imagine life with the child at home. One mother believed that she would always have to keep her eyes on the child at home and that she would hardly have time to do household tasks. The other stated that she realized how home health nurses could assist them after she actually brought her child home. This suggests that hospital nurses do not have sufficient knowledge about home health nursing to help parents imagine living at home with their child. During hospitalization, parents usually visit their child in the daytime and learn how to provide care, lacking the opportunities to be familiar with 24-hour condition of the child. Experiencing over-night stay will help parents capture the image of 24-hour life with their child. Referring the parents to similar families with children who are cared for at home and providing them with opportunities to make home visits is another option for assisting parents imagine home life [29,30].

Mothers felt excessive anxiety from anticipating the hardships of daily life after the child’s discharge, while fathers thought they won’t know until they try. Generally, mothers were more closely involved in the care of their child during hospitalization than fathers; therefore, they tended to feel more fear about providing technical care without the supervision of health care professionals. These differences may also be characteristic of how men and women think. Furthermore, the positive attitudes displayed by fathers may provide a source of support for anxious mothers.

Parents cannot really know what home life will be like until they actually bring the child home. Fears fueled by ignorance may be

reduced by providing appropriate anticipatory guidance [31]. This underlines the importance of nurses being familiar with home care for technology-dependent children, so that they can give appropriate anticipatory guidance to parents.

Most of the parents in this study demonstrated feelings of affection toward their child by going through the process of conflicted feelings and anxieties that arose from anticipating home care. One mother demonstrated obvious affection toward her child immediately after birth and recognition of child's anomaly. Another mother who did not want the child at home in the beginning was not optimistic about the child's discharge. But after going through a complicated process, she finally came to feel "let us try", and eventually demonstrated affection toward her child. Results from studies on parents of infants admitted to the NICU suggest that separating parents from their infants poses many challenges to the development of the parent-infant relationship [32,33]. The literature also suggests that prolonged hospitalization may lead to reduced parent-child attachment and make parents hesitate to bring the child home [5,34]. It is therefore vital for nurses to promote parent-child attachment.

Influencing factors

Awareness of the child's reactions and developmental progress might have facilitated the parents' decision to provide home care. Suzuki [20] analyzed the decision-making process of parents in determining the home life of their ventilator-dependent child and concluded that the quality of the parents' decision making was affected by how they perceived the child's reactions. It is therefore crucial that nurses help parents notice key events and reactions in relation to their child's development. Movement of the extremities conveys motor-stimulus from the brain, and thus the introduction of passive exercises is an option for promoting the child's reactions. Paying attention to the child's developmental progress facilitates affection toward the child, which might be the positive factor influencing the decision to provide home care.

Some of the parents reported that a harmony of views with their spouse was supportive. Ogata [32] reported that the more the father is involved in communication within the family, the less stressful it is for the mother. Nagato [28] recommended that nurses assess the current situation of the family and facilitate communication to support their decision making. Facilitating communication between the mother and father may therefore contribute to better decision making.

People surrounding the parents also influenced their decision making. Positive reactions from the child's siblings seemed to be a facilitating factor for choosing to provide home care. The presence and availability of a person with whom the mother could consult was also important. One mother mentioned that the public health nurse often visited her at home and accompanied her to places such as the municipal office, the child guidance center, institution-based respite care, and the hospital for procedures or conferences. However, this mother was the only one who mentioned support provided by a public health nurse during the decision-making process. Public health nurses comprise the key members of the care team [35] and can even act as coordinators [36]. In our previous study on nursing practice that supports the transition of technology-dependent children from the hospital to the home, although hospital nurses claimed that they provided information about the child and family to the municipal

public health nurses, no reciprocal communication was reported [31]. As one of the parents in the present study stated, public health nurses can play a supportive and encouraging role for parents.

Nursing Implications

The present study revealed the complexity of the decision-making process of parents choosing to provide home care for a technology-dependent child. In order to support quality decision making among parents, the following recommendations are offered:

1) Nurses should understand and empathize with the parents' conflicted feelings and ambivalence resulting from the decision making process. It is essential to take the time to listen to the parents, assess their conflicts, clarify their decision-making needs, provide information about various resources, and monitor the consequences. Nurses need to be patient so that parents can take some action on their own.

2) Parents tend to have vague anxieties; therefore, nurses should help them identify the cause of their anxieties and help them find solutions.

3) Nurses should help parents envision life at home with their technology-dependent child by providing opportunities to stay with the child for 24 hours prior to discharge. They should also refer the parents to other families with similar children. In addition, nurses should expand their knowledge of home care for technology-dependent children in order to provide appropriate anticipatory guidance for parents.

4) Support for promoting parent-child attachment is essential. Promoting parents' participation in care following the philosophy of patient-and-family centered care may relieve the helplessness that parents tend to possess. Helping parents notice the development and reactions of their child is a key intervention.

5) Public health nurses urgently need to be more closely involved with the parents of technology-dependent children. Referring the parents to the regional public health division prior to the child's discharge from hospital would provide the parents with more opportunities to receive information about community resources or childcare consultations.

Study Limitations and Future Perspectives

This study did have a limitation. It only included a small convenience sample of parents in one urban region in a single country, which limits the generalizability of the results. Additional intervention strategies to support parents' decision-making processes should be developed for nurses and evaluated in the future.

Conclusion

The decision-making process of parents who chose to provide home care for a technology-dependent child and the factors that influenced their decision were clarified. Most of the parents wanted the child to be at home and conflicted feelings and various anxieties were present throughout the decision-making process. Acceptance of the child's state and/or feelings of affection toward the child ultimately led the parents to opt for home care.

Factors such as awareness of their child's reactions and

development, positive responses from a sibling, a harmony of views between the couple, and the presence and availability of a person with whom the mother could consult were influencing factors behind the parents' decision to provide home care. Nurses are recommended to promote these factors in order to support quality decision making process.

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