






Original Research

Development of family empowerment programs for caregivers of children with disabilities at home: Interim report up to “implementation of pretesting”

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Abstract

Objective: For both children with disabilities and their families to continue living at home, families should achieve and maintain healthy family functioning. This is achieved by enhancing family empowerment. This pilot study systemizes the program development process and identifies the problems and results to move to the program implementation. **Methods:** The program was developed through a step-by-step process emphasizing on the previous research findings, theories, and collaboration with families. We identified the factors related to family empowerment from an in-depth interview study of 34 families and the Delphi method questionnaire survey of 158 professionals. Next, we identified a family empowerment model by a national survey of 1,659 families. We further reviewed literature on family intervention programs, set action goals based on the theoretical framework of program formulation, and finally developed a family empowerment program with the families. The problems and effectiveness of “implementation of pretesting” were qualitatively and quantitatively verified. **Results:** Through the program, the participants created eco-maps and life charts, dealt with issues in their daily lives, set goals for the life they wanted, worked toward those goals, and took actions to make adjustments in their lives and use resources. Due to the small number of participants, the efficacy of the program was not significantly confirmed; however, no adverse events were observed. **Conclusions:** We developed and pretested a participatory program to enhance family empowerment. As a pilot study, the results support the value of conducting the program on a larger scale. Further verification of the effects of our program is required.

Keywords

family empowerment, children with disabilities, intervention program, pretesting

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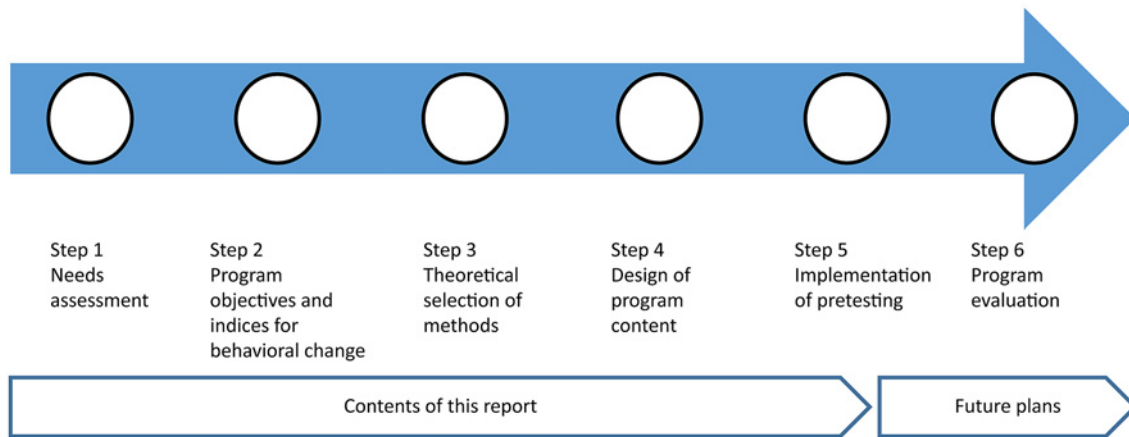


Figure 1. Six steps for the development of this program.

Introduction

Families raising children with disabilities face much higher risks to their own health and lives than families raising healthy children. Families caring for children with disabilities at home often do not enjoy a break. As such, this situation has a significant impact on these caregivers’ mental and physical health. The mother, who is usually the primary caregiver, carries the burden of time and responsibility associated with providing the required care to the child and, thus, tends to have poor mental health (Raina et al., 2005). Families become increasingly fatigued; it is common for members to develop physical and mental disorders (Ozawa et al., 2011). Their capacity to participate in social activities, including their work, is constrained (Okumura et al., 2009).

In Japan, advances in pediatric medicine have led to a rapid increase in the number of children with disabilities, especially those with more severe conditions (Maeda, 2015); thus, direct support for families raising children with disabilities is an urgent need. However, most studies of families raising children with disabilities are observational studies, and how interventions are more effective in improving the health and quality of life of these families has not been fully tested.

There are intervention studies that are focused on the parent carer (Bradshaw et al., 2019; Edelstein et al., 2017). Edelstein et al. (2017) reviewed that several interventions tackled many types of stressors (i.e., emotional stress, social isolation) and changes (i.e., well-being, satisfaction with care). The most recent review by Bradshaw et al. (2019) addresses more interventional outcomes (i.e., family functioning) by including the parents of children with special health-care needs as a scope. Families who care for disabled children at home should be cared for from several aspects (i.e., individual, family, social).

It is essential to enhance family empowerment, that is, the ability to appropriately control their own lives while utiliz-

ing social resources and working together with family members and professionals (Koren et al., 1992). This will enable the children and the family caring for children to continue with their lives at home (Noguchi & Ohmachi, 2020). The Family Empowerment Scale (FES) comprised three domains (i.e., family, social services, social-political) and total score. By assessing the FES from these four aspects, it is possible to examine measures to enhance family empowerment; however, no previous studies have directly considered these aspects (Bradshaw et al., 2019; Edelstein et al., 2017).

We are currently developing a program based on the intervention mapping (IM) approach model proposed by Bartholomew Eldredge et al. (2016; Figure 1). This program is implemented in six steps: needs assessment, program objectives and indices for behavioral change, theoretical selection of methods, design of program content, implementation of pretesting, and program evaluation. We have now implemented Step 5: implementation of pretesting. This study is a feasibility or pilot study that systemizes the program development process up to this point and identifies the problems and results to move to the next step, which is program implementation.

