

**SCCIP**



# **Surviving Cancer Competently Intervention Program**





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## **INTERVENTION MANUAL**

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## OVERVIEW



**Surviving Cancer Competently Intervention Program (SCCIP)** is a manualized intervention for 11-18 year-old adolescent survivors of childhood cancer, their parents, and their adolescent siblings. The content and format of the intervention emerged from our research on survivors and their families, documenting traumatic stress responses to cancer and its treatment, across members of the family (see references).

SCCIP addresses two specific areas:

- (1) Posttraumatic stress symptoms related to cancer and its treatment
- (2) Family interactions that facilitate long-term adjustment to illness

The program expands and integrates treatment frameworks from the cognitive behavioral perspectives of Ellis and Seligman and the Multiple Family Group approach of Steinglass and associates.

### **RCT Results:**

A randomized clinical trial of SCCIP with 150 adolescent survivors and their families demonstrated reductions in PTSS among family members.\* Through the use of cognitive-behavioral exercises, family members were able to identify their beliefs about cancer and the way these beliefs impact their emotions, behaviors, and relationships. They learned to reframe these unhelpful beliefs to reduce distress and to communicate with each other (sometimes for the first time) about their thoughts, fears, feelings and memories in ways that promoted individual and family coping, competence, and resilience. In addition, we found that the framework of the intervention enabled families to connect with others with similar survivorship experiences, which helped to normalize their own experiences.

\*For more information, see Kazak et al. (2004). Treatment of posttraumatic stress symptoms in adolescent survivors of childhood cancer and their families: A randomized clinical trial. *Journal of Family Psychology*, 18, 493-504.

## **GENERAL AIMS AND SPECIFIC GOALS**

The overarching aims of SCCIP are to:

- (1) Reduce posttraumatic stress symptoms in adolescent survivors of childhood cancer and their families;
- (2) Target anxiety, beliefs about cancer and its treatment, social support and family communication as specific areas of expected change.

Related to these aims are the specific goals:

- Educate adolescent survivors of childhood cancer and their parents and siblings regarding posttraumatic stress symptoms and other psychological sequelae;
- Help adolescent survivors and their family members identify ways in which cancer and its treatment have affected their family and individual and family developmental tasks;
- Identify symptoms of posttraumatic stress (such as intrusive memories, avoidance, or hypervigilance) for adolescent survivors and their family members, in a supportive environment;
- Teach adolescent survivors and their family members cognitive behavioral strategies which can reduce specific symptoms of posttraumatic stress;
- Facilitate discussion within the family of how cancer has affected the families of adolescent cancer survivors by focusing on developmentally relevant issues;
- Practice family discussions about posttraumatic stress and identify ways in which the cognitive-behavioral and family strategies can be implemented at home.

## **IMPLEMENTING SCCIP:**

- SCCIP is a manualized treatment program. The intervention must follow the manual protocol.
- SCCIP may not be used without consultation and permission of the authors. Our team is available to consult on the use of SCCIP clinically and/or in a research study.
- The flexibility and clinical judgment of interventionists is critical to successful implementation. As in any intervention, developing therapeutic relationships with individuals and families are necessary for positive outcomes. Familiarity with the underlying concepts, combined with genuineness, empathy, and clinical skill, will maximize the intervention.
- SCCIP is a one-day intervention, conducted with a group of families. Our experience has been that this is the most feasible and acceptable format for families of childhood cancer survivors, who may live several hours away from the cancer treatment center. This format also facilitates the group treatment milieu.
- In conducting SCCIP, scheduling difficulties must be considered. The challenge of having all members of the family available is often significant. It should be emphasized to families that the one-day program is intensive and condenses material that would ordinarily be presented over 6-8 weekly sessions.

## **RECRUITING AND SELECTING PARTICIPANTS:**

### **Appropriateness of Participants:**

- The intervention has been developed for adolescent survivors (ages 11-18), parents, and adolescent siblings of average intelligence and literacy. The types of learning difficulties sometimes seen in survivors of childhood cancer should have no adverse effect on participants' ability to complete the program successfully. The demands of the program should not be overly taxing for those of below average intelligence; if individuals are having difficulty comprehending the material, modifications such as slowing the pace of presentation of material, repeating presented materials, or additional coaching with completion of intervention exercises is recommended. Individuals of above average intelligence are able to grasp and retain the information readily and still find the material interesting, novel, and applicable.
- The question arises of whether younger survivors could benefit from SCCIP. The materials were developed with adolescents in mind and we expect that younger children would find the demands of the program (e.g., sitting still and listening quietly for lengths of time; speaking in a large group) more difficult. We have not conducted research with younger survivors. Given that the age range is already quite broad, it is not recommended that younger survivors participate in this program.

