

# Program Evaluation by Graduates of the Pediatric Cancer Peer Supporter Training Program

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## ABSTRACT

Pediatric cancer is the number one cause of illness and death in children and requires long-term and aggressive treatment. Consequently, families face physical, psychological, and social issues, and peer support among family members with the same experience is an important source of support. This study aimed to evaluate and verify a training program for Japanese families known as the “Pediatric Cancer Peer Supporter Training Program”. The program conducted a questionnaire survey with 219 participants who had attended up to the 10th training session. It examined the effect of the training on participants in the four categories of “interpersonal and social skills”, “counseling skills”, “self-efficacy”, and “motivation,” referring to the concept of self-efficacy proposed by Albert Bandura. The results showed that self-efficacy scores increased after the training in all cases, indicating that the training content had some effect on the participants. It is suggested that peer support is essential for families of children with cancer, and training programs that enable them to acquire skills as supporters should be continued in the future.

**Keywords:** Pediatric Cancer, Peer Supporter, Training Program, Evaluation.

## INTRODUCTION

In the 1980s, pediatric cancer was considered an incurable disease, and the long, grueling treatment and loss of a child created many crises for families. Parents who had lost their children had unresolved feelings for a long time, which led to the breakup of the family. Even after the cancer was almost cured, parents were terrified of a recurrence and tormented by their anxiety about the future. Parents who went through these experiences gained new strength to live by discussing, sharing, healing, and encouraging each other in a group of parents of pediatric cancer patients [1].

At present, many “pediatric cancer parent associations” (hereafter referred to as “associations”) exist in Japan, each with their own goals and activities in hospitals and communities [2]. They respond to the concerns of parents with children who are ill or undergoing treatment and provide

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a space for parents who have lost a child. This platform ensures that individuals gain experience and knowledge as well as support that can only be provided by peers, which cannot be offered by professionals.

In Japan, the Basic Law on Cancer Control was enacted in 2007 to promote patient-centered cancer care. In 2012, measures for patients and families with pediatric cancer, whose treatment and course differ from those of adults, were included. The government emphasized the need for peer counseling based on the experiences of patients and families and budgeted for a project to train peers in counseling skills to maintain the quality of peer counseling. In 2012, the "Training Program for Personnel Involved in Comprehensive Cancer Counseling" was established for adult patients with cancer.

However, pediatric cancer was excluded from peer counseling training programs due to the complexity of being a rare cancer and the fact that the patients involved are children and their families. For this reason, families of children with pediatric cancer formed the Pediatric Cancer Peer Support Promotion Council and began developing training programs in 2013 [3]. If families of children with cancer can make the most of their experiences and build a support system for counseling from the patients' point of view, it will lead to cooperation between medical care and patients and contribute to the development of medical care from the perspective of the parents of children with cancer. It is important for pediatric cancer patients and their families to systematically acquire counseling knowledge and peer support skills.

Therefore, we thought that it would be useful to review

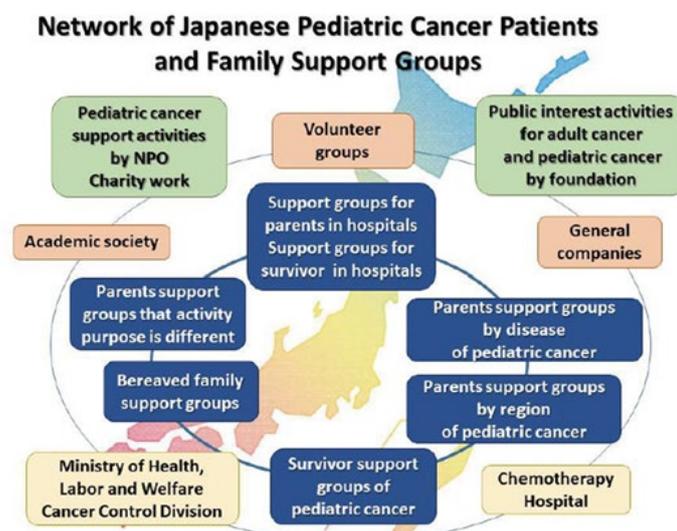
the effectiveness of the training content developed by the Pediatric Cancer Peer Support Promotion Council for the families who participated in the program, which could lead to the possibility of updating the content of new programs.