Materials and Methods

Program Creation (Step 1 to Step 4)

Based on the conceptual framework of family empowerment in caring for children with disabilities by Koren et al. (1992), we conducted a large survey of family caregivers raising children with disabilities at home (Wakimizu et al., 2018). In this survey, we measured family empowerment of children with disabilities and developed a Japanese family empowerment model for families raising children with disabilities. The theoretical framework of the program is based on this theory and model. This will be explained in more detail in Step 1: needs assessment. To reduce the caregiver burden of these families and promote the utilization of so-

cial resources, we developed a program to visualize the relationship between family, service, and community and lead to behavioral change based on the intervention theory steps.

Program creation was implemented in the following order: needs assessment, program objectives and indices for behavioral change, theoretical selection of methods, and design of program content. This order was based on the IM approach model proposed by Bartholomew Eldredge et al. (2016). This theoretical framework has also been used in intervention programs based on groups of parents caring for children with disabilities (Borek et al., 2018). The participants answered the questionnaire before and after the program implementation.

Step 1: Needs Assessment

We conducted various surveys on the empowerment of families with severely disabled children. We further conducted in-depth interviews with 34 families with severely disabled children living at home (mothers, fathers, and siblings aged 12 years or older; Wakimizu et al., 2015). We then extracted comprehensive information on each family member's experience and recognition of their roles living with a severely disabled child, expected roles of other family members, and support needs as a family. Along with mental support and nursing advice, support needs related to utilizing social resources were extracted from 56 people in families with severely disabled children living at home. These support needs include the expansion of effective and easy-to-use services and the provision of information and consultation to enable the use of services. A total of 48 nurses and 149 administrative staff were surveyed using the Delphi method on the content of families' support needs extracted from the said survey. Data were used to ascertain the importance and practicality of support for empowering these families (Wakimizu et al., 2016). The family support needs extracted from the survey results were as follows: "I would like to talk to someone when I do not know how to use the services," "I would like mental support for my family, including my siblings," and "I would like to be provided a place where I can interact with other severely disabled children and similarly situated families." However, while nurses and administrative staff are aware of support's importance, putting it into practice is impossible. We gradually visualized the direction of family support programs that we needed to work on from this point. The factors expected to define family empowerment were identified based on in-depth interviews with families with severely disabled children living at home (Wakimizu et al., 2015). A provisional family empowerment model was then formulated. A self-administered questionnaire based on this model was sent to 1,659 families nationwide with severely disabled children living at home. The goodness of fit and validity of the family empowerment model were verified using path analysis (Wakimizu et al., 2018). Consequently, family empowerment was mainly de-

finied by the "utilization of social resources" and "long-term care burden." The model clarified the axis of content that should be included as an intervention to enhance family empowerment in the future. Studies on families with children with developmental disabilities have also revealed that social resources' utilization is directly involved in family empowerment (Nachshen & Minnes, 2005).

Step 2: Program Objectives and Indices for Behavioral Change

We reviewed the literature on the previously reported programs before considering the program methods and content. First, we set the selection criteria for the literature as intervention studies on families living with severely disabled children to serve as a reference for the methods and content of our program; case studies were excluded. Second, we selected literature on interventions for family members living at home; studies dealing with support for transfer to home at discharge from the neonatal intensive care unit (NICU) were excluded. We also selected literature on interventions aimed at parental or whole-family effects; however, literature addressing interventions affecting severely disabled children living at home was excluded. The type of disability was not specified.

First, we searched the literature on intervention studies for family members (main caregivers) of children with severe mental and physical disabilities living at home from "Ichushi" (<https://www.jamas.or.jp/>), a literature database listing many medical and nursing journals. We conducted a search on August 23, 2018 and identified 68 search results. After reading the titles and abstracts of all papers and selecting literature based on the criteria, one paper remained (the main literature excluded dealt with support for transfer to home at discharge from the NICU and literature dealing with the admission of mothers and children for education). This paper addressed the facilitation of interactions among families of homebound persons in remote areas with severe motor and intellectual disabilities by constructing an Internet telephone environment (Hiramoto et al., 2017). We found no English language literature published in Japan. Based on these findings, we concluded that, in Japan, there were almost no intervention studies that quantitatively assessed the effect on parents living in a family with severely disabled children.

Next, we searched Ovid Medline for literature on intervention studies on family members (main caregivers) of children with severe mental and physical disabilities living at home. We conducted the search on November 8, 2018 and found 30 search results. After reading the titles and abstracts of all papers and selecting literature based on the criteria, four papers remained (the main literature that was excluded dealt with ethical reviews, observational studies, and interventions aimed at influencing severely disabled children living at home; Kuo et al., 2013; Looman et al., 2015;

Table 1. Various interventions for parents caring for their children with severe disability from our literature review.

First Author	Year	Country	Setting and Intervention	Provider	Type of Children	Improved Outcomes
Looman, W. S.	2018	USA	Telehealth care coordination and consultation	Advanced practice registered nurse	CMC	Family impact
						Family functioning
Looman, W. S.	2015	USA				Healthcare satisfaction
Toly, V. B.	2014	USA	Resourcefulness training based on a cognitive-behavioral intervention with four-week, face-to-face sessions	Pediatric nurses	TDC	Mothers' mental health
Kuo, D. Z.	2013	USA	Multidisciplinary and comprehensive care oversight and tertiary care center-based care coordination, especially in usual care	Coordinate nurses	CMC	Parents' QOL
Cohen, E.	2012	Canada	Community-based complex care clinics integrated with a tertiary care center	Nurse practitioners via online	CMC	Healthcare utilization Parents' QOL Family-centered care

Note. CMC, children with medical complexity; QOL, quality of life; TDC, technology-dependent children.

Looman et al., 2018; Toly et al., 2014). One additional paper was included after conducting a manual search (Arksey et al., 2002). The five papers show that various parents' and families' outcomes are improved (Table 1); however, almost no intervention programs attempt to improve the family empowerment of families with severely disabled children living at home. Moreover, it is possible to provide effective and comprehensive interventions in line with the needs of families without limiting the type of disease or disability. Lastly, many interventions reported to be effective are provided by or heavily involve nurses.

