

# Intervention Protocol: Technology-Based Psychosocial Motivation for Children with Cancer and Their Parents: A Randomized Trial

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## ABSTRACT

**Objective:** This experimental randomized controlled trial will be to examine the impact of a technology-based psychosocial motivation program on children and families who are being followed up on a diagnosis of cancer. **Methods:** The research is based on the “Transactional Model of Stress and Coping.” This study will be conducted on children with leukemia, aged 9–18 years, and their parents, who will be followed in the consolidation treatment phase in the hematology wards and outpatient clinic of a university hospital. Data collection will consist of the children’s and parents’ descriptive characteristic form, the Spielberger State Anxiety Inventory for Parents, the State-Trait Anxiety Inventory for Children, the Pediatric Cancer Coping Scale, the Pediatric Quality of Life Inventory, and process evaluation forms. A 10-week program will be implemented for the children in the intervention group through web-based training,

coaching interviews and counseling via video mobile calls, mobile messages and children’s stories, progressive muscle relaxation and breathing exercises, and imagination interventions. During the same period, parents will also receive web-based training, coaching sessions, counseling, mobile messages, and progressive muscle relaxation exercises. **Results:** It is thought that after the intervention the stress level of the child and the family will decrease, the coping skills of the children will improve, and their quality of life will increase. **Conclusions:** It is thought that the treatment process can be affected positively by providing psychosocial support to children and their families who receive cancer treatment.

**Key words:** Cancer, child, motivation, parent, program, psychosocial, technology

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## Introduction

The overall incidence rate of childhood cancer ranges from 50 to 200 million worldwide. The number of children who are diagnosed with cancer is increasing, and the life expectancy of children with cancer is being prolonged with improved diagnosis and treatment methods.<sup>[1]</sup> The increase in the number of children with cancer has led to a corresponding increase in psychosocial needs among children and their families.<sup>[2]</sup>

In this process, children are often concerned about their illness, feeling sad and isolated.<sup>[3]</sup> Children and adolescents may feel challenged and experience a deterioration in body image, a loss of independence, inability to plan for the future, a decrease in concentration and attendance, a decrease in cognitive abilities, impairment of daily routines, limitations in activity, difficulties with respect to peer relations, peer bullying, and ridicule.<sup>[4-7]</sup> The quality of life of children who are affected by psychosocial problems and have to cope with many stressful situations<sup>[6]</sup> is also diminishing.<sup>[8,9]</sup> It is for this reason that the development of psychosocial programs to support children is gaining more and more importance.

Cancer treatment affects families as well as children, both physically and psychosocially.<sup>[10,11]</sup> After a diagnosis of cancer, families experience difficulties due to uncertainties about the future, the disappearance of normal family life, issues related to siblings, and financial problems,<sup>[12]</sup> all of which lead to a deterioration of physical and psychosocial health. From a social perspective, the long treatment process increases the health costs of countries, creating an economic burden.<sup>[13]</sup>

Treatment for children with cancer has usually been focused on physical interventions, whereas psychosocial interventions have remained limited. There are some programs in literature that aim to improve psychosocial aspects in the case of children with chronic illnesses. These programs seem to have been aimed at patients with diseases such as cancer, asthma, and diabetes.<sup>[14-16]</sup> They include coping skills,<sup>[17]</sup> cognitive behavioral approaches involving relaxation exercises,<sup>[14,18]</sup> group-based therapeutic exercise programs,<sup>[19]</sup> yoga,<sup>[20]</sup> guided imagery,<sup>[15]</sup> hypnotic relaxation,<sup>[16]</sup> meditation,<sup>[21]</sup> physical exercise, and relaxation exercises. As a result of these programs, it was determined that children's anxiety levels had decreased, their sleep quality had increased, and their quality of life, self-efficacy, and coping skills had improved.<sup>[14,16-20]</sup> There are also programs for parents of children with chronic illnesses that include dimensions such as cognitive behavioral approaches, family therapy, and problem-solving therapy.<sup>[22]</sup>

A psychosocial health-promoting program with multiple dimensions for children with cancer and their parents was

not detected in literature. In the context of holistic care, there is a need for programs that improve the psychosocial health of children and families who are being followed up because of a cancer diagnosis. It is thought that these programs will enhance nursing care by decreasing stress, improving coping skills, and increasing the quality of life of both the child and the family. For instance, a number of psychosocial problems are likely to be encountered during the treatment process of children diagnosed with leukemia, which may affect their healing process. This study was aimed at providing psychosocial support to children with leukemia and their families. Today, the use of technology has become widespread in all areas. Thus, there have been effective initiatives to apply technology to the field of health, especially in diagnosis, treatment, and follow-up process of the disease, as individuals have started to receive health services online in their homes. In this study, technology-based programs were employed to ensure the continuation of health-care services and ease of communication. This article reveals the content and implementation plan of a psychosocial motivation program built for children diagnosed with leukemia and their families. The results of the study will be disseminated when the application has been completed.

