

Empowerment of families rearing children with severe motor and intellectual disabilities at home

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在宅で重症心身障害児を療育する家族のエンパワメントプロセス

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Reprinted from

Medical and Health Science Research, Volume 5, pp. 41–53

March 2014

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Abstract

To examine the empowerment of families rearing children with severe motor and intellectual disabilities, we conducted semi-structured interviews with the main caregivers in 19 families and used the modified grounded theory approach to analyze the data qualitatively. Through this analysis, a process was observed whereby the main caregivers, who had initially felt isolated during child-rearing, gained personal inner power through exchanges with others (mainly from a group of other parents who were also rearing children with disabilities), started approaching others (such as service providers and administrative staff), and finally established their own rearing systems. This process had a feedback effect of replenishing the inner power of individual caregivers and enabled them to continue with appropriate child-rearing. This empowerment process in the main caregivers suggested that practical care support can be provided in a specific direction to promote the empowerment of families who rear children with severe motor and intellectual disabilities. Examples of such support are encouraging parents to participate in groups with other parents who are rearing children with disabilities, providing advice on daily living, including management of the children's physical conditions, and approaching other family members instead of the main caregiver to coordinate the roles of family members. (Med Health Sci Res TIU 5: 41-53 / Accepted 21 Nov, 2013)

Keyword : Children with disabilities, Empowerment, Family, Home care, Qualitative research

Introduction

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Starting in the 1960s in Japan, the administration had encouraged the admission of children with severe motor and intellectual disabilities (SMID) to specialized institutions to provide rearing including whole-body management in order to support these children and their families (Ezoe, 2006). However,

after the concept of normalization spread following the International Year of Disabled Persons in 1981, the need for support centered on living at home has come to be advocated for those with SMID (Hori, 2006). Furthermore, in recent years, as a result of changes in medical and welfare policy to shorten hospital stays, there has been a shift toward more of these children being based at home from an early age. Of the approximately 40,000 children with SMID in Japan, about 70% live at home (Okada, 2006). Encouraged by advances in medical care and technology for these children, long-term care and securing of quality of life (QOL) at home have become possible (Origuchi *et al*, 2008).

On the other hand, however, rearing of a child with SMID at home imposes a great burden on the family – and the main caregiver in particular – because the child’s life and QOL will not be maintained without daily care by the family, including medical care (Kuno *et al*, 2006; Sugimoto *et al*, 2009).

For this reason, to support these families, services are provided by various specialized institutions in accordance with the relevant regulations centering on the Services and Support for Persons with Disabilities Act. These services include visits from carers and helpers and short-term admission for respite services, although they do not always meet the families’ needs. Although efforts are being made to determine the needs of families (in the form of investigations into families’ levels of satisfaction with services) and to evaluate the mental states of caregivers (*e.g.* feelings of burden and self-efficacy) (Kuno *et al*, 2006; Tanigawa and Nakamura, 2008 Yamamoto, 2009), these efforts are yet to have direct effects such as revision of existing services and regulations. To evaluate the situations in which the main caregivers and families are placed and provide services accordingly, it is necessary to view the families, their services, and the regulations as components of

a more comprehensive system.

Here, we introduce the concept of “empowerment.” The term empowerment in health and welfare science refers to “a process of gaining control over one’s life and influencing the organizational and societal structures in which one lives” (Segal *et al*, 1995). In Japan, only a small number of studies have been made on the empowerment of families rearing children with disabilities, and these studies have been limited to those focusing on just a single case or dealing with cases of participation in self-help groups (Hayashi *et al*, 2002 Ito *et al*, 2009). In particular, almost none has studied the empowerment of families rearing children with SMID. In this light, we aimed to study and clarify qualitatively the process of empowerment of families (in this case, main caregivers) rearing children with SMID.