## OBJECTIVE

To evaluate and verify the program developed by Pediatric Cancer Peer Supporter Training Seminar graduates.

## SUPPORT NETWORK FOR PEDIATRIC CANCER PATIENTS AND FAMILIES IN JAPAN

The first association between the parents of children with cancer in Japan was established in 1968. This association was founded by parents who had lost their beloved children to pediatric cancer and wanted to ensure that the tragic suffering would not be repeated [4]. In the late 1980s, small groups were formed in hospitals where patients battled one disease after another. These groups were formed by parents who had children with the same disease and had experienced the same disease in an identical environment. The purpose of these groups was to heal and encourage each other through sharing, expressing gratitude to the hospital, and improving the childcare environment [2]. At present, the existence of more than 60 parent associations in hospitals has been confirmed. In addition, the activities and types of pediatric cancer patient associations are not only limited to peer support, such as community-based parent associations, disease-based parent associations, associations of parents who have lost their children, charitable organizations, and volunteer groups but also include various forms of government, corporate, and private organizations that provide support (Figure 1).



**Figure 1.** Network of Japanese Pediatric Cancer Patients and Family Support Groups.

## OVERVIEW OF THE PEDIATRIC CANCER PEER SUPPORTER TRAINING

The Pediatric Cancer Peer Supporter Training is scheduled for 16 hours over 2 days. The purpose of the training is to provide family members of pediatric cancer patients with the counseling skills and knowledge necessary to provide support. The training consists of five hours of lectures to acquire basic knowledge, followed by professional training by physicians, nurses, psychologists, medical social workers, school nurses, and other professionals. There are five lectures on "Medical Knowledge of Pediatric Cancer", "Nursing Skills", "School Life", "Social Resources", and "Grief care". In addition, 10 hours of exercises and one hour of role-playing are conducted at the end of the unit. The exercises include "how to be close to the patient", "communication skills", and "self-control of peer counselors", which are taught by psychologists to acquire counseling skills [3].

## METHOD

### Research design

A cross-sectional questionnaire study using a self-efficacy framework.

### Survey method

The survey content was based on the concept of self-efficacy proposed by Bandura (1995) [5], which refers to recognizing one's potential to achieve goals and is closely related to changes in one's motivation. Therefore, an original questionnaire based on a four-item framework was developed to measure peer supporters' motivation to participate in the training and their ability to cope with the difficulties of being a family member of a child with cancer. The questionnaire consisted of 25 items: 6 on "interpersonal and social skills," 9 on "counseling skills," 4 on "self-efficacy," and 6 on "motivation" (Table 1), and responses were obtained on a 5-point Likert-type scale ranging from 0 (not at all) to 5 (very good). Data were collected using an anonymous questionnaire, and an online response was requested on the first day and after the training was completed. The training

content was the same twice a year for five years. Data from 10 training sessions over 5 years were pooled, and the means were compared before and after each session. The study was initiated after receiving approval from the organization's board of directors who conducted the training sessions. The target families were fully informed about the study and its ethical considerations and were asked to voluntarily return the questionnaires.

### Participants

Families of pediatric cancer patients who had attended any of the 10 training sessions held between 2013 and 2019.

## RESULTS

Responses were received from 94 pre-training (42.9% response rate) and 88 post-training participants (40.2% response rate). The valid response rate was 100% in both cases. All participants were parents of children with cancer, and none were grandparents, siblings, or other family members. The highest proportion of families had children with brain tumors (33), followed by those with leukemia (30). The age of the children was highest in the adolescent and young adult families, with 46 children aged 19 years and older, followed by 22 families with adolescents aged 13–18 years. More than half of the families had children receiving outpatient or regular follow-up care, followed by those receiving initial treatment.

Changes in self-efficacy due to participation in the training were observed in six "interpersonal and social skills" items. The average score before the training was 2.26 points while after the training, it was 2.71 points, an increase of 0.45 points. The mean score for the nine "counseling skills" items was 2.43 points before the training; however, the mean score after the training was 2.92 points, an increase of 0.49 points. Self-efficacy (four items) averaged 2.14 points before the course but averaged 2.66 points after the course, an increase of 0.52 points. The six items of "motivation" averaged 2.75 points prior to the course but increased by 0.43 points to 3.18 points after the course.