## Aims and hypotheses

This research was planned in an effort to examine the impact of a 10-week technology-based psychosocial motivation program for children with cancer and their parents.

Specific hypotheses include the following:

- $H_0$  – There is no meaningful difference between the coping skills, stress levels, and quality of life of children who have received psychosocial motivation programs and those of children who have not
- $H_1$  – The stress levels of children exposed to a motivational program are lower than those of children in the control group
- $H_2$  – The coping skills of children exposed to a motivation program are higher than those of children in the control group
- $H_3$  – The quality of life of children exposed to a motivation program is higher than that of children in the control group
- $H_4$  – The stress level of parents in the intervention group is lower than that of parents in the control group.

## Methods

### Study design

This pilot study was planned to be of a randomized controlled experimental research design. The research was

carried out from January 3 to 9, 2019, in the hematology outpatient clinic and wards of a university hospital in Turkey's Central Anatolia. The universe of the study will be children with leukemia aged 9–18 years receiving treatment in the hematology wards or outpatient clinic of a university hospital and their parents. To avoid any bias, children will be paired prior to randomization based on their age and sex. The children will be allocated to the intervention or control groups using the simple random method, which will be conducted by an individual blinded to the research. The inclusion criteria for the children are as follows: (a) receiving treatment at the consolidation phase, (b) diagnosed with leukemia, (c) Turkish speaking, (d) between the ages of 9 and 18, (e) having Internet access on a smartphone or computer, (f) agreeing to participate together with a parent, (g) and ability to participate in the program for 8 weeks. The inclusion criteria for the parents are as follows: (a) Turkish speaking, (b) Internet access on a smartphone or computer, (c) agreeing to participate in the study, and (d) ability to participate in the program for 8 weeks. The exclusion criteria for the study are as follows: (a) having experienced an important life event in the past 6 months (death, divorce, etc.), (b) having another important disease that can increase stress and suppress coping skills in the family, (c) wishing to leave the study, and (d) inability to continue the program for more than 1 week.

Children under 18 years who are diagnosed with leukemia are followed up in a hematology ward or outpatient clinic. Patients with leukemia are tracked in clinics during the diagnosis, treatment, and control stages.

### Data collection tools

In this study, the children and their parents will complete the Children's and Parents' Descriptive Characteristics Form and process evaluation forms. In addition, the children will fill out the State-Trait Anxiety Inventory for Children, Pediatric Cancer Coping Scale, and Pediatric Quality of Life Inventory. Parents will complete the Spielberger State Anxiety Inventory.

#### Children's and Parents' Descriptive Characteristics Form

The descriptive characteristics form was developed by the researchers in light of the literature.<sup>[23-26]</sup> There are seven close-ended questions about the children's age, education, and treatment status and six close-ended questions about the parents' age, education, and working status.

#### Spielberger State Anxiety Inventory

This scale was developed by Spielberger *et al.*<sup>[27]</sup> for the purpose of determining the anxiety levels of individuals aged 14 and over. The Turkish validity and reliability of the scale was assessed by Öner and Le Compte.<sup>[28]</sup> The State

Anxiety Inventory will be used in our study. The scores on the scale range from 20 to 80, and the higher the score, the higher the level of anxiety. The original Cronbach's alpha value ranged from 0.86 to 0.95.<sup>[29]</sup> Cronbach's alpha values in the Turkish form ranged from 0.94 to 0.96 on the State Anxiety Scale.<sup>[28]</sup>

