Research Article

Changes in Mothers' Psychosocial Perceptions of Technology-dependent Children and Adolescents at Home in Japan: Acknowledgement of Children's Autonomy

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Summary

Purpose: This research was conducted to reveal Japanese mothers' changing perceptions towards their technology-dependent children in the home care setting.

Methods: Fourteen Japanese mothers participated in semi-structured interviews, which were analyzed using a grounded theory approach.

Results: “Degree of preoccupation with the child” emerged as the category representing the mothers’ perceptions towards their child. Three categories emerged that represented the progression of maternal perceptions over time: “accepting the child’s conditions”, “mastering the management of care in various conditions”, and “considering social participation for the child”.

Conclusions: First, mothers gradually accepted the conditions of their child after his/her disease and disability were known. Second, others managed technology-required care and concurrently considered the social participation of their child through daily care at home. Third, the level of preoccupation with the child was affected by the mothers’ management of care and their attitude towards the social participation of their child in home care. In this study, as is widely alleged in historical recognition of Japan, mothers provided daily care almost without help from other family members. Additionally, they thought it natural and good for their children. Above all, especially in Japan, professional support for mothers are necessary so that they can take breaks from care.

Introduction

Advances in health care and medical technology have increased the survival rate of children with severe health conditions. In Japan, the mortality of children under 5 years of age decreased from 21.6 per 1,000 in 1979 to 2.2 per 1,000 in 2012 [1]. In addition to developing home medical equipment, Japanese government policy promotes home care [2], thus, aiding technology-dependent children at home. The Japanese Paediatric Society reports that at least 340 ventilator-dependent children live in eight prefectures in Japan [3], and the number of these technology-dependent children is rapidly increasing.

In most cases, mothers are the primary caregivers in the home care setting. They must practice not only standard care related to the child’s disability or disease, but also technology-assisted care that is related to medical devices. Several studies have shown that mothers of technology-dependent children find it difficult to manage medical technology care. They also suffer from lack of...
referring to related studies [6,8]. In addition, to ensure the relevance of the study, we asked the mothers to comment on it. Interviews began with questions about the participants’ demographic background, followed by the questions: “What were your learning medical care experiences during hospitalization?” and “What were your experiences while providing home care for your child?” During the interviews, participants were asked why they continued with home care for their child. When necessary, we added questions to elucidate the participants’ experiences. During the interview, we focused on the mothers’ experiences, beginning with when they first started technology-assisted care for their child up to and including current home care. All interviews were tape-recorded and transcribed verbatim. One mother, who refused to be recorded, gave permission for notes to be taken during the interview.

Data analysis

The constant comparative method of grounded theory was applied to the interview transcript data [10,11]. The M-GTA, developed by Kinoshita [11], and the theory followed the speciality of grounded theory [10] such as grounded on data.

The M-GTA makes unique modifications to technique, improving it for greater practicability. Unlike the GTA, the M-GTA does not use the technique of slicing data, but uses the concepts of the Analytical Theme and Analytically-Focused Person. This approach matches the characteristics of Japanese language. Regarding the Analytical Theme and Analytically-Focused Person, researchers use an adjustment method in which they change the Analytical Theme as necessary so that it is open to the specific variability of the data. Moreover, the Analytical Worksheet has a very important role in the M-GTA. Here, researchers write down the precise process of analysis in the Analytical Worksheet as this improves the credibility of the analysis. It is for these reasons that we used the M-GTA.

First, we reviewed the transcripts, focusing on the objective of this study. Through interpretive analysis, we then identified concepts and compared them with each other until no more new concepts emerged. Next, we analyzed the relationships among the concepts, and identified grouped concepts as a category. Finally, we reviewed the relationships between the categories and identified a core category. During the analysis, we focused on sample characteristics and repeatedly reviewed the data. To enhance the credibility of the analysis, an expert in qualitative research supervised the analysis and provided advice. All discrepancies were discussed until agreement was reached.

Because all of the verbatim data was in Japanese, all of the categories, concepts, and quotations in this paper were also originally in Japanese. These were translated into English with advice from a bilingual nursing researcher who is familiar with child rearing in Japan and the United States.

