



(RESEARCH ARTICLE)



Practical report on the CLIMB[®] program for supporting parents with cancer and their children

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International Journal of Science and Research Archive, 2025, 14(01), 917-923

Publication history: Received on 04 December 2024; revised on 13 January 2025; accepted on 15 January 2025

Article DOI: <https://doi.org/10.30574/ijrsra.2025.14.1.0088>

Abstract

When a parent is diagnosed with cancer, the parental role must be maintained and children receive support to understand and cope with their parents' illness. One form of support for such families is the CLIMB[®] program, a series of group sessions aimed at emotional expression and communication. In this descriptive study, we evaluated the CLIMB[®] program by surveying parents and children who participated. The study participants included 19 children (11 boys and 8 girls) along with 16 parents. Fourteen parents were mothers with cancer, and two were fathers with cancer. On a scale of 1 to 5, with 5 the highest children highly rated emotional expression craft activities. The highest parent rating was for "The support group my child attended was good." The next highest scores were for "the child was appropriately supervised" and "it was a positive, supportive environment for the child." CLIMB[®] provided valuable support in learning about feelings related to parental cancer.

Keywords: Cancer; Children with a parent who has cancer; CLIMB[®] (Children's Lives Include Moments of Bravery) program; Evaluation

1. Introduction

In recent years, the number of cancer patients who are raising children has increased. In Japan, there are approximately 56,000 cancer patients per year with children under the age of 18, with an average age of 46.6 years for males and 43.4 years for females [1]. The average age of the children is 11.2 years (standard deviation: 5.2), with elementary school-aged children making up more than half of the total [1]. Japan's Basic Plan for Cancer Control aims to improve the quality of care for all cancer patients and their families [2]. Cancer patients with children particularly need support tailored to their situation.

2. Literature Survey

Cancer patients raising children face challenges due to physical limitations, emotional struggles, social difficulties, and concerns about their children's future [3][4] Parents sometimes avoid sharing information about their illness to prevent placing a psychological burden on their children.[5] On the other hand, children are sensitive to changes in their parents at home, often feel guilty thinking their parents' cancer is their fault, and experience anxiety about the future[6] They also report more physical complaints [7] and emotional problems, higher stress response symptoms [8], and a lower quality of life (QOL) compared to children whose parents do not have cancer [9]. In school, they reported a decrease in both motivation and grades [10]. Support should be provided that alleviates the difficulties faced by both parents and

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children. This enables parents to fulfill their roles despite having cancer and assists children to cope with their parents' illness. During this stressful time, support is needed to strengthen the bond between parents and children. Neill et al. report that providing opportunities to talk about cancer can help minimize future psychosocial problems [11]. Akagawa et al. found that after attending CLIMB® program, parents and children were able to face cancer together and communicate their feelings to each other [12][13]. Furthermore, she reports that in the parent-child relationship, parents and children were able to face cancer together and communicate their feelings to each other.

One such support program is the Children's Lives Include Moments of Bravery (CLIMB®) program, developed by The Children's Treehouse Foundation in the United States [14]. The aim is to build on the child's strengths and enhance their ability to cope with the stress associated with their parent's illness. In the CLIMB® program, children learn about cancer and its treatment and express their feelings through crafts. Parents have the opportunity to discuss their feelings with staff and other parents who have participated in the program. CLIMB® has multiple benefits. Kobayashi et al. reported that participation in CLIMB® in Japan improves the quality of life for parents with cancer who exhibit post-traumatic stress symptoms [15].

2.1. Problem Definition

In Japan, CLIMB® can be conducted by those who have completed a facilitator training course offered by the NPO Hope Tree [16]. Although facilitators ensure a certain level of quality, the effectiveness of CLIMB® may vary depending on the skills of other staff members and the scheduling of the event. At the author's facility, CLIMB® is lead by two facilitators, and the original six-session program is condensed into four sessions. Due to this irregular implementation, we felt it necessary to evaluate whether the quality of CLIMB® was affected. In the area surrounding the author's facility, the number of cancer patients of child-rearing age is increasing, and the demand for CLIMB® among parents and children is expected to grow in the future. The leaders needed feedback on the best format to use to offer CLIMB®. The purpose of this study was to evaluate the four sessions per set CLIMB® program by surveying participating parents and children.