#### State-Trait Anxiety Inventory for Children

This scale was developed by Spielberger to measure the level of anxiety in children.<sup>[30]</sup> The validity of the Turkish version was assessed by Özusta on children aged 9–12 years. Cronbach's alpha values ranged from 0.78 to 0.81 on the original scale.<sup>[30]</sup> The Cronbach's alpha values of the scale in the Turkish version were found to be 0.82 for the State Anxiety Scale and 0.81 for the Trait Anxiety Scale.<sup>[31]</sup> The scale can be used in our country for children aged 9 and older.<sup>[31]</sup> National and international studies had reported that the scale can be used for ages up to 17–18 years.<sup>[32-39]</sup> It is observed that the scale has been used in studies to determine the stress situations of children with cancer.<sup>[40-42]</sup>

#### Pediatric Quality of Life Inventory (PedsQL™)

This scale was developed by Varni *et al.*<sup>[43]</sup> to measure the quality of life of children and adolescents aged 2–18 years. The scale consists of 23 items and is scored from 0 to 100. The higher the score, the higher the quality of life.<sup>[44]</sup> The original form's Cronbach's alpha value was 0.93.<sup>[43]</sup> The validity and reliability studies for the Turkish version of the scale for 8–12 year olds were conducted by Cakın Memik *et al.*,<sup>[45]</sup> and the Turkish validity and reliability studies for 13–18 year olds were carried out by Cakın Memik *et al.*<sup>[46]</sup> The Cronbach's alpha coefficient was found to be 0.82 in the adolescents' form and 0.86 in the children's form.<sup>[45,46]</sup> The scale has been used in studies to determine the quality of life of children with cancer.<sup>[47,48]</sup>

#### Pediatric Cancer Coping Scale

This scale was developed by Wu *et al.*<sup>[23]</sup> for children with cancer between the ages of 7 and 18 years. The scale comprises 33 items related to cognitive coping, problem-oriented coping, and defensive coping. The items are measured on a scale of 0 (never) to 3 (always). Higher scores on the scale indicate a high level of coping strategies. Cronbach's alpha coefficient in the original study was 0.91. The Turkish validity reliability study of the scale was initiated by the researchers.

#### Process evaluation forms

The following six forms developed by the researchers will be used to evaluate the process of the study:

1. Website training follow-up form – Completion status of training modules, problems experienced during the follow-up of modules, and frequently asked questions will be tracked with this form

2. Mobile video interview follow-up form – Interview dates, time, contents, and questions will be recorded on this form
3. Counseling follow-up form – The reason for the counseling request, the time, and the results will be recorded on this form
4. Children’s follow-up form for interventions – Interventions such as progressive muscle relaxation, breathing exercises, imagination, story reading and writing, and the awareness wheel will be monitored weekly and related problems will be recorded on this form
5. Parents’ follow-up form for interventions – Progressive muscle relaxation, breathing exercises, parents’ approach to the child, and the problems experienced will be recorded on this form
6. Satisfaction and suggestion form – This is a feedback form for the program to be given to the children and their parents at the end of the intervention.

### Theoretical underpinnings

When we look at the studies in which the coping strategies of children with cancer have been examined, it can be seen that Lazarus and Folkman’s “Transactional Model of Stress and Coping” has been most commonly used.<sup>[23-25,49]</sup> According to this model, an individual employs coping strategies that are problem focused or emotion focused when faced with a stressful situation.<sup>[50]</sup> Interventions in the study were planned using the Transactional Model of Stress and Coping [Table 1].

### Pre-application

A preliminary application of the data collection forms and the technology-based program will be administered to five children between the ages of 9 and 18 years with a diagnosis of leukemia and their parents. After the

preliminary application, changes and corrections will be applied to the forms and program if necessary.

### Technology-based psychosocial motivational program interventions

A 10-week program involving web-based training, mobile video coaching interviews and counseling, mobile messages and children’s story reading and writing, progressive muscle relaxation and breathing exercises, and imagination interventions will be implemented on the children in the intervention group. The flowchart of the study is shown in Figure 1. The interventions for children and parents are shown in Figure 2. The research forms for the children and their families in the intervention group will be implemented at the beginning and end of the program.

### Education modules

In the first 2 weeks of the program for children, four training modules will be presented via a web-based training site [Table 2]. The application of modules 1 and 2 of the training on the website will be carried out in the 1<sup>st</sup> week of the research, and the implementation of modules 3 and 4 will be done in the 2<sup>nd</sup> week.

Parents of the children in the intervention group will also be exposed to two training modules for relaxation and communication with children through the website [Table 3]. Once the website modules have been developed by the researchers, experts will be consulted for content validity to assess the appropriateness of the content for children and parents.