Methods

Subjects

Subjects were recruited from users of the short-term admission services of a specialized institution in Tokyo and those of a support institute in a prefecture near Tokyo. Subjects were selected on the basis of the following criteria:

- The individual is a main caregiver of a child with disabilities.
- The individual is in a stable condition, both physically and mentally.
- The individual’s child suffers severe motor and intellectual disabilities, has an intelligence quotient ≤ 35 , and is unable to maintain a standing position.
- The individual’s child is ≥ 5 years old and ≤ 18 years old as of the time of enrolment in the study.

Procedure

The chief nurse of the specialized institution in Tokyo and the person in charge at the support institution near Tokyo briefed prospective subjects who met the criteria described above about the research and asked their permission to give their telephone numbers for later contact by research staff. Those who agreed to their numbers being used were called by research staff at a later date, asked for their cooperation, and given a date for an interview.

We conducted semi-structured interviews with subjects in accordance with an interview guide. The interview guide was prepared on the basis of the empowerment model by Koren et al. (1992). This model recognizes empowerment at three levels: family; services; and community. Typical questions in the interview guide were: "As a rearer of your child, how do you see the child with disabilities and interact with him/her?"; "Can you voice your opinions and ideas to professionals of welfare services? Do they value your opinions and ideas?"; and "Can you voice your opinions and ideas to the administration concerning current systems and relevant policies? Do you think that voicing your opinions and ideas to the administration will affect the ways in which systems and policies are made?"

Interviews were conducted individually for about an hour and in a place where privacy was ensured (e.g., a private room). Conversations in the interviews were recorded on an audio recorder after consent from the subject had been obtained; recordings were subsequently transcribed verbatim for data extraction. The data were collected in the period from May 2009 to February 2010.

In conducting the research, we received continuous supervision by support staff experienced with children with SMID and their families, in addition to experts in qualitative research.

Analysis

We adopted the modified grounded theory approach (M-GTA) to perform qualitative and inductive analysis of the collected data (Kinoshita, 2003).

Analytical procedures based on the M-GTA can be outlined as follows. We had a closer look at certain parts of the collected data, interpreted their meaning, and formulated a definition. On the basis of the definition, and through comparison with other, similar cases, as well as with different cases, we worked out concepts that could explain a certain range of cases using the definition. While further elaborating these concepts in light of the collected data, we examined the relationships among the concepts, and also elicited categories and processes encompassing more than one of these concepts. When no further concepts had been worked out within the range of the collected data, we considered that we had reached a theoretical saturation point.

Ethical considerations

Before the interviews, we assured all subjects, both verbally and in writing, that their free will would be respected. They were always allowed to withdraw their statements, refusal of cooperation would not disadvantage them in continuing with current medical treatment and care, and their information would be treated confidentially. We ensured that all of these points were observed. We received the written consent of subjects to cooperate with the research before starting the interviews.

To avoid situations in which a subject would be forced into cooperating, we arranged for a researcher who was free from direct involvement in the services used by the subject to ask for cooperation. We also assured subjects before the interviews that what was talked about during the interviews would not be repeated to the staff of the

institutions in a form in which the individuals could be identified.

The research was conducted with prior approval of the ethics committee of the National Rehabilitation Center for Children with Disabilities and the Graduate School of Comprehensive Human Sciences, University of Tsukuba.

Results

Characteristics of subjects

Among 20 families that were rearing children with SMID and were introduced to us by the support institution, we interviewed 19. We could not interview one family because of the poor physical condition of the subject. Mean (\pm standard deviation) interview length was 65.8 ± 10.8 min (range, 48–93 min).

In 17 of the 19 families, only the mother participated in the interview as the main caregiver; in one family only the father participated, and in one family both parents participated. The subjects were in their 20s to their 40s.

In 18 of the 19 families, the number of children

with SMID being reared by the family was one. In the remaining family, two children had SMID. Accordingly, the total number of children with SMID (hereafter called “child” or “children”) being reared by the subject families was 20. The mean age of the children was 10.7 ± 3.7 years (range, 5–18 years). The children’s disabilities included cerebral palsy and sequelae of cerebropathy; 17 of the conditions were congenital and three were acquired as a result of events such as injury in a traffic accident. Other attributes of the children reared by the subjects are shown in Table 1.