**Table 1.** Changes before and after participation in the Pediatric Cancer Parents Peer Supporter Training

Question items		0: Not at all 1: Not so much 2: Moderate 3: Good 4: Very good	Mean (before training) n= 94	Mean (after training) n= 88
<b>Interpersonal and social skills</b>	I can talk to anyone, even to someone who looks difficult to talk to.		2.13	2.74
	I can make others feel safe when I am with them.		2.22	2.60
	I can build a relationship of trust with another person.		2.23	2.59
	I can create a cooperative relationship with another person.		2.22	2.59
	I can seek assistance from a third party who may be helpful.		2.55	2.91
	I have access to social services that may be helpful.		2.26	2.83
<b>Consulting skills</b>	I do not care about giving appropriate advice.		2.16	2.74
	I can avoid bombarding the other person with questions.		2.46	2.95
	I can separate my own experiences and perspectives from those of others.		2.39	2.86
	I may not be able to accept others as they are, but I can try to accept them as they are.		2.34	2.93
	I can be helpful and considerate.		2.43	2.86
	I can say that "I don't know" and that "I don't want to do something".		2.26	2.82
	I can try to differentiate between my own (territory) and the other person's (territory).		2.51	2.85
	I try to understand pediatric cancer and stay up to date with the latest information.		2.72	3.19
<b>Self-efficacy</b>	I can listen to what the other person says without criticizing it.		2.64	3.10
	I can control my anxiety and worries.		2.22	2.67
	I can temporarily put my concerns aside.		2.20	2.73
	I can stay calm even when I am irritated.		2.02	2.60
<b>Resilience and motivation</b>	I can calm myself down after stressful or exciting events.		2.14	2.65
	Even if things are hard for me, I can avoid being extremely depressed.		2.02	2.69
	I can bounce back from disappointment even when nothing seems to work.		2.02	2.72
	I want to support people who are experiencing hardship through peer support.		3.00	2.22
	I want to learn more as a peer supporter.		3.11	3.38
	I want to further improve my abilities as a peer supporter.		3.14	3.35
	I want to be useful as a peer supporter.		3.07	3.35

## CONSIDERATION

This program is an original training program that incorporates the skills that families with children with cancer “want to know”, “want to hear”, and “want to learn” through their own experiences. Therefore, it can be said that the program attracted highly motivated families and met their needs. The number of training points has increased over the five years, indicating that the training was highly effective. In particular, “counseling skills” and “self-efficacy” among the participants significantly improved. The results for consultation skills were thought to be the outcome of the 10-hour training in which participants felt that they had grown as peer supporters through two days of intensive lectures and exercises, which led to increased confidence in their ability to carry out activities in the field and improved their sense of self-efficacy. A few families participated in the training more than once; however, most participated only

once. This training can help improve the quality of peer supporters and maximize their potential.

Since 2020, the COVID-19 pandemic has made it difficult to conduct group training. The pandemic significantly affected peer supporters and others, preventing them from conducting activities. However, we received many requests to continue the program, and we considered a system that would make the existing training content available anytime, anywhere, and accessible to families of children with cancer. Therefore, we decided to move to a hybrid on-demand and live learning content delivery system in 2021. The on-demand lecture series is organized as 30-minute videos per unit and consists of the following 10 units: “Who is a Peer Supporter”, “Prospects for Pediatric Cancer Genomic Medicine”, “Pediatric Cancer Nurse Consultation”, “Environment and Social Resources for Children and Families with Pediatric Cancer”, “Return to School Support

for Children with Pediatric Cancer”, “Psychological Support for Children and Families with Pediatric Cancer”, “Pediatric Palliative Care”, “Hospice for Children and Families”, “Peer Supporter Grief Support”, and “How to be a Peer Supporter”. The live video was streamed from a studio where five peer supporters and the trainer demonstrated exercises on “How to be Close”, “Communication Skills” and “Peer Counselor Self-control”, which were viewed by the trainees, who then responded to questions in a chat room. The live video was made available on the website for a one-month viewing period [3].

It was considered important to keep the study content of the workshop the same but rather create an environment more conducive to participation and a system that would allow for ongoing study.

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