### Mobile video coaching interviews and counseling

A mobile face-to-face coaching interview with the children will be conducted once a week for 45–60 min. There will be a total of nine coaching interviews in the program. The researchers will offer parents two mobile online video interviews and 24/7 telephone counseling services for both children and families.

Table 1: Use of transactional stress and coping model within motivation program

Model section	Sub-section	Description	Application	Evaluation/scale
Problem focused	Seeking social support	Describes individual’s search for support regarding information and emotions	Coaching interviews with child and parents Training module on website Counseling weekly reminder and motivation messages on mobiles	Process evaluation forms (follow-up forms of mobile video interviews, follow-up forms of counseling service, follow-up forms of website, suggestions form) Pediatric Quality of Life Inventory
Emotion focused	Self-control	Attempt to control individual’s own emotions	Training modules on website Progressive relaxation and breathing exercises for children and their parents Imagination method	State-Trait Anxiety Inventory for Children Spielberger State-Trait Anxiety Inventory Pediatric Cancer Coping Scale Pediatric Quality of Life Inventory Evaluation forms of the process
	Positive reappraisal	Placing positive meanings on individual’s situation	Awareness wheel Therapeutic stories for children	Grading the items on the wheel from 1 to 10 Child’s composing his/her own story at the end of 8 weeks
	Accepting responsibility	The individual takes responsibility for solving the problem	Commitment of children and parents about what to do during coaching interviews	Process evaluation forms