As a result of the analysis, three categories were identified in the process of empowerment of the main caregivers rearing children with SMID: Isolation in child rearing; Exchanges with others; and Establishment of rearing system. Of these three categories, a core category was identified: Continuation of appropriate rearing. Categories and concepts and their respective relationships are shown in Figure 1. In the text and figure, [] indicate subcategories, and “ ” indicate concepts.

Details of the respective categories and concepts are as follows.

Table 1. Process of empowerment for families rearing children with SMID

Table 1. Characteristics of subjects' children with severe motor and intellectual disabilities		n = 20 (19 families)
Sex	Male	6
	Female	14
Diagnosis (This count may include more than one diagnosis for a child)	Cerebral palsy	20
	Permanent damage from encephalopathy	8
	Epilepsy	8
	Mental and motor retardation	5
Medical care (This count may include more than one type of care received by a child.)	Tube feeding	10
	Suction	8
	Gastric fistula	6
	Tracheotomy	5
	Respirator	3
	Urethral catheter	2
	Oxygen inhalation	1
Services (This count may include more than one service utilized by a child, but excludes school and hospital/clinic visits)	None	7
	Home help service	15
	Home-visit nursing	13
	Short stay	11
	Daycare	9
	Doctor's visit	2
Other (Transportation service, etc.)	3	

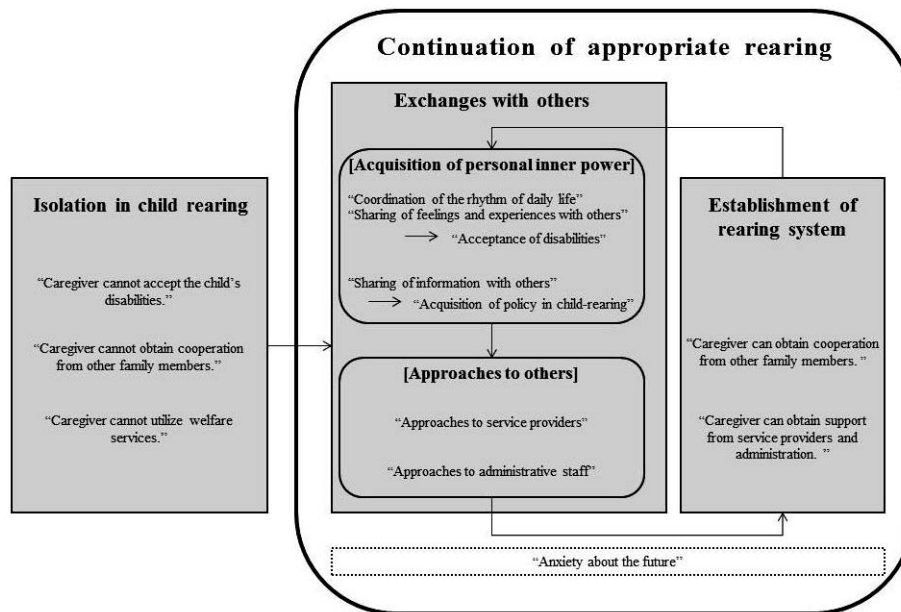


Figure 1. Process of empowerment of families rearing children with severe motor and intellectual disabilities

Isolation in child rearing

In cases where subjects could not accept their child's disabilities, had excessive expectations, and resorted to unreasonable coping styles, they were also unable to accept support services for child rearing. They could not obtain cooperation from other family members or utilize welfare services because of insufficient quality or quantity of service providers, nor could they obtain cooperation from the people around them, partly because of insufficiency in the relevant legal systems. They were therefore isolated in their child rearing.

“Caregiver cannot accept the child’s disabilities”

These subjects could not accept their children's disabilities and therefore could not think of anything other than investigating causes and correcting problems. For example:

My child was normal at first... why does he have disabilities now? When did he acquire his disabilities?