Based on the results of the aforementioned literature review and the needs identified in Step 1, we decided to develop a program to enhance family empowerment. The program enables families to "utilize social resources" and "reduce the long-term care burden" for families with severely disabled children living at home. Family empowerment was set as the main outcome. Further, improving social resource utilization and reducing long-term care burden were set as the first secondary outcomes (other secondary outcomes will be added in the later steps).

Based on the concept of family empowerment, the family itself can grow and self-actualize by focusing on its advantages, abilities, and strengths rather than simply receiving assistance. Currently, interventions reducing caregiver stress in children with medical complexity (CMC) are categorized into "care coordination," "respite," "telemedicine," "peer and emotional support," "insurance and employment support," and "health support" (Arksey et al., 2002; Edelstein et al., 2017). The results of the literature review indicated that "care coordination" was the most common type of support (Cohen et al., 2012; Kuo et al., 2013; Looman et al., 2015; Looman et al., 2018), followed by "peer and emotional support" (Toly et al., 2014; Hiramoto et al., 2017). Therefore, we believe that "care coordination" and "peer and emotional

support" are important elements in our program; however, in our program, families with severely disabled children living at home must develop a behavior that enables them to improve their own social resources and reduce the long-term care burden. This should be done rather than directly tampering with the amount of care and family relationships. Therefore, "enabling families with children with physical and mental disabilities living at home and their children to take the necessary action based on the gap between their current situation and their desired life" was set as the program's goal and the (target) behavioral change desired for the families participating in the program.

Step 3: Theoretical Selection of Methods

The goal of Step 3 is to select a theoretical method and an associated practical method to achieve the behavioral change objective. This program equips families raising children with disabilities, particularly the main caregiver, with the ability to coordinate their family life in cooperation with other families, medical and welfare service providers, local people, and government officials. It ultimately achieves family empowerment. We selected social cognitive theory (Bandura, 1986) for this program in anticipation of this behavioral change. Social cognitive theory regards human behavior as the interaction of behavioral, cognitive, and environmental factors; moreover, it emphasizes the interaction between individuals and the environment. We identified knowledge, skills, social support, and awareness as factors related to behavior modification in these families. These are the determinants of change, based on the main concepts of social cognitive theory. Self-compassion was also added to this list based on a review of previous studies (Bohadana et al., 2019).

The taxonomy of behavior change techniques (BCTs; Abraham & Michie, 2008) was used as a practical intervention method. This taxonomy, which involves 26 types of

BCTs, presents techniques to achieve behavioral change. Accordingly, techniques, such as encouraging clear goal-setting, self-monitoring, providing information, and identifying barriers for the benefits and risks of health and life, were selected based on the characteristics of families raising severely disabled children.

This program also confirmed that peer support's effect between parents of children with disabilities has already been verified in previous studies (Shilling et al., 2015; Bray et al., 2017); therefore, a group-based learning program emphasizing peer support is set. Based on the selected theoretical and practical intervention methods, this group was set up for primary caregivers raising severely disabled children at different developmental stages, with intervention by peer facilitators. These strategies provide opportunities to observe a model person performing the desired behavior (role model); thus, it facilitates modeling behavior.

When we developed this group session, we encouraged the families to imagine their goals and attempt to undertake their target actions on the basis of self-monitoring, which recognizes the current situation of their families, including their children and themselves. Subsequently, we decided that those experiences would be shared with the group; moreover, feedback and praise were provided when actual actions were taken to reinforce the outcomes. We intended to use a textbook for the participants and a booklet on family empowerment as tools to put the series of group sessions into practice.

Step 4: Program Design and Production

Adjustments were made in Step 4 to enable continuous implementation of the practical method in the program, based on the theoretical method found in Step 3.

First, four hours of discussions were held with three caregivers of children with disabilities (hereinafter referred to as concerned family members) to inquire about their opinions on the program structure's validity and feasibility, content, and management method. These caregivers support activities, such as patient associations and parent associations. The program structure was set once a week (two hours per session), using a group work format that would be completed in four sessions, based on the opinions expressed in the discussions. The concerned family members expressed their desire for a program content that would provide participants with an opportunity to allow deep self-disclosure, fun, and friends. Based on these expectations, a management method policy that focuses on activating the group work between concerned parties was adopted. This method is conducted by minimizing transmission from the program managers (comprising the research team) to inspire the participants themselves to realize child-rearing knowledge and skills and share local resource information, lifestyle benefits, and barriers related to risk. A policy was also established to assign the concerned family members as "program peer sup-

porters" who participated in the program as observers or advisors, separate from the program managers.

We also incorporated work to create life charts and eco-maps (Hartman, 1995; Ray & Street, 2005), based on the BCTs, to allow the subjects to reflect on the lifestyle of their children and families. In the life chart, children and their family members were asked to describe their daily life on weekdays, holidays, and other days, and in the eco-mapping, the participants were asked to describe their family genogram, relationships among family members, and social relations outside the family, such as school and social resources. This work uses eco-mapping to self-monitor and visualize their ability to coordinate family life in cooperation with other families, medical and welfare service providers, local people, and government officials. It also helps them visualize family life and the collaboration and cooperation between families within this framework. Furthermore, modeling opportunities were provided by sharing the visualized work deliverables with other participants. This task allowed the participants to become aware of their ability to adjust family life and their situation of family empowerment, which they had not been conscious of until now. This will lead them to generate change (Tsuda et al., 2007). Mechanisms were prepared to promote these changes by imparting knowledge and skills to family empowerment. The first mechanism is a booklet on family empowerment created by the representatives of our research group, based on the results of our research to date. Presenting the three aspects of family empowerment clearly with illustrations will make it possible to immediately acquire knowledge about empowerment through self-work; moreover, sharing this information during group work also allows knowledge to be established by promoting discussion (Borek et al., 2018). The second mechanism is eco-mapping. Eco-mapping the lifestyles of their children and families enabled them to acquire natural knowledge about social support. Such a concept is difficult to understand with words alone. The third mechanism is the textbook and facilitator book. The textbook contained the structure of the program and the work to be done in each session of the program. The textbook systematically lists the work and clearly shows the goals to be achieved for each task. It is a tool for participants to look back on their work outcomes when needed. It was decided that facilitators do not need to have any specific qualifications to aim for use in peer support in the future. Using the facilitator book, the facilitators answered questions and encouraged group dynamics so that the subject's thinking could progress during the work. This program included parents of disabled children at home who responded to the call for participation in flyers and who signed up to participate in the program.