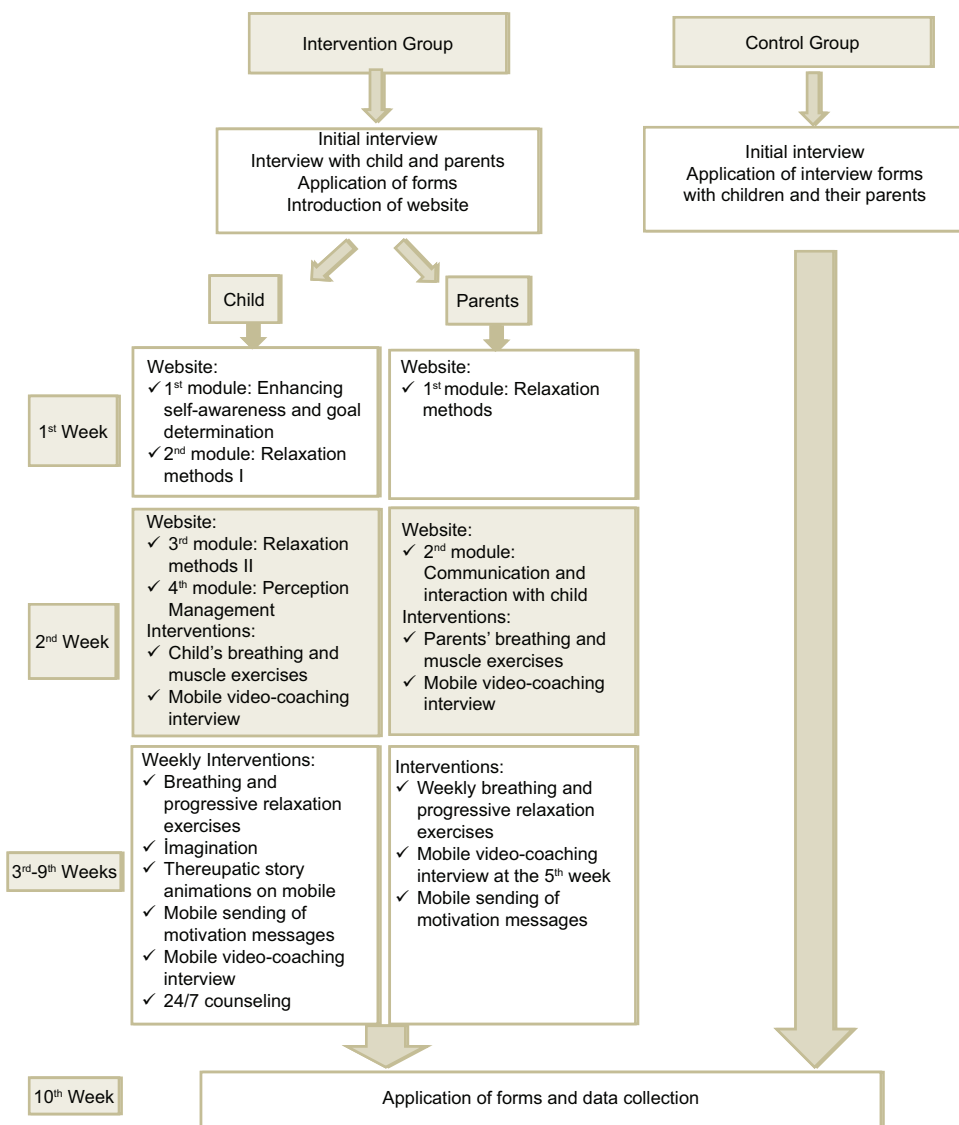


Figure 1: Flowchart of the randomized controlled research

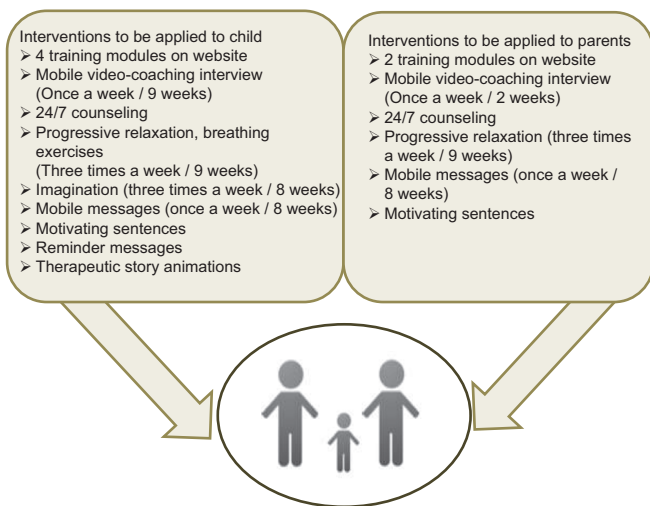


Figure 2: Interventions to be applied to children and their parents in the technology-based psychosocial motivation program

**Progressive muscle relaxation, breathing exercises, and imagination**

The videos of relaxation exercises containing progressive muscle relaxation exercises prepared by the Turkish Psychological Association will be shown in the second module. The training module will feature imagination videos of the sky accompanied by the sound of a rhythmic drum to be prepared by the researchers, as well as imagination videos of purification from emotional burdens, along with water sounds and a voice accompaniment.

Children will be asked to perform a progressive muscle relaxation technique (one application/day) and breathing (three breaths/day) for at least 3 days/week for 9 weeks. Following the completion of module 3 in the 2<sup>nd</sup> week, an imaging technique will be added to the muscle relaxation and breathing exercises. Parents will be asked to perform

**Table 2: Motivation program modules and contents for children on website**

Modules	Purpose	Content
1 <sup>st</sup> module: Self-consciousness and goal determination	Development of child's self-consciousness	Goal: Ensuring child to establish goals for factors increasing self-motivation Period: 20 min Materials: Theoretical knowledge and awareness wheel activity on website (goals on self-care, social life, motivation, positive perspective, coping with stress and happiness) Evaluation: Asking child to grade the units on the wheel from 0 to 10
2 <sup>nd</sup> module: Relaxation method 1	Identification of stress and child's development of coping	Goal: Promotion of child's relaxation with appropriate breathing and relaxation exercises Period: 30 min Materials: Theoretical knowledge and relaxation exercises video prepared by the Turkish Psychologists Association Evaluation: Checking to see whether child performs exercises appropriately during online coaching interviews in the 2 <sup>nd</sup> week
3 <sup>rd</sup> module: Relaxation methods 2	Development of child's effective coping	Goal: Child's spiritual relaxation by imagining a relaxing situation Period: 20 min Materials: Theoretical knowledge and imagination video of the sky and sand along with a rhythmic drum beat, imagination video of purification from emotional burdens along with water sounds Evaluation: Checking to see whether child performs imagination exercises appropriately during online coaching interviews in the 3 <sup>rd</sup> week
4 <sup>th</sup> module: Perception management	Development of child's positive perception	Goal: Child's positive consideration of events while perception changes positively Period: 20 min Materials: Theoretical knowledge and animation of a therapeutic story chosen from literature Evaluation: Composition of a story showing the positive change of child's perception at the end of the program

