

Empowerment process of mothers rearing children with disabilities in mother and child residential rehabilitation program

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Abstract

The aim of this study is to identify the process of how a mother rearing her child with disabilities becomes empowered in Mother and Child Residential Rehabilitation Program and the role of nurses in the process. An interview survey was conducted for 15 mothers who had experienced that program. The interview data were then analyzed qualitatively and inductively. The participants had difficulties in everyday life regarding child-rearing, and suffered isolation with regard to the child rearing, both psychologically and in terms of a lack of information. By participating in the program, the children improved physically and emotionally, while the mothers deepened their understanding of their children, and felt solidarity with other mothers. As a result, their motivation for child-rearing was strengthened. Throughout the program, nurses should care for both children with disabilities and their mothers physically and psychologically. It is necessary that nurses understand the needs of those mothers in their everyday life, providing appropriate information with regard to the rearing of children with disabilities, and supporting efforts to create opportunities for the mothers to help each other effectively.

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Keyword : Children with disabilities, Empowerment, Mother, Mother and Child Residential Rehabilitation

Introduction

In rehabilitation medicine, intensive therapeutic training has been effective for children with physical disabilities such as cerebral palsy that intervention

begins at particularly early ages (Bower et al, 2001). In consideration of such facts, a lot of centers for children with disabilities in Japan provide a 'Mother and Child Residential Rehabilitation Program' in which the mothers stay in the same facility with their pre-school age children with physical disabilities for a fixed period, and receive developmental and child-rearing support from a multi-disciplinary team consisting of medical doctors, nurses, physiotherapists, occupational therapists, speech therapists, clinical psychotherapists, nursery nurses and medical

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social workers.

Such residential programs have been provided by various facilities since about 1950. Recently, children with severe disabilities requiring medical care are increasing (Tanabe et al, 2010), and there have been changes in the function of the family due to later marriage and the nature of the nuclear family (Statistics Bureau, Ministry of Internal Affairs and Communications, 2010). Additionally, with the introduction of the Service and Support for Persons with Disabilities Act, the social welfare system surrounding children with disabilities and their families is becoming complex (Miyata, 2009). Under such a situation, a thorough improvement of the Mother and Child Residential Rehabilitation Program is imperative.

The present study focused on the empowerment process of the mothers during the stay, since the empowerment facilitates the formation of the mother-child attachment and the mother's will to rear her child with disabilities, which is essential for child-rearing (Wakimizu et al, 2010). Empowerment in this context expresses itself in the attitude and actions of the mothers to solve problems either by themselves or in cooperation with others for their children. The aim of this study is to identify the process of how a mother rearing her child with disabilities becomes empowered in a Mother and Child Residential Rehabilitation Program and the role of nurses in the process.

Methods

Participants

Participants were mothers rearing children with disabilities. They participated in the Mother and Child Residential Rehabilitation Program in a center for children with disabilities (Faculty A).

Summary of the program

The following is the summary of the Mother and Child Residential Rehabilitation Program that the participants experienced in Faculty A. In most cases, the children with disabilities were brought in from other facilities, because they were given diagnoses calling for intensive therapeutic training at an early age. When the medical doctors in the center gave the same diagnosis, the doctors suggested that the children with disabilities should receive the mother-child residential program. At the same time, the doctors explained that the effect of the program varies among individual cases, and it may be hard for both mothers and the children physically and psychologically because the residential program required living together with others. When the families agreed, an interview survey was conducted by the head nurse and the social worker. The beginning date of the program was decided in consideration of the situations of the family and the ward, i.e., availability of beds, prevalence of communicable disease. The stay in the center usually lasts 8 weeks. The ward can accommodate up to 9 mother and child pairs at any time. Table 1 shows further detail of the program.

Procedures and analysis

When the stay in the center was almost completed, the mothers were given an explanation of the aim of the present study and asked to participate. Semi-structured interviews were conducted after the mothers agreed. The questions in the interviews were as follows: 'What did you think before entering into the program?', 'What do you think now?' and 'How do you feel about the staff of the center?' The content of the interviews was recorded with the permission of the participants, and were transcribed verbatim. The data were then analyzed qualitatively and inductively using the modified

Table 1. Summary of Mother and Child Residential Rehabilitation Program in a center for children with disabilities

Duration	8 weeks
Capacity	Max. 9 mother-child pairs
Staff	Each service user is allocated a team of 8 disciplines consisting of doctor, nurse, physiotherapist, occupational therapist, speech therapist, clinical psychotherapist, nursery nurse and medical social workers.
Training sessions	Physiotherapy (3 times a week), Occupational therapy (3 times a week), Speech therapy (2 times a month), Psychology (2 times a month), General nursery class (5 times a week) 45 minutes individual sessions tailored to the child's and family's needs
Other activities	Lectures provided by doctors and therapists, Welfare consultation, Mothers' group workshop, Family day etc.

grounded theory approach (Kinoshita, 2003) which was developed for Japanese on the basis of the grounded theory approach (Glaser and Strauss, 1967).