The content of the program completed throughout this process (Figure 2) is described below for each session every week.

First session "Know the current situation surrounding children and families"

- Self-introduction among participants
- Understand the current situation of children and families through creating and sharing the eco-map

(Homework) Writing down the descriptions of the past week's daily lives of the participants and their families

Second session: "Reflect on the life of children and families, and clarify the life participants want"

- Sharing the past week's situations of the daily lives of participants and their families with other participants
- Clarifying issues on daily lives and the lives that participants want

(Homework) Planning goals for the lives participants want

Third session: "Set goals for the life children and families want"

- Sharing goals for the lives participants want with other participants
- Positive and concrete goal-setting

(Homework) Execution toward goals and self-evaluation

Fourth session: "Reflect on the group work"

- Sharing what participants have done toward goals, changes in life, and self-evaluation
- Reflect on the entire group work

Figure 2. Overview of each session in the program.

First session: The roles within the family, utilization awareness and utilization of social resources, and relationships with professionals were discussed through the participants' self-introduction and the creation of genograms/eco-mapping. Figure 3 shows an example of a participant's work. The participants were also given homework to record a week in their lives and that of their families. They were asked to summarize the information in a table. Figure 4 shows an example of a participant's entries.

Second session: The content of the previous group work and homework (i.e., a record of a week in their lives) was shared among the group. The participants thought about the problems they faced and the kind of life they wanted. The homework for this session was to set goals to achieve the lives that they wanted.

Third session: The lives that they wanted and their goals were shared among the group. The participants were then

asked to set more positive and concrete goals. The homework for this session was to evaluate their own practices toward reaching their goals.

Fourth session: The actions, lifestyle changes, and self-evaluation practiced for working toward their goals were shared among the group. Then, the participants praised each other's efforts.

In the first session, the participants ascertained the current situation of their own lives and promoted awareness of family empowerment's current status. The second, third, and fourth sessions aimed at further promoting family empowerment awareness and enhancing self-compassion. Through these sessions, it was also hoped that the participants would enhance their own changes and awareness throughout their participation in the program.

The facilitator book was designed to present the facilitator method (such as approximate time for proceeding, how to

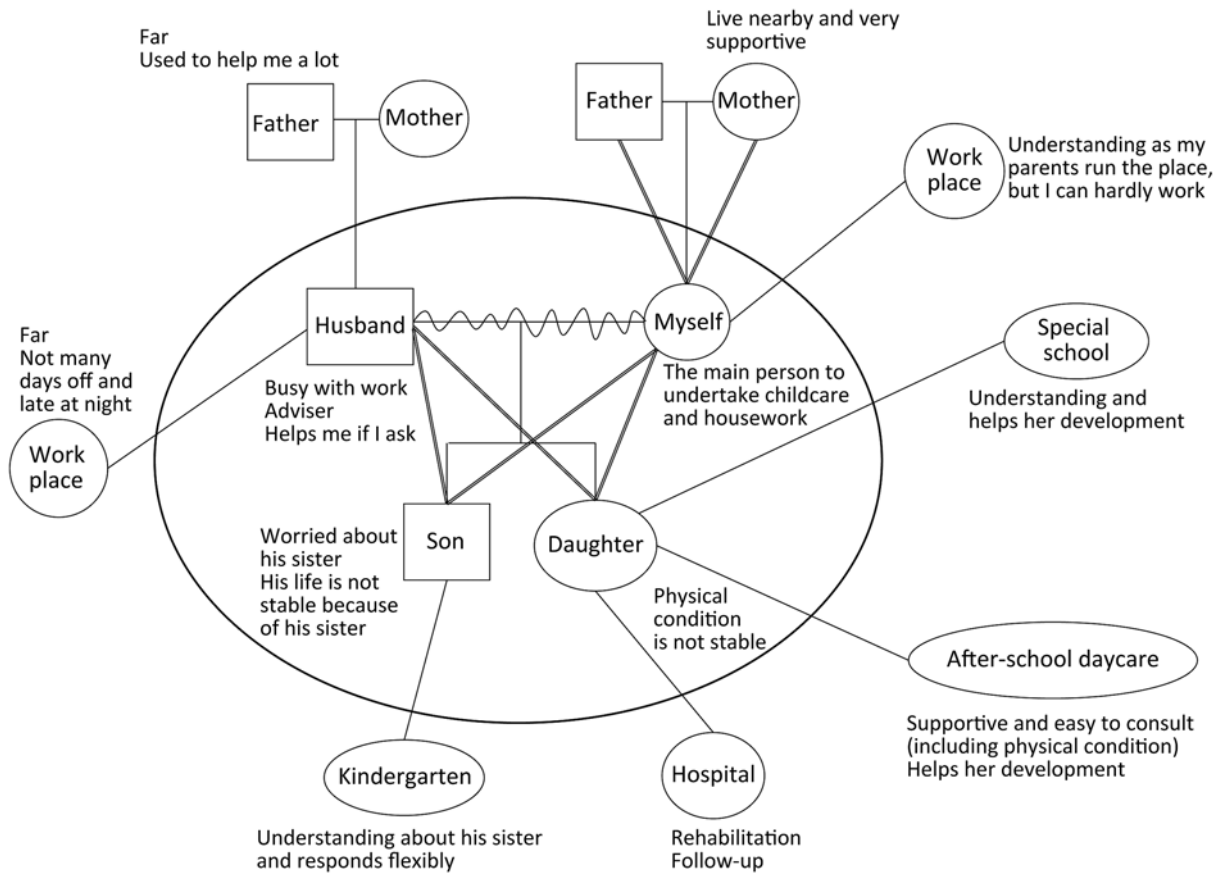


Figure 3. Example of the created eco-map. The participants directly wrote in Japanese onto the map in the workbook. In the interest of sharing the contents, what they wrote is shown in English.