These subjects had unrealistic expectations that their children could do what healthy children could do, thus making unreasonable demands on their

children. For example:

I used to force my child to eat through her mouth, even though she choked. Although I thought that being forced to do such a thing every day would cause a lot of suffering, I strongly believed then that my child would be able to eat normally someday, and I could not think in any other way.

Subjects did not want other people to find out about the differences between their children and healthy children. They disliked being asked about the differences and did not like being seen going to facilities for children with disabilities. For example:

It was an enormous pain to be asked, “Why can’t your child do what others can?” I didn’t want other people to see us going to a facility for children with disabilities, so we used to look outside before we left home to confirm that no one would see us. In that regard I was on tenterhooks.

“Caregiver cannot obtain cooperation from other family members”

Even though these subjects could accept the disabilities of their children, in some cases, they

could not obtain appropriate support from other family members in child rearing, because the other family members could not accept the child's disabilities. For example:

Although I was thinking about what was best for the child, in that she was disabled, it was difficult for the child's grandparents, who could not help feeling ashamed of the fact that we had a child with disabilities in our family. I felt pressured by this attitude.

When the family had a member who needed care in addition to their child, there were cases where family members could not participate in child rearing because they had to care for the other family member. For example:

The parents of my wife live in our neighborhood, and my wife goes there to help them every day. My father-in-law developed health problems recently and has to be hospitalized on and off. My wife is almost completely staying away from caring for our child.

In one case, the family was engaged in a family business and all family members were too busy to establish a system to support the main caregiver in child rearing. In this particular case, the parents of the main caregiver could not visit the family to help, because they were hindered by the attitudes of other family members. For example:

Both my husband and his parents, who were living with us, were too busy and were not the type to take care of the children. My parents could not visit us under these circumstances, so I had almost no support from other family members.

In some cases, the subjects could not obtain support from other family members because of the type of medical care the child needed. For example:

The moment the child needed suction and tube feeding, my parents said, "We can't take care of the child any longer." My husband's parents had already been staying away from caring for

the child.

"Caregiver cannot utilize welfare services"

The subjects felt awkward about people other than family members coming into their homes. Because they could not accept the disabilities of their child, they also felt aversion to receiving services. For example:

I disliked very much the fact that a helper, who was not a family member, came into my home. I disliked accepting help from other people and the possibility that it would let other people know about my child's disabilities.

There were cases where the subjects could not utilize welfare services because staff or facilities were insufficient. For example:

They often turn down our request for a short stay, or they don't accept the child for the entire period we request. This is because the number of facilities that can provide short-stay services is far too small!

The subjects were in very difficult life situations and felt indignant about the insufficiency of the legal system in relation to child-rearing support services and the attitudes of administrative staff. They wished that a legal system that was more suited to their actual conditions could be developed. For example:

When I went to apply for a supportive device or a wheelchair, I was told that I could apply for them only once every two years, or, at worst, only once in a lifetime. I felt very indignant about that. The person in charge told me, "Your child already had a wheelchair made for her when she was born."... "How can my child, who is now 14 years old, use the wheelchair that was made when she was a baby? In regard to support devices, I was told that there were cases where an adult could receive a subsidy for a support device, whereas there was none for children... does this mean that children do not

have to walk? Don't they have to be able to walk?

As seen in these cases, the subjects felt isolated in their child rearing, both psychologically and socially. For example:

There were times when I struggled to take care of the child all by myself. I came to hate everything and was psychologically destroyed. I had no one to consult about child rearing and no one gave me an answer, because I was all alone then. I was always at a loss and not knowing what I should do next.

Exchanges with others

Through exchanges with other people, the subjects gradually came to accept their children's disabilities and acquire their own policies on child rearing, which led to the acquisition of personal inner power. This personal inner power made it possible for the subjects to approach others regarding better child rearing. The main targets of the subjects' approaches were service providers and administrative staff.