3. Methodology/ Approach

3.1. Study Setting and Participants

The descriptive study design was used a questionnaire. The subjects were Japanese elementary school children aged 6-12 years whose parents had been diagnosed with cancer and were informed about their parents' illnesses, and their parents who participated in CLIMB®. Exclusion criteria included children with severe intellectual or mental disabilities. This exclusion is due to the group nature of the program which would not allow for individual explanations. Before the first session, we explained the questionnaire and obtained verbal consent from the parents and children. After the CLIMB® sessions, we asked them to complete the survey. From November 2014 to January 2020, 12 sets of CLIMB® (four sessions per set) were held, with a total of 36 children and 23 parents participating.

3.2. About CLIMB® Program [14] [15] [16]

CLIMB® stands for "Children's Lives Include Moments of Bravery. CLIMB® is a group-support program for school-aged children whose parents have cancer. The aim is to build on the child's strengths and enhance their ability to cope with the stress associated with their parent's illness. CLIMB® is a structured program conducted in closed groups. The program proceeds as follows: Children, parents, and staff gather in a room and wait for everyone to arrive. Once everyone has arrived, parents and children move to separate rooms. Parents have a free discussion with the medical staff, while the children participate in the program with the staff. See Fig.1. The program has three goals: 1) learn how to express feelings, 2) learn how to communicate feelings to others, and 3) learn to cope with feelings. Each session addresses specific feelings, and participants interact with others in similar situations through crafts.

The program is typically held six times, for two hours per week. However, in this study, due to difficulties in coordinating the schedules of the medical staff and participants, and because it coincided with children's long vacations, the program was condensed into four sessions held at intervals of approximately 1 to 3 weeks, each lasting about two hours. Additionally, each group was assigned two to four staff members, with the same staff member overseeing the group from start to finish. The number of children participating in each group ranged from 2 to 5, varying among the groups. The CLIMB® program staff includes a leader and an assistant. Leaders are individuals who have completed a facilitator training course conducted by the NPO Hope Tree [16].

The primary role of a leader is to monitor the progress of the program, oversee the overall situation, and empathetically observe the participants. The assistants consist of a multidisciplinary team of doctors, nurses, clinical psychologists, and

nursing students. Their main role is to help the children grasp the essence of the program, assist them with any difficulties during activities, and facilitate interactions among the children.

Table 1 Content of the CLIMB® Program for the children's group (4 sessions per set)

| sessions | Goal | Feeling | Activity |
|----------|--|--------------------------|--|
| 1 | Decrease children's isolation by sharing their cancer story with other children. | Happy | Introduce yourself. Share about your family's cancer and treatment. Children will share what they do for fun and what people, things, or events make them happy. |
| | Normalize feelings of sadness. | Sad | Let the children share times when they felt sad. It is normal to feel sad when someone in your family has cancer. Make a mask to express the sad feelings they might have when a parent has cancer. |
| 2 | Increase the child's knowledge about cancer and its treatment. | Confusion | Let the children share when they feel confused and then learn about cancer to help them feel less confused. Children will learn how cancer spreads, how it is treated, and how treatment affects a person. They will also learn that they cannot cause cancer to happen, cannot catch it, and that they can help. |
| 3 | Assist child to identify strengths and normalize anxiety. | Scared | Make a strong box and decorate the outside with pictures that make them feel strong. Then, write down their worries and put them in the box. Explain that their strengths can help with their worries. |
| 4 | Assist child to manage anger in healthy ways. | Mad | Children will discuss things that make them angry about their parent's cancer and learn healthy ways to cope with their anger. They will also create a cube featuring six different anger management strategies and share them with the group. |
| | Facilitate communication with their parent who has cancer. | Facilitate communication | Children will create a caring card by filling in blanks such as "Sometimes I worry...", "One thing I want you to know is...", and "I hope you...". They will then decorate the outside of the card. When the parents join the group, the children will present their cards to their parents. The leader will hand out certificates, and children, parents, and staff will celebrate the completion of the CLIMB® program with some sweets. |

3.3. Questionnaire Contents

A feedback questionnaire prepared by the NPO Hope Tree was used. The children were asked 10 questions, including "I was glad to be here," "I liked the art," and "The staff was easy to talk to and fun to play with." The questionnaire evaluated the overall program, interest in the activities, and communication with the staff.

Parents were asked 13 questions, including "I liked the CLIMB® support group my child attended," "My child benefited from the CLIMB® program," and "The staff was competent and knowledgeable about families trying to live and cope with cancer." The questions covered overall evaluation, the program's effects on the child from the parent's perspective, and evaluation of the staff. Two common questions asked of both parents and children were: "I (My child) was glad to be here." and "I (My child) learned things that helped him/her understand cancer.". For all items, the response method was a 5-point scale from Agree to Disagree. Children were also asked what they enjoyed the most, what they wished they had tried, and for their general opinions and impressions.