proceed with the work in the program, and what to say to participants) in detail in a form corresponding to the textbook to increase the program’s versatility. Ultimately, we created a textbook and workbook as tools to enable the participants to conduct self-monitoring by visualizing their own learning and work throughout the program. The concerned family members also confirmed the content’s validity and feasibility.

The program improved awareness, self-monitoring, and self-compassion of children and their families. This was achieved by combining group work with self-work at home using textbooks for participants and booklets on family empowerment. We also decided to set tasks in the latter half of the program to encourage participants to consider actions from the perspective of family empowerment, help them imagine the life they wanted for their family, and further promote change.

Implementation of Pretesting (Step 5)

Design

We conducted a controlled pretest to identify the likely effects of our program.

Procedure

Information leaflets were placed at medical treatment and care facilities near the program site to publicize the program and recruit participants. We provided detailed information about the date, time, venue, and who to contact for those who wished to participate. The applicants were divided into intervention and control groups. The program was implemented for the intervention group, whereas no particular intervention was used for the control group during that time, and they were asked to wait. The intervention group participants were asked to complete the questionnaire just before (the first session) and after the program. The control group participants were asked to complete the questionnaire at the same time as the intervention group via email.

The program (four times in total) was conducted in a seminar room that could be used for public purposes where privacy was assured. The group facilitator prepared snacks and drinks so that people would feel relaxed. The participants and supporters sat around the desk. When the group work was presented, the facilitator took a picture of the participants’ workbooks. The facilitator then projected them so that the contents could be shared with the entire group.

The program was implemented from January to February

Time	I	Child (the child)	Husband, Eldest son
6:00	I can't get up even though I feel my family is getting up	Sort of awake	Husband getting up, going to work
7:00	Change the child's diaper and fall down again	Diaper change	The eldest son gets up and eats by himself
8:00			
9:00	I manage to inject the medication and sit down	Medication/injection	The eldest son does his homework
10:00		Drowsy	
11:00	(I can't do anything)		
12:00	Finally cleaning the injection		The eldest son has lunch
	Preparation for lunch		
	Take lunch		
13:00		Enema/diaper change	The eldest son spends time at home playing blocks and reading magazine
14:00	Check the eldest son's homework, school submissions	Injection (not taken orally)	The eldest son reads a picture book to his younger sister (the child)
	(Forget about assisting child's ingestion)	Play with brother	
15:00			
16:00	(I can't do anything because I fell down) Cleaning the equipment	Change the diaper	The eldest son sees me exhausted and prepares the bath
17:00	Supper preparation		
18:00	Bathing (with her)	Bathing	
19:00	Supper (in a fog)	Injection	The eldest son has a bath and dinner
20:00	Serve a meal to my husband		Husband returns home, bathes, has dinner
21:00	I talk with my husband and take a nap		Husband watches over children
22:00		Drowsy	Equipment cleaning
23:00	Wake up and watch the injection being done, but fall asleep	Injection	I take over and my husband went to bed
		Medication	

Figure 4. Examples of life described. In actuality, the participants wrote directly in Japanese onto the maps in the workbook. In the interest of sharing the contents, what they wrote is shown in English.

2020.

Questionnaire

Because of research feasibility, we set all outcomes of this pretest as parent (themselves)-reported outcomes. The questionnaire asked about the basic attributes of the participants and their families (including children with disabilities) and life-related matters and included measures of self-compassion (a secondary outcome defined at Step 3), caregiver burden (one of the first secondary outcomes defined at Step 2, including daily sleep time and nocturnal awakening), social resource utilization (one of the first secondary outcomes defined at Step 2), health-related quality of life (new outcomes from our literature review (Table 1)), and family empowerment (main outcome). Furthermore, the questionnaire was used after the program's implementation to seek the intervention group's input regarding their satisfaction level while attending the program. It also looked into their opinions on the number of sessions and program content.

The questionnaire included questions on the participant's age, relationship with the child or children, educational background, working status, the number of hours of sleep, nocturnal awakening frequency, marital status, total number of adults living in the same house, total number of children,

total number of children with special needs, household income, child's age, severity score, diagnosis name, and age at diagnosis.

The short form of the Japanese version of the Self-Compassion Scale (SCS-J-SF) was used to measure self-compassion (Arimitsu et al., 2016). The SCS-J-SF comprises 12 items that are rated on a five-point scale, with two items each for the following six subscales: self-kindness, self-judgment, common humanity, isolation, mindfulness, and overidentification; the higher the total score, the more compassion one has for oneself.

The short version of the Japanese version of the Zarit Caregiver Burden Interview (J-ZBI_8) was used to measure the caregiver burden (Arai et al., 2003). The J-ZBI_8 is composed of eight items that are rated on a five-point scale. The questions posed relate to the physical and mental burden and social restrictions associated with elderly care; the higher the score, the greater the caregiver burden. This scale is also used in the context of parents raising children with disabilities (Toki et al., 2010).