Trustworthiness

To ensure the accuracy and validity of the data analysis, the principal author analyzed the data under constant discussion with other authors.

Results

Fourteen mothers with a mean age of 38.0 years (SD = 7.5 years) were interviewed for 53–143 minutes (Mean = 85 minutes). None of the mothers worked outside the home. All children had two or more diseases or disabilities including cerebral palsy, tracheostenosis, and hypoxic brain damage. Two children were dependent on ventilators (14.0%). Other characteristics of the participants are shown in Table 1.
Four categories and eight concepts emerged from the data (Figure 1). They are indicated in the text below, respectively.

1. Accepting the child’s conditions

Two concepts constitute this category: “accepting the child’s disease and disability” and “accepting the need for medical devices to allow the child to be at home”. When a child had a disease, disability, or medical technology need, mothers faced this reality. When technology-assisted care began, all participants had difficulty accepting their children’s conditions, and the need for devices. Although mothers did not completely accept their children’s conditions, they thought about the future. This was the home care premise for the mothers.

Accepting the child’s disease and disability

Once mothers recognized that their children had a disability or disease that required technology-assisted care, they spoke freely about this to people outside the family by comparing their children with other children in similar situations (i.e., those with a disease or disability). For the mothers, this was a difficult and painful experience.

When I first met other children in situations similar to that of my child, many different thoughts occurred to me all together. I first thought that he would get better; for example, he would be able to speak and move his hands. Hence, I struggled against accepting reality. After a few years, I realized, “He will not change any more.” (ID4)

Accepting the need for medical devices to allow the child to be at home

The mothers had positive experiences with medical devices throughout their daily care, evidenced, for example, by the children’s steady body weight gain and increased ability to breathe clearly. Through these experiences, mothers gradually accepted the need for medical devices for their children at home. All mothers were hopeful that eventually the medical devices would no longer be necessary.

It was a big decision for my child to undergo a tracheostomy. Once she was discharged, she needed various medical devices due to the tracheostomy. I am glad about it. It would be better if she could be without them; but being able to breathe comfortably and being discharged is much better than being in the hospital for a long time. (ID8)

2. Mastering the management of care in various conditions

By accepting the reality of their child’s condition, the mothers learned about technology-assisted care. Once the mothers mastered the skills for home care, they integrated the child’s care into their family life. They learned to accommodate technology-assisted care based on their children’s changes in physical and social condition. During the initial phase of home care, the mothers experienced difficulty until they became familiar with the new medical devices and their children joined an educational institution.

Performing care according to strict rules

During this period, the mothers were inexperienced in care and strictly followed the rules taught by professionals. Therefore, care did not meet the individual needs of daily family life. This caused worry and created difficulties. Care represented an enormous challenge for the mothers. In this concept, all mothers’ duration of home care was within two years.

At first, I tried to do the same thing with technology-assisted care that was done in the hospital. I tried to maintain the hospital routine as much as possible. I was afraid of not doing everything correctly. (ID10)

Managing appropriate care with ease

The mothers’ fears decreased as they became accustomed to technology-assisted care. The child’s communication ability, growth, development, and stable physical condition also facilitated the mothers’ delivery of home care. Information from professionals and other parents helped them to continue. Mothers could easily adapt the care for their children along with meeting the daily needs of her family’s routine.

I fed my child through a tube at 7 o’clock at the hospital but at 5 o’clock every morning at home. It was an appropriate time because of his physical condition and school schedule. I got accustomed to coordinating my schedule between technology-assisted care and daily family tasks. (ID10)
3. Considering social participation for the child

The mothers began to think concurrently about social contact for their children while still managing technology-assisted care for them. They understood the significance of social life for their children, and age-appropriate educational opportunities. This led to a vision of their children’s future based on their conditions.

Thoughts about social contact for the child

The mothers thought about what was best for their children when age-appropriate opportunities, such as entering kindergarten and other educational institutions, were available. In addition, they spoke about opportunities to play with other children. Such age-appropriate opportunities served as cues for the mothers to think about social contact for their children. However, they could not think about future social participation for their children unless their children’s physical and cognitive conditions were stable.