Parents were asked open-ended questions such as, "The most helpful part of the CLIMB® program was...", "The part of the CLIMB® program my child liked best was...", "I think the CLIMB® program should also include...", as well as for their general opinions and impressions.

3.4. Analysis

Personal attributes such as grade and gender were tabulated, and averages were calculated for each item in the questionnaire. The free-response answers were categorized by a psychologist and two nurses working in childcare into similar themes.

3.5. Ethical Considerations

This study was approved for ethical review by Saiseikai Hospital (review number 2022-001).

The study was verbally explained to the parents and children participating in CLIMB®. The explanation included: 1) the research background, objectives, and methods; 2) the methods for protecting personal information; and 3) assurance that no personally identifiable information would be released when publishing the results. After the explanation, consent for the study was obtained from both parents and children. Parents and children were not given incentives to participate. However, the program was provided free of charge, and food, beverages, and craft materials were provided during the program.

4. Results and discussion

Responses from 19 children and 16 parents were included in the analysis. Eleven children did not respond to the questionnaire. Two children and two parents had incomplete responses, and the responses from four children who were unable to attend all sessions were excluded.

The demographics of the participants analyzed included the gender and age of the children: 11 were boys and 8 were girls (n=19). The mean age of the children was 8.3 ± 1.8 years, with a median age of 9.0 years.

In 13 cases, the parent with cancer was the mother, and in 3 cases, it was the father. The types of cancer included breast cancer (6 cases), stomach cancer (2 cases), colon cancer (1 case), ovarian cancer (1 case), brain tumor (1 case), and uterine cancer (2 cases). All eligible children lived with their parents, and the parents' medical conditions were stable during the CLIMB period.

4.1. Children's Questionnaire (Table 2)

The highest mean score was 4.9 (SD=0.32) for "I liked the art," and the lowest was 4.2 (SD=1.01) for "Drawing and making things helps me talk about myself and my feelings."

Table 2 Average of Children's Evaluations

| Questionnaire | Mean (\pm standard deviation) |
|--|----------------------------------|
| I was glad to be here. | 4.6(0.68) |
| I liked the art. | 4.9(0.32) |
| The staff was easy to talk to and fun to play with. | 4.7(0.45) |
| It was good to talk to others about our feelings. | 4.5(0.77) |
| I felt less alone after hearing others talk about cancer. | 4.6(0.77) |
| I learned things that helped me understand cancer and its treatment. | 4.7(0.56) |
| I hope to see the friends I made in this group again. | 4.5(0.70) |
| I believe this program will help other children. | 4.6(0.60) |
| I would come to another meeting in the future. | 4.3(1.00) |
| Drawing and making things helped me express myself and my feelings. | 4.2(1.01) |

In the free description section, the children related that they enjoyed "making strong boxes," "making Kiwanis dolls of parents with cancer," "crafts in general," "painting," "making caring cards," "the anger cube," and "snack time." While some said the current content was sufficient and that there was "nothing else they wanted to do," others mentioned they wanted to play games, repeat the same activities, have parties and barbecues, take pictures, and play cards.

Free opinions and impressions included: "I enjoyed it," "I want to participate/learn again," "It was good to talk with friends and staff," "I was glad to learn about cancer," and "I want to talk about cancer more."

4.2. Parent Questionnaire (Table 3)

The highest mean scores were 4.9 (SD=0.25) for "I like the CLIMB® support group my child attended" and 4.9 (SD=0.34) for "My child was appropriately supervised when not with me." The lowest mean score was 4.2 (SD=0.75) for "I feel CLIMB® helped me worry less about how to help my child deal with my (or my partner's) illness."

Table 3 Mean Parental Ratings of the Program

| Questionnaire | Mean (\pm standard deviation) |
|--|----------------------------------|
| I like the CLIMB support group my child attended. | 4.9(0.25) |
| I would recommend CLIMB to a friend or family member with cancer. | 4.6(0.63) |
| The online format was convenient. | 4.5(0.63) |
| Staff was competent and knowledgeable about families trying to live and cope with cancer. | 4.4(0.51) |
| I felt comfortable asking about CLIMB and my child's needs. | 4.5(0.52) |
| My child benefited from CLIMB. | 4.5(0.52) |
| Staff was sensitive to my family's cultural/ethnic background and our health beliefs. | 4.6(0.50) |
| My child was appropriately supervised when not with me. | 4.9(0.34) |
| CLIMB helped me and my child share feelings about my diagnosis and the changes in our family. | 4.6(0.51) |
| I believe CLIMB helped my child cope better with my (or my partner's) illness. | 4.3(0.60) |
| I feel CLIMB helped me worry less about how to help my child deal with my (or my partner's) illness. | 4.2(0.75) |
| I found CLIMB Program to be a place of positive support for my child. | 4.8(0.45) |
| My child liked the CLIMB Program. | 4.6(0.51) |

In the free descriptions, the children mentioned that the things they liked best were "crafts/activities," "learning about cancer and its treatment," "meeting other children in the same situation," "being able to talk about their feelings," and "meeting the staff."