The questions on social resource utilization were based on the original items used in a previous study (Wakimizu et al., 2018). Specifically, using a four-point scale, questions on the general awareness of social resource utilization were

asked. More detailed questions on the service utilization status, type of service used (e.g., medical, nursing care, day-care), and social resource utilization awareness (e.g., public services, medical institutions, schools) were asked.

The SF-8 standard version was used to measure the health-related quality of life. It comprised eight items (Fukuhara & Suzukamo, 2005). A component summary score can be calculated, based on the responses received, for each of the two subscales: the physical component scale (PCS), which assesses physical health, and the mental component scale (MCS), which assesses mental health. Higher PCS and MCS scores indicate higher physical and mental health-related quality of life, respectively.

The Japanese version of the Family Empowerment Scale (J-FES) was used to measure family empowerment (Wakimizu et al., 2010). The J-FES assesses the ability to coordinate the lives of oneself and one's family; moreover, it collaborates with service personnel and government officials to raise children. It comprises 34 items rated on a five-point scale; the higher the scale score, the higher the level of family empowerment.

Analysis

Descriptive statistics were calculated relating to the subject attributes and each variable's score based on the questionnaire response results. The scores for the SCS "self-compassion" domain could not be calculated due to a printing error; therefore, these results were excluded from the analysis. The changes before and after the intervention were evaluated using the paired t-test for the intervention and control groups. The number of changes in the scores before and after the program was compared between the intervention and control groups. SPSS version 26 was used for statistical analysis. The significance level was set at 5%; moreover, the level of satisfaction, opinions, and free responses related to the program was all listed.

Ethical Considerations

We promised each participant that we would comply with the following to ensure that they participated in the program: participation was at the participant's free will, whether or not they could participate would not affect children's care and their families' lives, they could withdraw from participation in the middle of the program, and personal information collected for participation (completed questionnaires and group work contents) would be strictly managed so that no individual was identified when publishing the results. Written consent has been obtained from all participants to publish their information, including their comments for the program. This study was conducted with prior approval from the ethics committee of the institution to which the principal investigator belongs.

Results

Participant Attributes

The responses were obtained from seven participants. Three participants were from the intervention group and four from the control group. All subjects were mothers of children with congenital disorders, such as cerebral palsy or chromosomal abnormality, aged 4-12 years. The children were 8.14 ± 3.64 (mean \pm standard deviation (SD)) years old. The participants (mothers) were in their 30s ($n = 2$), 40s ($n = 4$), and 50s ($n = 1$). The choices for the highest level of education were high school ($n = 2$), junior college ($n = 2$), and university ($n = 3$). The mothers' employment statuses were part-time employment ($n = 5$) and housewife ($n = 2$). There was no significant difference between the intervention and control groups, except for the highest level of education (Table 2).

Table 3 presents the scores for each variable before and after the program for the intervention and control groups. There was a significant improvement in total family empowerment scores in the intervention group.

There was no significant difference in any variable when the change in scores before and after the intervention was compared between the groups (Table 4).

Evaluation and Revision of the Program

The program was revised on the basis of the questionnaire responses from the intervention group ($n = 3$) at the program's completion, opinions provided during participation in the program, and the subsequent social conditions, including the COVID-19 pandemic. The comments and the program's revisions are listed in Table 5. The participants looked back on the course in general and commented, "I could tackle the problem, thanks to the company of other participants," "I gained confidence by performing plans toward the goal," "I got a positive feeling," and "It was good that an experienced mother led us to talk about our stories."

Discussion

This family empowerment program was systematically developed in collaboration with the participants using an IM approach model characterized by adapting theoretical interventions to each behavioral and environmental factor. The program improves the empowerment of caregivers of children with disabilities.

Consequent to the pretest for this program, there were only few participants in the intervention and control groups ($n = 7$). This resulted in insufficient statistical power, which may have been the reason for not detecting any significant difference between the two groups in the family empowerment score or any other variable. However, there was a significant improvement in the total family empowerment score

Table 2. Attributes of both groups.

		Intervention group (n = 3)	Control group (n = 4)	p
		N/mean ± SD	N/mean ± SD	
Relationship	Mother	3	4	
Age	30s	1	1	.65 ^a
	40s	2	2	
	50s	0	1	
Marital status	Married	3	4	
Living with partner	Living together	3	3	.35 ^a
	Husband living away for work	0	1	
Highest level of education	High school	0	2	.03 ^a
	Junior college	0	2	
	University	3	0	
Employment	Part time	2	3	.81 ^a
	Housewife	1	1	
Household income	≥3 to <5 million yen	1	2	.19 ^a
	≥5 to <7 million yen	0	1	
	≥7 to <10 million yen	2	0	
	Not answered	0	1	
Age of child with disability		6.67 ± 3.51	9.25 ± 4.35	.44 ^b

^a Chi-squared test; ^b, t-test.

Table 3. Intragroup comparison before and after intervention.