[Acquisition of personal inner power]

“Coordination of the rhythm of daily life” and “Sharing of feelings and experiences with others” promoted “Acceptance of disabilities”. That is, by coordinating the rhythm of daily life, which includes child rearing and sharing feelings and experiences with other parents who also had children with disabilities (mainly at school), the subjects gradually came to accept their children's disabilities and acquire mental stability. For example:

After my child started commuting to daycare, I began to interact with more people. It was encouraging to talk with other mothers who also had children with disabilities. In the process

of coordinating the rhythm of my own daily life, I was able change my mental orientation. I gradually came to see the disabilities as characteristics of my child.

“Sharing of information with others” promoted “Acquisition of policy in child rearing”. That is, the subjects shared useful information on child rearing, mainly through conversations with other parents, and came to establish their own policies of child rearing, including approaches to service providers and administrative staff. For example:

There was an occasion where I made a request in relation to child rearing to administrative staff and was turned down for policy reasons. Afterwards, however, I received advice from other mothers, such as “It would be good if you say it this way,” or “You should assert your opinion more strongly,” which was very useful.

[Approaches to others]

“Approaches to service providers”

Thanks to the policies on child rearing they had newly acquired as a result of information sharing, the subjects exploited new and useful service facilities. For example:

I asked the doctor in charge to introduce us to the best hospital in this prefecture. After that, we moved to a nearby district in order to be able to commute to that hospital.

When a service was insufficient, the subjects advocated improvement. For example:

If a service provider says no to what they can improve, I continue to demand that they take action to achieve improvement. When they take no action to improve what can be improved, I say so plainly.

When they obtained more useful information from a service provider, they collaborated to utilize it for child rearing. For example:

I ask home nurses, for example, before they attend a workshop on the respiratory system, to

let me know about any useful information they obtain. This way, they bring me the information they have learned, and then I ask the doctor or physical therapist in charge whether or not we can apply the information to my child's case. I can comprehensively examine, and decide on, the best care for my child by asking various people about it. In this way, I can be involved in child caring positively and convincingly.

When the quality of a service was insufficient or a problem occurred between the child and a service provider, there were cases where the subjects changed the service provider they used. For example:

When a certain application of medical care was not improved after repeated requests, I declined visits by the helper.

“Approaches to administrative staff”

When applying for support allowances or supportive devices, or when they were dissatisfied with the ongoing legal system relevant to a service, the subjects contacted and negotiated with administrative staff until they obtained satisfactory results. For example:

I present my request plainly. If it is not accepted, I negotiate by myself until I am given a satisfactory reason.

As an option for negotiation, the subjects considered submitting requests as a group.

They are not pressured at all by our individual approach. Therefore, we have to advocate our requests positively as a group. In any case, they don't understand our situations if we don't voice them.

As a result of negotiation, there were cases where subjects could apply for allowances or other necessities through proper channels, or where the relevant legal system was improved. For example:

After my child started commuting to daycare accompanied by a nurse, it became an accepted

fact that children with disabilities could commute if accompanied by a nurse. Afterwards, the system was changed and now nurses under exclusive contract with the daycare home can provide the necessary care. In future, it will become easier for children like my own, who have tracheotomies, to commute to their daycare facilities. With the increasing proportions of children with severe disabilities, I suppose that staff will become accustomed to dealing with these children, too.

On the other hand, there were cases where the subjects could not help but give up on their negotiations. For example:

Although the administrative staff listens to us, they have no other option but to comply with the decisions made by their boss or the higher organization.

Establishment of rearing system

Through exchanges with others, subjects acquired the personal inner power to approach others, facilitating effective forms of child-rearing support by family members, service providers, and the administration, thus establishing a rearing system centered on the children and subjects.

“Caregiver can obtain cooperation from other family members”

All family members became closely united around the child to participate in child rearing in a cooperative manner. For example:

After the child was born, all the family members seemed to be drawn to her as if they were drawn to a magnet. We often find ourselves gathering around her. Our daily lives revolve around the child. If my husband comes home earlier than usual, he fixes a meal. Since I scarcely have time for shopping, the child's older sister or my husband does it for me.