When my child was a baby, I had no view for his future. There was no way of knowing how to best care for him during each growth stage. I put all my heart into caring for my child. It was the only thing I could do, like it or not. (ID1)

Educational opportunities were the form of social contact most frequently discussed by the mothers. They negotiated with educational associations and government offices to arrange the best for their children. In this study, 7 of the 14 children were preschoolers, 2 attended kindergarten, and 3 went to the center for development. When an educational opportunity differed from their hopes and desires, it was difficult for the mothers to give up hope.

There is a limited choice of schools for my child because he needs medical devices. I fought the board of education to get him admitted to an appropriate school. I fought bitterly but he could not go to the school I wanted for him. (ID10)

Looking toward their children’s future

The mothers became accustomed to looking toward their children’s future with their medical devices, diseases, and disabilities in addition to the children’s age. They began thinking about the future social participation of their children.
He gradually wants to be on his own as he grows up. One day he was upset; I never saw him smile or laugh. I left him in his class at school. After class, his teacher said to me, “He was in a very good mood today.” Such surprises often occurred. My relationship with my child changed. Therefore, I increased the length of separation from him. (ID4)

4. Degree of preoccupation with the child

In this study, “preoccupation” refers to the mother’s psychological and physical distance from her child. According to the statements regarding care management and their attitude towards the possibility of social participation for the children, the mother’s preoccupation changed over time depending on their home care experience.

Continuously watching the child

In this context, the mothers were excessively preoccupied with their children. They relinquished their duty only when they had to go out without their children, such as to unavoidable outpatient visits or important family events. It was difficult to spend time away from their children because they wanted to monitor them closely at all times. They became worried when they were unable to observe their children. This continuous vigilant attention limited their time to do other things, such as household chores, caring for other children, and taking breaks from care. This situation was a burden for themselves and their families.

[At the beginning of technology-assisted care], I was always anxious about my child. Will my child get sick again? When will my child need tube feeding? I could not take my eyes off my child. I felt very uneasy when I had no choice but to do it. (ID2)

Thought about autonomy of their child

In this context, the mothers were preoccupied with their children; however, they could spend time away from their children without feeling anxious. They allowed themselves a few breaks from care and spent time on themselves and with their families. However, no mother stepped away from her children for a break; they only separated from their children without being worried when they thought that the situations were beneficial to their children. The mothers realized that their children’s futures were not going to be the same as those of healthy children. Increasing age and stabilization of the children’s physical condition helped the mothers consider their children’s future and autonomy. They admitted that the importance of their children’s future autonomy was related to their physical conditions. Here, the duration of home care for all mothers was under 2 years.

When he leaves school and goes out into the world, how could he survive? We [parents] must think about it and let him prepare. And when [parents’ death] happens, he will suffer the most if he has not been able to get along and is stuck with no way out. He is handicapped, but we want him to be able to do more on his own. (ID12)

Discussion

This study examined Japanese mothers’ preoccupation with their technology-dependent children cared for at home. Preoccupation with their children changed in relation to their management of home care and recognition of the possibility of the children’s social participation.

As per earlier reports that working mothers’ parenting stress were lower compared to other mothers [13]. This means that mother-child separation decreased mother’s parenting stress. Then, mother-child separation may contribute to maintaining an appropriate degree of maternal preoccupation. Therefore, in this study, some mothers who care for school-aged children could not consider the autonomy of their child as related to the length of time spent by the mother with the child. The greater the time spent by the mother with the child, the greater the increase in the maternal preoccupation for the child.

Similar to earlier reports [6,9], performing technology-assisted care for children was challenging for the mothers in this study, particularly for those with a short history of home care. In particular, although all mothers followed the rules which were taught to them by medical professionals when they first confronted with home care, they experienced difficulty integrating such care into daily family life. This situation created their excessive preoccupation with their children, thereby increasing their psychological distress. Medical professionals should teach mothers how to integrate technology-assisted care in everyday life while they are still in the hospital. An advanced home-visit nursing service supports the intensive period from the start of home care to just before school age. This service plays a significant role in the Tokyo metropolitan area [14].