	Intervention group (n = 3)			Control group (n = 4)		
	Pre Mean ± SD	Post	p	Pre Mean ± SD	Post	p
Mean daily sleep time (hours)	5.33 ± 0.58	4.67 ± 1.15	.18	4.75 ± 0.96	4.63 ± 0.95	.39
Frequency of nocturnal awakening	2.67 ± 0.58	2.67 ± 1.15	1.00	2.25 ± 1.50	2.75 ± 1.26	.39
1 = every night 2 = several times a week 3 = several times a month 4 = only during attacks						
Social resource utilization	2.67 ± 1.53	3.67 ± 0.58	.23	2.75 ± 1.26	2.25 ± 1.26	.18
1 = do not utilize at all 2 = do not utilize very often 3 = utilize a little 4 = utilize often						
SCS-J-SF self-judgment	5.00 ± 1.73	5.33 ± 1.53	.42	7.25 ± 0.96	6.25 ± 1.50	.31
SCS-J-SF common humanity	6.67 ± 2.52	9.00 ± 1.73	.07	7.50 ± 1.00	7.25 ± 0.96	.79
SCS-J-SF isolation	6.33 ± 3.51	7.00 ± 3.00	.18	6.75 ± 0.96	7.25 ± 1.50	.18
SCS-J-SF mindfulness	5.33 ± 1.15	7.33 ± 2.52	.18	7.50 ± 0.58	8.25 ± 0.96	.22
SCS-J-SF overidentification	4.00 ± 2.00	5.33 ± 3.06	.18	6.75 ± 1.50	5.50 ± 1.29	.55
J-ZBI_8	14.00 ± 9.54	17.33 ± 9.71	.15	9.00 ± 6.24	8.75 ± 5.12	.42
SF-8 PCS	46.00 ± 2.54	49.62 ± 6.89	.57	41.74 ± 5.00	49.28 ± 4.71	.20
SF-8 MCS	43.19 ± 7.39	47.76 ± 7.35	.54	46.24 ± 8.23	45.71 ± 7.95	.74
J-FES family	41.67 ± 8.14	46.67 ± 5.03	.14	38.00 ± 6.68	39.25 ± 3.50	.62
J-FES service system	45.00 ± 9.54	46.00 ± 8.72	.42	39.75 ± 7.68	41.75 ± 6.34	.12
J-FES community/political	28.33 ± 7.51	34.67 ± 16.77	.36	25.75 ± 6.29	29.50 ± 6.45	.09
J-FES total	115.00 ± 25.16	126.67 ± 26.27	.01	104.00 ± 18.02	110.25 ± 13.05	.19

Paired t-test.

Note. J-FES, Japanese version of the Family Empowerment Scale; J-ZBI_8, short version of the Japanese version of the Zarit Caregiver Burden Interview; MCS, mental component scale; PCS, physical component scale; SCS-J-SF, short form of the Japanese version of the Self-Compassion Scale; SF-8, scale measuring health-related quality of life and consisting eight items.

Table 4. Intergroup comparison of the amount of change before and after the intervention (after intervention–before intervention).

	Intervention group (<i>n</i> = 3) Mean ± SD	Control group (<i>n</i> = 4) Mean ± SD	<i>p</i>
Mean daily sleep time (hours)	-0.67 ± 0.58	-0.13 ± 0.25	.15
Frequency of nocturnal awakening	0.00 ± 1.00	0.50 ± 1.00	.54
1 = every night 2 = several times a week 3 = several times a month 4 = only during attacks			
Social resource utilization	1.00 ± 1.00	-0.50 ± 0.58	.05
1 = do not utilize at all 2 = do not utilize very often 3 = utilize a little 4 = utilize often			
SCS-J-SF self-judgment	0.33 ± 0.58	-1.00 ± 1.63	.24
SCS-J-SF common humanity	2.33 ± 1.15	-0.25 ± 1.71	.08
SCS-J-SF isolation	0.67 ± 0.58	0.50 ± 0.58	.72
SCS-J-SF mindfulness	2.00 ± 1.73	0.75 ± 0.96	.27
SCS-J-SF overidentification	1.33 ± 1.15	-0.75 ± 2.22	.20
J-ZBI_8	3.33 ± 2.52	-1.00 ± 1.73	.07
SF-8 PCS	3.62 ± 9.42	7.54 ± 9.31	.61
SF-8 MCS	4.57 ± 10.68	-0.53 ± 2.88	.39
J-FES family	5.00 ± 3.61	1.25 ± 4.57	.30
J-FES service system	1.00 ± 1.73	2.00 ± 1.83	.50
J-FES community/political	6.33 ± 9.29	3.75 ± 3.10	.68
J-FES total	11.67 ± 1.53	6.25 ± 7.41	.28

t-test.

Note: J-FES, Japanese version of the Family Empowerment Scale; J-ZBI_8, short version of the Japanese version of the Zarit Caregiver Burden Interview; MCS, mental component scale; PCS, physical component scale; SCS-J-SF, short form of the Japanese version of the Self-Compassion Scale; SF-8, scale measuring health-related quality of life and consisting eight items.

in the intervention group after participating in the program. This result suggests that this program is effective for enhancing family empowerment.

The reason for the total family empowerment score’s improvement is the visualization effect using the tools, participants’ modeling, and the “program peer supporters.” First, this program reflected on the children and family support systems and current life situations using eco-maps and life charts as part of group-based, participant-led work. This process promotes the visualization of behavioral and environmental factors related to the outcome of empowerment. Adams et al. (2017) qualitatively surveyed the experience of creating care maps by the parents of children who require medical care. They stated that creating care maps clarifies the priorities and needs of these families. The experience of objectively visualizing how family members spend their time in their daily lives by creating life charts has led to an understanding of their family’s current situation within their busy lives.

The participants, who were mothers in similar situations,

discussed specific behaviors to create the future of their children, their families, and themselves based on the eco-maps and life charts; moreover, they set life goals to achieve that end. They said that they could tackle problems more positively due to interactions with other participants. This finding suggests that self-compassion, an element of the program, was enhanced through positive exchanges among the participants. Furthermore, it may have had a positive effect on the participants’ empowerment as well. In prior research, families caring for children with thalassemia, who have experienced family empowerment programs, reported that sharing information and other families’ experiences and beliefs related to the care of their children improves their ability to make decisions about family problems and needs and manage the care of their children and family relationships (Wacharasin et al., 2015). This suggests that it is appropriate to set up group work with families of children with disabilities as a program format.

The participants’ caregiver burden was significantly higher than the caregiver burden (8.9 ± 6.4 ; Matsuzawa et

Table 5. Comments identified by the participants through “implementation of pretesting” and improvements made for the program implementation.