While I am fixing a meal in the kitchen, the child's sister sometimes sucks her.

“Caregiver can obtain support from service providers and administration”

Through consultation with service providers, subjects were able to obtain proper advice to solve their worries about child rearing. For example:

Physical therapists give me advice on how to accommodate the child's posture to a wheelchair that does not fit the child's body size in order to make him more comfortable. Nurses listen to me and give advice, particularly in regard to physical issues, such as what we need to look out for at home to avoid hospitalization.

Service providers are not limited to professionals. In patient groups, which also act as groups for parents who rear children with disabilities, the parents themselves can act as service providers. Subjects were able to obtain advice from other parents in the group to help them solve their worries about child rearing. For example:

If I ask how to do suction through the patient group mailing list, I will receive a lot of advice from all over the country. It's so great! I myself have asked for, and received, advice this way.

As a result of negotiations with administrative staff, the legal system that covers children with disabilities has been corrected and improved. For example:

A respite service in the ward has come to accept children who need medical care. A children's hall is also examining how it accepts children with disabilities. I think the ward is giving consideration to children with disabilities in various ways.

By obtaining support from other family members and service providers, the subjects became more positive in their child rearing and succeeded in establishing a child-rearing system centered on the child and themselves. For example:

Thanks to the many people involved, my burden has decreased. Now I can face my daughter in a good mental condition. Since I am emotionally stable, I can do various things in a good, and calm, state of mind, thinking, “I will do that for my daughter, too” and “Perhaps I can do that, too.” It is for the best that we are supported by many people and see our daughter grow together.

Continuation of appropriate rearing

Through exchanges with others, subjects gained personal inner power. This made it possible for them to approach others, and led them to establish their own rearing systems. This process had a feedback effect of replenishing the inner power of the subjects, thus enabling them to continue with appropriate child rearing.

On the other hand, subjects were exposed to constant anxiety over continuation of the current rearing system.

“Anxiety about the future”

Subjects felt anxious over continuation of the current rearing system, considering possible changes in the future (aging, sickness, etc.) among family members, including in themselves, as well as changes in the service system, even though they were currently capable of appropriate rearing. For example:

We have no place to leave my child after he graduates from school. What do they think we should do with children who need medical care? As my child grows older, and I myself age. I am very anxious thinking who will take care of him after I die – I cannot die leaving him behind.

Discussion

Process of empowerment of main caregivers and direction of care support for them

The subjects were originally in a state of powerlessness when they were isolated in rearing their children. Every parent expects their child to be born, and grow, healthy (Nakatsukasa, 1988). For the subjects, who are also parents, their children's disabilities were a great shock that upset their expectations, representing a source of distress that was very hard to accept. Accordingly, the parents initially resorted to an invalid method of coping in which they maintained unattainable hope that their children would be cured of their disabilities. Because doctors or nurses frequently have occasion to be involved in the outpatient department or on wards with parents whose children are newly diagnosed with disabilities, they are required first of all to accept the parents' feelings, as mentioned above, sympathize with them, and consider ways in which support staff can help the parents to rear the child.

Through exchanges with other parents who have reared children with disabilities, the subjects gradually came to share feelings and experiences with others, accepted the disabilities of their children, and acquired mental stability. At the same time, through sharing of information on child rearing, the subjects came to acquire caring skills and techniques for coping with problems, in addition to their own policies of child rearing, including approaches to service providers and administrative staff. In this way, we observed that exchange with other parents contributed greatly to the empowerment of subjects. In fact, the basics of empowerment are said to be participation in a group (Segal *et al.*, 1995). In the case of our subjects, too, it may be said that their participation in a group of other parents rearing children with

disabilities served as a starting point for the promotion of empowerment that followed. The efficacy of peer support among parents in promoting their empowerment has already been demonstrated (Kitagawa, 2008). For this reason, nurses are required to consider introducing parents to other parents or a patients' association based on their needs, in order to promote exchanges among the parents.

