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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

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social support, sleep disturbance due to providing 24-hour care, and difficulty communicating with professionals [4,5].

Considering these difficulties, many studies have reported that care for technology-dependent children causes psychological distress in mothers [5–8]. O'Brien and Ratliffe reported that mothers have anxiety caused by the uncertainty of their child's chronic condition [6,7]. Kuster and Adachi reported that mothers of technology-dependent children are at risk for poor well-being and heavy care burden [5,8]. Although many mothers suffer from child care related stress, most do not decide to discontinue home care [8,9]. Thus, mothers who can continue to provide home care have particular perceptions regarding its management. Therefore, it is useful to describe changes in a mother's perception of the continuity of home care, although few studies have investigated this issue. The purpose of this study was to investigate mothers' perceptions of the home care of their technology-dependent children in Japan in order to elucidate how to appropriately continue their home care.

Methods

Study design

We conducted a qualitative study using the modified grounded theory approach (M-GTA) [10,11].

Setting and sample

In Japan, most technology-dependent children are treated in outpatient care at hospitals that have tertiary emergency medical care. Thus, mothers were recruited from the outpatient departments of a Japanese university hospital in the Tokyo metropolitan area according to the following inclusion criteria: (a) they had technology-dependent children under 19 years of age, and (b) they have cared for their children at home for more than 6 months.

We defined "technology-dependent children" as those who belonged to any of the groups (I–IV) acknowledged by the Office of Technology Assessment [12]. Group I: children dependent for at least part of each day on mechanical ventilators. Group II: children requiring prolonged intravenous administration of nutritional substances or drugs. Group III: children with daily dependence on another device-based respirator or nutritional support (including tracheostomy tube care, suctioning, oxygen support, or tube feeding). Group IV: children who require daily or near-daily nursing care, and with prolonged dependence on other medical devices that compensate for vital body functions.

Ethical considerations

All participants were informed of the study objective, benefits, potential risks, their rights, how their identifiable information and their children's information would be kept private, and that they had the option to withdraw from the study at any time. Following this, we obtained written informed consent from all participants. This study was approved by the Ethical Committee of the University of Tokyo, Japan (No. 1150).

Data collection

Purposive sampling was used to obtain data representative of mothers who care for their children with various conditions of technology dependence, such as age, diagnosis, medical devices, and the duration of home care. A semistructured interview was conducted with the mothers in a private area using the interview guide. Participants chose either the outpatient clinic or their home as the site for their interview. The interview guide was prepared by referring to related studies [6,8]. In addition, to ensure the relevance of the guide, 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.