Throughout the design to the data analysis in the present study, the author was given ongoing supervision from veteran staff members of the center with regard to the program as well from as an expert of qualitative studies. Transcriptions of the interview were confirmed by the participants later in order to ensure the accuracy of the content.

Ethical considerations

The participants were given assurances, verbally and in writing as follows: the participation of the present study was voluntary; they could withdraw from the study at any time; non-cooperation with the study would not disadvantage them in terms of their ongoing treatment and care; and their personal information would be kept confidential. The consent to participation in writing for each participant was obtained prior to the study. We received approval for the present study through the Institutional Review Board of the National Rehabilitation Center for Children with Disabilities, Tokyo, Japan.

Results

Summary of the participants

An interview survey was conducted for 15 of 16 mothers (acceptance rate of 93.8%) at 26 to 46 years of age (mean age = 36.1 years). All of them were healthy physically and mentally. The duration of interviews varied from 15 to 57 min (mean time = 38.4 min). The children of the participating mothers were pre-school age and physically handicapped, i.e., cerebral palsy, mental and motor retardations. The individual condition and affected body parts varied, while all of them were unable to walk unassisted. Table 2 shows the characteristics of the children of the participants.

Empowerment process

Five concepts were extracted in the empowerment process of the participants described in detail below. The examples of the verbatim transcription are in italics.

a. Difficulties faced in everyday life rearing the child

The mothers were frustrated that they were not given enough outpatient therapy sessions and could not feel any improvement in the child's physical or

Table 2. Characteristics of the participants' children (n=15)

Items		Number of children
Sexes	Male	9
	Female	6
Ages	1 year	5
	2 years	3
	3 years	2
	4 years	4
	5 years	1
Given diagnosis (with duplication)	Cerebral palsy	7
	Mental and motor retardation	11
	Epilepsy	5
Motor function	Unable to maintain sitting position	4
	Able to maintain sitting position (but unable to maintain standing position unaided)	11
Medical intervention (except taking medication)	None	11
	Tube feeding only	3
	Others	1

emotional functions.

We had been working on the feeding training for some time but my child remained incapable of doing it. Since the training session was only once a month, there was no improvement even after one year. I was feeling really frustrated. (ID4)

The mothers felt isolated with regard to child-rearing both psychologically and in terms of a lack of information. They did not communicate with other mothers in similar circumstances.

I had very few friends and acquaintances through my child. I was unaware not only of the information about children with disabilities, but also of the day-service, nursery service or the various therapies offered by hospitals. I was totally in the dark. (ID13)

b. Physical and emotional improvements of the child

The mothers could observe the child's physical and emotional improvements during the stay, and could feel the effect of the intensive therapy program.

My child can ride a tricycle now. I used to think that it would take years to be able to do that. So, this fact that she is riding a tricycle alone is so

impressive that I can cry...really, the 8 weeks (of the residential program) was a big event for us. (ID15)

c. Understanding of the child (through the therapeutic training)

The mothers were impressed with the way that the therapists work hard with the children, which made them realize the importance of continuing the training. Through the training they have deepened their understanding towards their children and learned how to communicate with them.

My child started to hand the photo cards that were made by the speech therapist to other people. I think he might have at last started to find the way to communicate his own feeling. I had been so attached to speaking. But seeing the training, now I learnt that the most important things in communication are forms and attempts, but not words. I will certainly communicate with him in such ways, i.e., using photo cards, but not using words. (ID11)

d. A sense of solidarity among mothers

The mothers have developed a sense of solidarity with other mothers and children through the residential program.

I was encouraged by seeing other mothers and

the people around them working so hard. Each case of disabilities differs, but I want to confront and overcome the difficulties together with them. (ID5)

e. Strong motivation to rear the child

The mothers learned about the future of child rearing positively with a strong motivation to keep going through the residential program.