On the other hand, families rearing children with disabilities show strong demand for information relevant to local service resources, and this indicates the importance of providing information (Burton-Smith *et al.*, 2009). Nurses themselves are required to be effective information providers, by sharing appropriate information with other professionals, such as social workers, on a daily basis.

Subjects also consider an appropriate rhythm of daily life essential to maintaining their mental stability. However, the health of children with SMID is inclined to be easily upset (Nakanishi, 2006). This may directly upset daily routines in both the children and their parents who provide the necessary care. For this reason, nurses are required to give the parents advice on daily living, including on the management of their children's physical conditions.

The main targets of the subjects' approaches to better child-rearing were service providers and administrative staff. In contrast, the subjects did not make obvious approaches to other family members. In the case where all family members had already united to cope with the child's disabilities, it is possible that there was no need to approach other family members. In other cases, the subjects appeared to place priority on approaching service providers rather than other family members to help with child rearing. This may be because other family members are non-professionals and do not have access to the special information and skills that the subjects (and their children) need. If

elements of a strong struggle over roles in child rearing are observed among family members, then intervention by a nurse is required to coordinate the roles of the family members (Strauss *et al*, 1984). The research results also suggested that non-family-members, such as nurses and social workers, were required to approach other family members about some subjects in some cases.

Subjects felt anxious over continuation of the current rearing system, given the fact that when their children graduated from school, the parents would no longer have a place to leave them on a daily basis. They were also concerned about their own aging and sickness, even though they were currently capable of appropriate rearing and in a fully empowered state. This was typical in the case of our subjects, who were serving as the main caregivers for their children. As Japanese society moves toward a super-aging society, the aging of caregivers is also becoming a serious problem for parent and partner caring (Ono, 2002). However, in cases where children with disabilities are cared for by their parents, the situation is much more serious. Taking into account a generational change in caregiving, construction of a rearing system looking into the future is indispensable.

Limitations and future themes

The subjects of the research were limited to those who agreed to talk with the researchers about their empowerment. For this reason, it is possible that these subjects were already in a somewhat empowered state and thus able to talk about the empowerment process in a positive manner. In future research, to gain a more multilateral understanding of empowerment, we will need to focus on contrary cases and approach those who are in a state of powerlessness and those who have experienced disempowerment.

The age of the subjects' children was limited to

between 5 and 18. The subjects were therefore in their 20s to 40s. In future research, it will be necessary to approach older parents rearing children with SMID.

Conclusion

To examine the empowerment of families rearing children with SMID, we conducted semi-structured interviews with the main caregivers in 19 families and applied the M-GTA to analyze data qualitatively. The results clarified the process of empowerment of the main caregivers. Main caregivers who had initially been isolated in child rearing achieved individual inner power through exchanges with others. They started approaching others and then finally established their own rearing systems. The process was then fed back to replenish the inner power of individual caregivers and enable them to continue with appropriate child rearing. The research results suggest that practical caring support should be supplied in specific directions to promote the empowerment of families who rear children with SMID.

Acknowledgement

We are very grateful to the families who participated in the study. This study was supported by a grant from the Kimura Foundation for nursing education (2009-2010).

References

Burton-Smith R, McVilly KR, Yazbeck M, Parmenter TR, Tsutsui T (2009) Service and support needs of Australian carers supporting a family member with disability at home. J