Comments from the participants		Improvements made for the program implementation (specific details of how the program content and management format were revised in response to each issue)
Program overall	<p>The program gave me pleasure.</p> <p>The program was so good that I could confidently recommend it to my friends.</p> <p>It would be better for everyone to make the most out of the opportunities, such as medical checkups, so basically, everyone raising children with disabilities can participate in this program.</p> <p>Participating in the program was helpful. I felt positive. It was good that the experienced mothers led the discussions.</p> <p>The input from other participants was inspiring.</p> <p>Face-to-face implementation is no longer possible due to the COVID-19 pandemic.</p>	<p>All participants were generally positive. This content will be kept as is.</p> <p>The presence of other participants and supporters was favorable. There is no problem with proceeding with this format.</p> <p>The program’s format has been changed from face-to-face to online. Some of the textbooks and facilitator books will be modified to deal with this situation.</p>
Participants	<p>Parents with children aged around 1 year should be able to participate in the program.</p> <p>It would be better to participate in the program with my spouse.</p>	<p>This program was originally designed to include participants with children of any age up to school age, so the content and structure will remain unchanged. However, during the recruitment process, we will request the participation of parents with younger children.</p> <p>Although the participation of spouses is expected to be effective, it is necessary to consider the consent and privacy of the other participants. This will be considered carefully in the future.</p>
Program sessions	<p>The number of program sessions is good as is.</p> <p>It would be good if there were a number of different patterns for the days of the week when the program sessions will be held.</p> <p>The length of one program session is perfect.</p>	<p>The content will remain unchanged.</p> <p>It was decided to set suitable times and days of the week for holding the program sessions based on the needs of the participants at the time the program is run.</p>
Program content structure	<p>The homework of setting goals for the future was a painful task that made me sad and distressed because I could not see any future or hope.</p> <p>It may be easier to tackle the tasks by giving the participants time to discuss their efforts toward the goals.</p>	<p>The content will remain unchanged.</p> <p>If the participants are distressed about setting future goals, they are unable to receive follow-up from the other participants. Therefore, it was decided to invite these participants to join a group work to enable them to make presentations and hold discussions on the spot.</p> <p>It was decided to color-code the goals set representing the three levels of family empowerment so that the participants can discuss the tasks they can do at each level.</p>
Communicating program to other family members	<p>The language used in the program is difficult to comprehend, which makes it challenging to understand the purpose and intent of the program.</p> <p>I told my family a little about the content of the program and what I had learned ($n = 2$) / I did not tell my family about it at all ($n = 1$).</p>	<p>It was decided to explain the purpose of empowerment and the programs at the beginning of the program using a separate pamphlet.</p> <p>The program includes a task where the participant is asked to share his or her problems with their family. However, some participants reported that they did not tell their families about it at all. Therefore, it was decided to use the individual consultations after the program to try to understand the situation of individual participants during the program.</p>

al., 2019) of Japanese parents raising children with severe motor and intellectual disabilities in a previous study. The reason for the higher caregiver burden score among the participants in this study may be because the children’s mean age in the aforementioned study (Matsuzawa et al., 2019) was 12.0 ± 3.6 years, which was higher than that of the children in this study. Mothers tend to establish their own child-rearing style, their own lifestyle, and their family’s lifestyle while learning how to care for their child. This en-

ables them to explore ways to incorporate rest and well-being into their lives; thus, it is assumed that the participants in this study were still in the process of establishing their child-rearing styles. Furthermore, the participants wished to participate in the intervention program to enhance their empowerment. They had a desire to improve their child-rearing styles and their own and their family’s lifestyles; therefore, it can be assumed that the participants were mothers with a high caregiver burden.

A characteristic of this program was that it was developed in collaboration with the participants. Consequently, there were no negative comments from the participants regarding the way the program was run, including ones regarding the length and number of sessions; moreover, no participants dropped out midway through the program. Therefore, incorporating the participants' viewpoints on the program's aspects, such as the length and number of sessions, is considered effective, without overburdening the participants. Furthermore, no participants reported any negative impacts, such as family discord and psychological instability, because of participating in the program. These findings suggest that Step 6 (program evaluation) can be performed, based on the program management and content in the pretest.

The program was conducted face-to-face; however, programs should be conducted online during the COVID-19 pandemic. The methods for advertising the program and facilitating group work should be adapted to support programs remotely.

Limitations and Future Research

The effect of this program on enhancing family empowerment was clearly confirmed by the statistical results from the data gathered through the questionnaire and participants' verbal responses; however, it is impossible to generalize its efficacy because there were only three participants in the group. Considering that this study is a pilot study, the results are promising; however, the efficacy of the program should be further evaluated, applying some revisions to the program as suggested above.

Additionally, feelings of family empowerment before the program could be characterized as "sometimes" for two participants and "often" for one participant. Future programs should be conducted and evaluated with participants who "seldom" or "never" have feelings of family empowerment. The efficacy of the program can then be verified on a larger scale.

Conclusions

We developed and implemented a participatory program to enhance family empowerment. The results indicate that the program was effective in enabling participants to take actions regarding adjustments to their lives and use social resources; therefore, their sense of family empowerment had increased. As a pilot study, the results support the value of conducting the program on a larger scale; however, further verification of the program's efficacy is needed in future research.

Author Contributions

All authors had full access to all data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

- Conceived or designed the study: RW, HF, KN, IS, NI, and AM
- Performed research: RW, HF, KN, IS, NI, and AM
- Analyzed data: RW, HF, KN, IS, NI, and AM
- Wrote the paper: RW, HF, KN, IS, NI, and AM

Declaration of Conflicting Interests

We received no financial support or relationships that may pose a conflict of interest in connection with this manuscript.

Ethical Approval

This study was conducted with prior approval from the ethics committee of the University of Tsukuba (No. 1420).

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