I am stronger than I was 8 weeks ago, and now I can go home with a more positive outlook than before. (ID10)

The mothers hoped that other mothers would follow, and wished the program system to continue.

(During the stay) all of the mothers began to change. We became like comrades that can understand each other's pain. During the stay, everyone had begun to perk up. It is hard to live together under one roof for 8 weeks, but it is very effective by moderate stimulation. I hope that the mothers suffering badly with rearing their children will participate in the program, so that they can learn to live positively by being given power in the program. Therefore, the Mother and Child Residential Rehabilitation Program (system) should continue. (ID10)

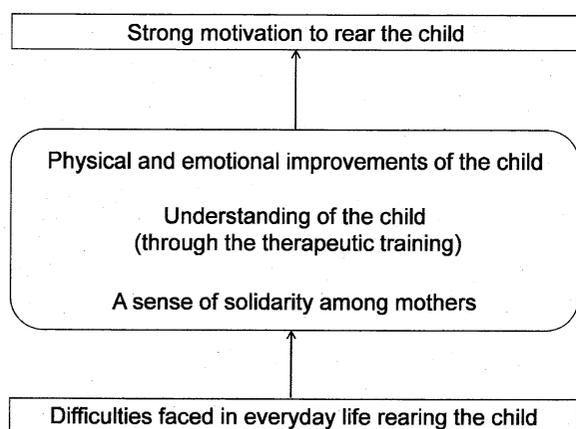


Fig. 1. Empowerment process of mothers rearing children with disabilities in Mothers & Child Residential Rehabilitation Program

The empowerment process of the mothers participating in the Mother and Child Residential Rehabilitation Program identified in the present study is summarized in Figure 1. The participating mothers had difficulties in everyday life regarding the nurture of their children, and suffered isolation with regard to child rearing, both psychologically and in terms of a lack of information. By participating in the program, the children improved physically and emotionally, while the mothers deepened their understanding of their children, and they felt solidarity with other mothers. As a result, their motivation for child rearing was strengthened.

Discussion

Throughout such a program, nurses may help to facilitate the empowerment process of the mothers. Specific points of the program where nurses may help are as follows.

1) Therapeutic training. This is the core of the residential program (Asagai et al, 2000). Improvements in the children's condition reduce parents' stress and promote parents' empowerment (Nachshen and Minnes, 2005). Nurses can provide physical and psychological support during the training.

2) Communication with children. Most of the mothers rearing children with disabilities had difficulties in communicating with their children (Power et al, 2009). The residential program led the participating mothers to deepen their understanding of the children with disabilities, and was helpful for them to communicate with their children in the present study. In another institution, support to promote the mother-child interaction by nurses was reported (Araki and Katayama, 2003).

3) Information about child rearing from other mothers or the staff members. This promotes the empowerment process of the mothers (Mitchell and Sloper, 2002). It has identified the importance of

providing information about the service resources, which is needed for families that have children with disabilities (Burton-Smith et al, 2009). Nurses are often asked to provide information with regard to everyday care (Sen and Yurtsever, 2007). Thus, nurses should understand the needs of the mothers in their everyday life, and provide appropriate information throughout the residential program.

4) Communication and friendship with other mothers and children. This was found to be contributing to empowerment in the present study. The effect of peer support in residential program has been demonstrated in previous studies (Yamamoto et al, 2003). It is necessary that nurses help in creating an environment in which the mothers can support each other effectively.

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原著論文

母子入園における障害児を養育する母親のエンパワメントプロセス

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【要 旨】 本研究の目的は、母子入園における障害児を養育する母親のエンパワメントプロセスと、そのプロセスにおける看護師の役割を明らかにすることである。母子入園を経験した母親15名に対してインタビューを実施した。インタビュー内容を質的帰納的に分析した。対象者は、児の養育に関して日常生活上の困難を抱き、情報面でも心理面でも孤立していた。しかし、母子入園によって、児の身体的・情緒的機能が向上し、児に対する理解を深め、母親同士の連帯感を得た。そして、今後の児の養育に向けて前向きに取り組む意欲が充足された。母子入園において看護師は、母子の心身管理、日常生活上のニーズを把握した上での適切な情報提供、母親同士で有意義な交流が図れるための環境調整を行う必要がある。(医療保健学研究 第3号 : 41-48頁 / 2012年2月16日採択)

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