- Intellect Dev Disabil 34:239-247.
- Ezoe T (2006) Juushoushinshinshougaiji no gainen to teigi. In: Asakura T (Ed). Juushoushinshinshougaiji no total-care.1st edn. Herusu Shuppan, Tokyo, pp. 4-6.
- Hayashi C, Ito BM, Hayasaka K (2002) The relationship between involvement in self-help groups and the psychological empowerment of handicapped children's mothers. The Journal of the Japanese Society of Health Education and Promotion 10: 9-20.
- Hori T (2006) Lobbying movements by parents of children with severe motor and intellectual disabilities during high economic growth and their background. Japanese Journal of Social Welfare 47: 31-44.
- Ito A, Yanagihara K, Tanaka K (2009) Family nursing and empowerment for mother of children with severe intellectual disabilities receiving living kidney transplants: Content analysis of nursing records. Japanese Journal of Research in Family Nursing 14:49-56.
- Kinoshita Y (2003) Grounded Theory Approach no Jissen. Koubundou, Tokyo.
- Kitagawa K (2008) Methods of conducting support group meetings to promote empowerment among mothers of handicapped children and adults. Japanese Journal of Research in Family Nursing 14:48-57.
- Koren PE, DeChillo N, Friesen BJ (1992) Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. Rehabil Psychol 37:305-321.
- Kuno N, Yamaguchi K, Morita C (2006) The sense of burden of mother with severely disabled children at home and the related factors. Journal of Japanese Society of Nursing Research 29: 59-69.
- Nakanishi K (2006) Vital signs no check to kansatsu no ryuiten. In: Asakura T (Ed). Juushoushinshinshougaiji no total-care.1st edn. Herusu Shuppan, Tokyo, pp. 45-49.
- Nakatsukasa T (1988) Shougaiisha Shinri. Minervashobo, Kyoto.
- Okada K (2006) Juushoushinshinshougaiji no rekishi. In: Asakura T (Ed). Juushoushinshinshougaiji no total-care.1st edn. Herusu Shuppan, Tokyo, pp. 15-20.
- Ono I (2002) The actual situation of "Elder-to-elder nursing". MIN-IREN IRYO 357:54-57.
- Origuchi Y, Miyanomae T, Imai M, Nishima S (2008) Annual changes in the death rate among patients with severe motor and intellectual disabilities (SMID) show a downward trend. Journal of Severe Motor and Intellectual Disabilities 33: 83-86.
- Segal SP, Silverman C, Temkin T (1995) Measuring empowerment in client-run self-help agencies. Community Ment Health J 31: 215-227.
- Strauss AL, Corbin J, Fagerhaugh S, Glaser B, Maines D, Suczek B, Wiener C (1984) Chronic Illness and the Quality of Life. 2nd edn. Mosby, St. Louis.
- Sugimoto T, Nakamura Y, Umeda H, Akahane E, Naijo E, Shibutani H (2009) The characteristic of family function in family having a child with disabilities: Research in A prefecture. Journal of Japan Academy of Human Care Science 2:49-56.
- Tanigawa R, Nakamura Y (2008) Acceptance of disabilities, self-efficacy, and health condition in families rearing children with disabilities. Journal of the Japan Society of Nursing (pediatric nursing) 38:137-139.
- Yamamoto S (2009) Home medical care and supports for patients with severe motor and intellectual disabilities. Iryo 63:720-726.

原著論文

在宅で重症心身障害児を療育する家族のエンパワメントプロセス

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【要 旨】 重症心身障害児を療育する家族のエンパワメントに関して、19家族の主介護者に半構造化面接を行い、修正版グラウンデッド・セオリー・アプローチを用いて質的に分析した。療育において孤立していた主介護者が、障害児をもつ親同士の集団を中心とする他者との関わりを通じて、個人内の力を充足させ、サービス提供者や行政担当者などの他者へ働きかけるようになった。そのことで、療育体制を確立することができていた。この一連の流れは、個人内の力の充足へフィードバックされ、適切な療育が継続されていた。このような主介護者のエンパワメント・プロセスの結果から、障害児をもつ親同士の集団に参加できるよう促したり、児の体調管理を含めた生活上のアドバイスをしたり、家族内役割の調整を主介護者に代わって家族に働きかけたりするといった、エンパワメント推進に向けた具体的な看護支援の方向性が示唆された。(医療保健学研究 第5号 : 41-53頁 / 2013年11月21日採択)

キーワード : 障がい児, エンパワメント, 家族, 在宅ケア, 質的研究