Mothers who thought about their child’s future experienced a positive response from schools. As the previous research reports, the interaction with other children with disabilities in schools encouraged mothers’ acceptance of the disability [15]. It is difficult for technology-dependent children to achieve developmental task appropriate for their chronological age. Mothers consider their child’s future autonomy in relation to their physical condition. Rehm reported that mothers caring for technology-dependent children who are not overwhelmed, consider their family situation to be “not ordinary but fine” [16]. These mothers were satisfied with their family conditions, even though they were unusual. Conversely, mothers with significant uncertainty, have a heavy care burden [17]. In this way, acceptance of her child’s conditions affected the preoccupation for the child. A mother’s preoccupation for the child decreased, when she believed that her child could achieve autonomy despite his or her disability.

In April 2007, special needs schools in Japan were integrated so that they treat all disability types [18]. There are insufficient numbers of nurses in special needs schools to provide care to children. As a result, mothers could not frequently leave their children at school, because the school is short of nurses and teachers who can perform technology-assisted care [19]. Therefore, most mothers of technology-dependent children attended school along with their children. However, they said that they would consider being separated from their children to allow their children to engage in more social participation (i.e., school and kindergarten). Furthermore, Japanese mothers are opposed to using social services for the child, such as short-stay services, helpers and so on [17], and the services available are insufficient. In this study, all mothers wanted to care for their child themselves, as they believed that family care was the best for their child. In particular, Japanese mothers worried about the negative effects of using social services for their child [20]. Therefore, mothers did not want to use social services without clear benefits for their child. Thus, school is a valuable opportunity to separate technology-dependent children from their mothers.

Mothers acknowledged their child as an independent person once they recognized the importance of a certain level of autonomy for their child. During this process, their preoccupation with the child was appropriate. Furthermore, they achieved one of their own developmental theme—middle adolescence—which involves “giving freedom to the child” [21]. Achieving this developmental theme contributed to a mother’s personal growth.
This research had a limitation. Because the children’s primary doctors were responsible for inviting mothers to participate in the study, mothers who had unstable relationships with their doctors were excluded from the sample. However, judging from the age, diagnosis, and medical devices of the children, there was no sample representativeness confound.

In Japan, psychological distress of mothers is a significant problem to the continuation of home care for their child [8,22]. Therefore, this research revealed the appropriate degree of preoccupation for the child serves a significant role for mothers to complete the developmental task in their middle-age. Then, these effects contributed to the reduction of psychological distress of mothers. Mothers who gave up home care became excessively preoccupied with their child. Then, professionals should support mothers to keep appropriate degree of preoccupation for the child. To approach such mothers who are at risk for giving up home care, the results of this study can be utilized by professionals to assess the phase of the intervention. To be specific, depending on what the mothers’ difficulties are, professionals should provide appropriate education and support. In the earlier reports, mothers of technology-dependent children got anxious about the use of respite services [23,24]. When viewed in light of result of this study, some of these mothers may have excessive preoccupation for the child in the area of “autonomy of the child”. In such cases, professionals should try to inform mothers to recognize future autonomy of the child from using respite services.

Conclusion

This study described the degree of preoccupation with children of Japanese mothers who care for technology-dependent children at home. The mothers’ preoccupation referred to the psychological and physical distance from the children, which is essential for continuity of home care. It changed in response to their management of technology-assisted care and attitude towards their children’s social participation.

If the mothers appropriately managed technology-assisted care and created a future vision for their children, they could become less preoccupied with their children and could take a few breaks from care. However, when the mothers face difficulties in managing their children’s care and still desire to have appropriate social contact with their children, they feel the need to intensively observe their children. This situation, then would lead to excessive preoccupation. Professional support to assess the point of the intervention, referring to the results of this study may change mothers’ psychosocial perceptions. It is important for the mothers to take breaks from care.

Conflicts of Interest

The authors declare no conflict of interest.

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