### **Including Fathers and Siblings:**

- This is a family-oriented program and the participation of survivors, mothers, fathers, and siblings is critical to the program. Positive outcomes of SCCIP are seen across family members, including fathers and siblings. Some additional steps may be necessary to encourage father participation (e.g. speaking directly with fathers) but the weekend scheduling of sessions is helpful in this regard. In scheduling, some families choose to not include siblings because finding a time when the survivor and one or more siblings is available can be difficult. While this is a realistic concern, our experience has been that, after attending, parents often wish that they had encouraged siblings to participate.

### **Dealing with Complex Family Structures:**

- Respectful of the diversity of family structures, we have found that flexibility in defining who can participate within the family is important. For example, step-parents who were not a part of the family during the child's illness are appropriate to include, but will generally have different memories and perspectives. Single parents are also appropriate. Parental partners and extended family members who function in parental or caregiving roles may be included. Also, siblings born after the cancer diagnosis and treatment and step-siblings, half-siblings, or even co-habiting cousins may be invited. It is not uncommon for a family to indicate that not all family members can or are willing to attend. Participation of all family members is strongly encouraged; however, we have conducted interventions successfully with only one parent present (from a two parent family) or without siblings (in a multi-child family). Complex family structures may require discussion on a case-by-case basis as to which family members attend. In all circumstances, we require that the survivor adolescent and one parent participate.

### **Defining the Survivorship Period:**

- Adolescent patients should have completed treatment for cancer prior to the intervention program. SCCIP has been used successfully with patients and families across a range of time since treatment ended.
- Recruitment efforts should anticipate that one of the symptoms of posttraumatic stress is avoidance. Sensitivity to these concerns is necessary. We have found the following strategies helpful: A brochure describing the program; Letters sent to the family inviting them to participate should include one to the parent(s), one to the adolescent survivor and another for siblings. Follow-up contacts by a staff member should occur shortly after mailing the letters.

## TRAINING AND EVALUATION

### Interventionist Requirements:

- Effective implementation of SCCIP requires four interventionists to lead the individual discussion groups for mothers, fathers, survivors, and siblings (Sessions 1 and 2); and one to lead the multiple family group discussions (Sessions 3 and 4). Interventionists can be psychologists, social workers, nurses, and/or nurse practitioners. Having a diversity of professional perspectives offers a more comprehensive approach to understanding the family experience and underscores the connection between the medical and psychosocial aspects of survivorship. Trainees, including graduate psychology, social work and nursing students, and psychology or medical interns and fellows, can be trained as interventionists. Knowledge of general issues in cancer survivorship is an important pre-requisite. Prior training in cognitive-behavioral therapy is needed to lead sessions 1 and 2, and prior training in family therapy is necessary for sessions 3 and 4.

### Training Requirements:

- Training is a required and ongoing activity for interventionists. A training syllabus is available from the authors. All staff (including graduate students and interns) should be introduced to basic cognitive behavioral and family therapy approaches prior to training for the intervention. Reading (including familiarity with the manual), viewing of videotapes, and role-playing are all necessary steps in the training process.
- Student trainees should begin by observing the intervention and then assisting the interventionists prior to assuming more independent roles in the program. Regular meetings of the intervention team are also important. It is recommended that the intervention sessions be audio or videotaped and that staff use the tapes as part of ongoing feedback, refinement, establishing the fidelity of the intervention, and for teambuilding purposes.

## **SESSION LOGISTICS**

### **Optimal Number of Families:**

- We have found that the optimal group size per intervention is 6 families, although fewer families can work well too. It is recommended that at least 8 families be scheduled for a given session to ensure a viable turnout.

### **Participation by Medical and Psychosocial Staff:**

- The program introduction includes a pediatric oncologist and a pediatric psychologist. This is an important component in illustrating the linkages between medical and psychosocial care. The participation of medical and nursing staff throughout the program strengthens it by allowing full integration of the range of late effects associated with childhood cancer treatment.