Free opinions and impressions included positive evaluations of the experience and opportunities for the children, such as "I realized that I am not the only child whose parent has cancer," and noted changes in the children, such as "Communication between parents and children became easier." There were also positive evaluations of the staff, such as "The staff listened to me and provided emotional care," and "The staff listened to me, which helped me take care of myself." Requests included "ongoing programs that match the growth of the children and meetings where parents can talk with each other," and "more specific explanations of the purpose of the programs."

5. Discussion

The purpose of this study was to evaluate the CLIMB® program, which consists of four sessions per set, by surveying participating parents and children. The results showed that both parents and children rated the program highly.

The children rated "making things" as their favorite activity. Vallerand et al. (1997) describe this as intrinsic motivation, which is the enjoyment and satisfaction felt when engaging in a self-initiated, challenging task. This sense of intrinsic motivation is also connected to the drive to learn [18]. Children participating in CLIMB® often feel nervous about being in a new environment. Enhancing their internal motivation through crafts may encourage them to continue participating in the program.

Regarding items related to children's emotional expression and coping, "It was good to talk to others about our feelings" received high ratings. One reason for this was believed to be the "conversations among the children and questions from the staff," as mentioned in the open-ended responses. In CLIMB[®], staff members particularly encourage children to interact by identifying and emphasizing their commonalities. For children to express their feelings, it is important to have interaction with peers in similar situations and appropriate encouragement from the facilitator.

Comer et al. (1996) found that a warm and supportive environment positively influences children's motivation to learn [19]. The supportive environment at CLIMB[®] is believed to foster children's motivation effectively.

The highest-rated response in the parent survey was, "I like the CLIMB support group my child attended." The highest-rated response in the parent survey was, "I like the CLIMB support group my child attended." Other highly rated responses included, "The child was appropriately supervised when not with me" and "I found the CLIMB Program to be a place of positive support for my child."

Parents value useful, practical, and high-quality support over the quantity of support as a communication resource with their children.17) As a parent, the satisfaction of receiving a program from professionally trained staff is significant in itself.

On the other hand, the lowest-rated item was, "I believe CLIMB helped my child cope better with my (or my partner's) illness." Based on the free comments, it appears there was insufficient feedback on the children's behavior during the program and on the program content. It seems necessary to hold a parent program concurrently and to explain the program to the parents afterward.

The study has two limitations: the first is the method of implementation. The study was conducted at a single medical facility, where the staff and intervals between meetings were irregular. This made it difficult to provide consistent responses to parents, such as explanations and feedback after four sessions per set. Additionally, parent feedback indicated a desire for a more detailed explanation of the program's objectives. In the future, it will be necessary for staff to communicate and work closely together to ensure a consistent approach when dealing with parents.

Additionally, while a questionnaire was used to evaluate the program, a deeper understanding of parent-child communication was needed. Therefore, interviews will be conducted in the future to understand how the CLIMB[®] program affects the relationship between children and parents.

6. Conclusion

Both parents and children gave high evaluations of the CLIMB[®] program. Children enjoyed the crafts and the opportunity to learn about their parents' cancer. Parents felt reassured by the professional staff's appropriate involvement with their children. In the future, it is necessary to incorporate this program as an ongoing effort, even if it is held irregularly at medical facilities.

6.1. Future Scope

This study implemented the CLIMB[®] program in a modified form, reducing the planned six sessions per one set to four per one set and utilizing different staff members each time, yet it remained effective for children whose parents had cancer. With the onset of COVID-19, the program was adapted to an online format when in-person sessions became difficult. Moving forward, we aim to compare the effectiveness of online versus face-to-face delivery and continue supporting children of cancer patients, regardless of future challenges.

Compliance with ethical standards

Disclosure of conflict of interest

No conflict of interest to be disclosed.

Statement of ethical approval

This study was approved for ethical review by Saiseikai Hospital (review number 2022-001).

Statement of informed consent

Informed consent was obtained from all individual participants included in the study.

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