**Table 3: Motivation program modules and contents for parents on website**

Modules	Purpose	Content
1 <sup>st</sup> module: Relaxation methods	Development of parents' effective coping	Goal: Parents' recognition of relief through appropriate breathing and relaxation exercises Period: 30 min Materials: Theoretical knowledge and videos of relaxation exercises prepared by the Turkish Psychological Association Evaluation: Checking to see whether parents perform exercises appropriately during the coaching interviews in the 2 <sup>nd</sup> week
2 <sup>nd</sup> module: Communication and interaction with child	Parents' learning communication and interaction methods with child	Goal: Parents' ability to conduct appropriate communication with child Period: 20 min Materials: Theoretical knowledge Content: Age period characteristics, activities fostering child's competence feelings, importance of love and hugs Evaluation: Receiving feedback on parts parents want to inquire or comment about on the issue on the website and providing consultancy by encouraging parents to talk about the subject during online coaching interviews in the 5 <sup>th</sup> week

muscle relaxation and breathing exercises for 8 weeks after completing the training modules.

### **Messages via mobile**

Three separate messages will be sent to the children's mobile phones every week. The first message's content will be motivation messages. The second type of message content will be a reminder to do the muscle relaxation, breathing, and imagination exercises. The third type of message will be a therapeutic children's story. To help the child manage his/her perception in a positive way, eight therapeutic stories selected by the researchers will be prepared as an animated video and sent to the child's phone. At the end of the program, the child will be asked to write a personal narrative about the importance of perception.

### **Control group**

Routine practices in the control group of children and their families will continue. The data collection forms will

be administered to the children and their parents at the beginning of the study. Except the descriptive characteristic form, the questionnaires will be readministered at the end of the program.

### **Ethical approval**

Permission has been obtained from the university's Ethics Committee (Approval No. 2018-368) and the hospital (No. 98206329/770). The informed written consent of children and parents agreeing to participate in the study will also be collected.

### **Statistical analysis**

Data obtained in the study will be analyzed with the IBM SPSS for Windows Version 21.0 program, and the frequency values and percentage distributions will be calculated. The variables' compliance with normal distribution will be examined with visual (histogram

and probability graphics) and analytical (Kolmogorov–Smirnov) methods. The Chi-square test or Fisher’s exact test will be employed to compare the nominal data between the groups. For the comparison of the data in the two groups that have continuous variables (ordinal), the Mann–Whitney U-test will be used for nonnormally distributed data and the Student’s *t*-test will be used for normally distributed data. On investigating the associations between nonnormally distributed and ordinal variables, the correlation coefficients and their significance will be calculated using the Spearman’s test.<sup>[51]</sup> The significance level was set at 0.05.

## Results

After the motivation program, it is thought that the stress level of the child and the family will decrease, the coping skills of the children will improve, and the quality of life will increase.

## Discussion

With the advancement of technology, children and their parents can access the Internet easily and use web pages as a source of information. Considering that children and their parents can reach reliable information and find answers to problems encountered during the treatment process via the Internet, and that the maintenance of care can be ensured by means of the Internet providing the dissemination of scientific knowledge, a web-based motivation program was planned to be conducted in the study. There is a need for separate modules for children and their parents in the organization of programs. Meanwhile, it is necessary to prepare program contents which could appeal to children of different ages and their parents, to make content analysis, and to take expert views on the content. The challenges of the program include children’s participation in relaxation exercises, imagination and coaching interviews within program contents, and staying online continuously during interviews via Whatsapp. The obstacles against the implementation of the program include failure to carry out the program due to lack of internet access by the children and their parents, difficulty in reaching the sample group in the clinics, insufficient area allocated for the introduction of the program in the hospital, and the difficulty of children and their parents for spending 60 min to participate in the program.

In this study, a combination of various methods will be employed for both children and parents. Considering that no similar study was encountered in literature, it is thought that this study will contribute to evidence-based information. With regard to the limitations of the study, the information obtained by the measurement tools is limited to

the responses of the patients to the scale questionnaires. In addition, the research will be conducted at a single hospital. Hence, the results are likely to vary across individuals and cultures. Furthermore, the fact that only children and parents with internet access were included in the study may prove to be a limitation.

## Conclusion

Supporting children and parents in the long and challenging process of cancer treatment plays a crucial role in maintaining compliance with treatment, increasing comfort, and dealing with stress. It is believed that a motivation program to be applied with family-centered care, cognitive behavioral methods and coaching techniques will contribute to helping children and parents control their emotional status and develop effective coping skills during the course of illness and through the treatment process.

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Nil.

### Conflicts of interest

There are no conflicts of interest.

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