### **Meeting Room Requirements:**

- For sessions 1 and 2, you will need 4 rooms, since these sessions are conducted with survivors, siblings, mothers and fathers separately. For sessions 3 and 4, one large room is needed for the whole group.

### **Interventionist Logistics:**

- For sessions 1 & 2, each of the four groups (adolescents, mothers, fathers, siblings) should have one primary interventionist. It is desirable to also have an assisting interventionist for each group, and particularly for the adolescent groups who may vary greatly in age and learning capacity. The primary interventionist leads the session. The assisting interventionist provides additional support if participants experience any difficulty with the program and facilitates the completion of written materials and activities within the session. It is appropriate for the assisting interventionist to be a trainee.
- During Session 3, after the discussion (led by the primary therapist for each of the four respective groups), two interventionists should lead the multiple family discussion groups. The introduction to Session 4 is led by one interventionist, with a second assisting. The closing group discussion is facilitated by both interventionists, serving as co-therapists.

### **Stipends, Food, and Breaks:**

- Lunch and food for breaks should be provided. Complementary parking is greatly appreciated by families. A stipend to reimburse families' travel expenses and/or to help motivate adolescent participation is also helpful.
- Over the lunch break, the intervention team should discuss informally the morning sessions and plan ways in which the topics discussed during the cognitive behavioral exercises can be integrated with the family therapy focus of the afternoon. Families may also appreciate the opportunity to talk informally with the medical and nursing personnel during lunch as questions about medical as well as psychosocial issues may be important to families.

## **FLEXIBILITY IN USING A MANUALIZED INTERVENTION**

SCCIP is an innovative program for families who have faced and survived cancer. This Intervention Manual provides a suggested script and guidelines on how to implement the components of the SCCIP protocol. However, the protocol is meant to be flexible so that families, with the help of their interventionists, may discover how the SCCIP principles apply to the unique qualities of their families and their situations. Interventionists are encouraged to be themselves and to get to know the families who participate in SCCIP. It is our hope that both the interventionists and families find SCCIP to be a useful complement to pediatric oncology survivorship.

## **INTERVENTION MATERIALS**

The required materials include:

### **Recruitment:**

- Recruitment letter
- Information sheet or brochure about the program

### **Intervention:**

- The manual
- Nametags for all participants and staff (color-coded to easily identify members within families)
- Copies of handouts, cartoons, or worksheets needed for each group
- Flipcharts for each group (with colorful, pre-made examples demonstrating ABC and Reframing)
- Large meeting room with 4 private break-out rooms
- Audiotape or audiovisual recording equipment
- 2 roles of toilet paper for teen icebreaker activities
- Props for role plays
- Multiple boxes of facial tissues
- Cards from the Impact of Traumatic Stressors Interview Schedule (2 sets of adult cards; 2 sets of teen cards)

### **Post-Intervention:**

- Evaluation form

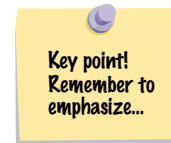
### **Other – Intervention Day:**

- Be sure to greet each family and family member personally as they arrive. For some survivors and family members, it can be difficult to face reminders of the cancer experience. For some, a group experience is a new and potentially difficult situation. The goal is to begin the process of joining with each person right from the beginning.




## USING THIS MANUAL

- This manual is divided into sections according to the needs of the primary interventionist. For example, Sessions 1 and 2 for the different groups: mothers/fathers; survivors; siblings, are collated together.
- Note that the content for sessions 1 and 2 is the same for mothers and fathers, even though they will participate in separate groups.
- Each section of the manual contains a suggested script and notes for the interventionist, summarizing key points, and special instructions.

- Notes for the interventionist are designated with a sticky note:



- Key ideas in the script are highlighted in bold, for easy reference. Sub-heads are also included to remind you where you are in the session and what to emphasize. There are also reminders in the script that let you know when to pause to allow participants time to absorb the material or formulate responses.
- A number of icons also provide an at-a-glance guide throughout the script:

	Denotes important questions to ask participants.
	Designates use of the A-B-C Model
	Designates use of the Reframing Tool

- Remember, the suggested script is just a guide and not meant to be read word for word. It is important that you, as an interventionist, put the ideas and concepts into your own words, and in ways that the families that you are working with will understand. So, relax and be yourself!





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