

SURVIVING CANCER COMPETENTLY
INTERVENTION PROGRAM –
NEWLY DIAGNOSED (SCCIP-ND)



Intervention Manual

 The Children's Hospital *of Philadelphia*

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Version 1.1, © November 10, 2004

I. INTRODUCTION

The Surviving Cancer Competently Intervention Program - Newly Diagnosed (SCCIP-ND) is a manualized three-session intervention for parents and caregivers of children recently diagnosed with cancer. SCCIP-ND is an integrated cognitive behavioral and family systems intervention that was developed by a multidisciplinary team in the Division of Oncology at The Children’s Hospital of Philadelphia. The purpose of SCCIP-ND is to promote healthy family adjustment to pediatric cancer and treatment and to prevent cancer-related posttraumatic stress symptoms in family members.

SCCIP-ND was developed based on research indicating the presence of symptoms of posttraumatic stress in childhood cancer survivors and their parents (see reference list). A randomized clinical trial, funded by the National Cancer Institute (CA88828) to evaluate the efficacy and effectiveness of this intervention, is currently underway.

This Intervention Manual comprises the information and materials that therapists need in order to conceptually understand and implement SCCIP-ND. It includes an Intervention Protocol, handouts and worksheets, a glossary, and references. A Therapist Training Syllabus is available on request.



The Intervention Protocol

Four Key Constructs

We have identified four constructs, instrumental to the implementation of SCCIP-ND. Taken together, these constructs are believed to contribute to the efficacy of SCCIP-ND and should be evident in all three sessions of the intervention.

1. **Joining.** In SCCIP-ND a therapist relates to parents/caregivers using acceptance, respect, curiosity and honesty (ARCH; Micucci, 1998). The therapist first seeks to establish trust with the parents/caregivers and to understand and accept the family’s point of view. The therapist then integrates him/herself in the family’s pattern of interactions to accomplish the specific objectives of the session.
2. **Maintaining an Interpersonal Focus.** The therapist facilitates interactions and communication between caregivers throughout the intervention by encouraging caregivers to listen and respond to each other. When possible, the therapist uses opportunities to highlight how caregivers’ beliefs impact their relationships within the family and within their social network.
3. **Normalizing the Family’s Experience.** Throughout the intervention, the therapist attempts to help parents/caregivers decrease feelings of isolation and feel connected to others. The therapist should communicate to the parents/caregivers that their reactions

to their child's cancer are part of the wide range of responses that parents typically experience.

4. **Focusing on the Family's Strength and Growth.** One of the fundamental assumptions of SCCIP-ND is that parents and families are competent, able to adapt to adverse circumstances even as they sustain normal family functions, and will continue growing throughout the course of cancer treatment. Based on the interactions with the caregivers, the therapist is expected to identify, reflect and emphasize areas of strength for the family throughout the intervention, particularly strengths noted in the interactions between the parental/caregiver dyad. By focusing on family growth, the therapist also helps parents/caregivers to consider life for the family over time, with cancer occupying a diminishing but ever-present role.

In addition to integrating the key constructs throughout the intervention, therapists should use the SCCIP-ND Intervention Protocol to guide the three 45-minute sessions. The Intervention Protocol describes the goals of each session and specific tools the therapist will use to accomplish these goals. The tools include a DVD of other parents discussing their experience with cancer and treatment (the Video Family Discussion Group), cognitive-behavioral techniques for understanding and adjusting one's beliefs (the A-B-C model and reframing), and metaphors to help caregivers think about the role cancer plays in their family and how they would like their family to adjust in the future (the Unwelcome Visitor and the Family Survival Roadmap). The intervention protocol also provides examples of what a therapist may say. These appear in the form of scripts embedded in the protocol.

Goals and Overview of Each Session:

Session 1: Identifying Beliefs About Cancer, Its Treatment and the Impact on the Family

- Goal 1: To establish a collaborative therapeutic relationship with the family.
- Goal 2: To identify parents' beliefs about the illness and its treatment.
- Goal 3: To discuss how each parent's beliefs influence his/her emotions, behaviors and interpersonal relationships.
- Goal 4: To maintain a systemic focus.
- Goal 5: To reduce isolation and normalize the family's experience.

Session 2: Changing Beliefs to Enhance the Family's Functioning

- Goal 1: To continue developing a collaborative therapeutic relationship with the parents.
- Goal 2: To facilitate the parents' understanding of how their beliefs are related to their family's functioning.
- Goal 3: To teach the parents how to reframe their beliefs.
- Goal 4: To discuss how beliefs impact relationships.

Session 3: Developing a Family Survival Roadmap

- Goal 1: To discuss how cancer may impact the family's continued growth.
- Goal 2: To discuss how the parents can influence the role cancer plays in the family by recognizing, changing and talking with each other about their beliefs.



Session 1: Identifying Beliefs About Cancer, Its Treatment and the Impact on the Family.

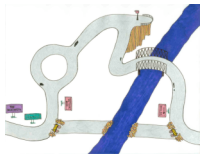
The primary purpose of the first session is for the therapist and family to begin discussing beliefs about the illness and their impact on each parent/caregiver within the family. Initially, the therapist joins with the parents/caregivers by establishing a collaborative relationship and reinforcing the importance of the parents/caregivers' participation (i.e., potential benefits of the study). The therapist then provides a framework for examining the relationship between adversities (like the diagnosis of pediatric cancer) and beliefs, and between beliefs and their emotional, behavioral and relational consequences. To do so, parents become familiar with the A-B-C Model, a cognitive-behavioral technique described by Ellis (2001) that helps individuals examine the relationship between their perceptions of an event and their feelings, actions and relationships. In this intervention, A represents adversities, B represents beliefs, and C represents consequences, which can be emotional, behavioral or interpersonal. Parents/caregivers are encouraged to examine how B influences C, that is, how their beliefs influence their feelings, actions and interactions.



Session 2: Changing Beliefs to Enhance the Family's Functioning.

The second session is designed to address the advantages of changing one's thoughts to produce different consequences for each parent / caregiver and for the family. During this meeting, the therapist continues to join with the family and reaffirms the link between beliefs and relational consequences. For example, parents/caregivers expand their discussion of the impact of cancer and their beliefs on familial and social relationships. In addition to reviewing the A-B-C Model as a way to examine beliefs, parents/caregivers learn how to modify their beliefs using the concept of reframing.

Expanding upon the A-B-C model, reframing focuses on altering beliefs in order to change emotional, behavioral and interpersonal consequences. Therapists describe reframing to parents/caregivers as a technique to help them think differently about adversities, and present reframing as a four-step process: 1) Accept the uncontrollable (accept those things that can't be changed like the cancer diagnosis); 2) Focus on the controllable (identify aspects of the family's experience that can be changed); 3) Acknowledge your own strengths; and 4) Use the positive (that is, identify the realistically positive aspects of the situation). Thus, the major work of the session is for the therapist and parents/caregivers to work together to identify the potential benefits of reframing, particularly having new interpersonal consequences for the family.



Session 3: Developing a Family Survival Roadmap.

The primary intent of this third and final session is for parents/caregivers to engage in a guided discussion about how cancer might impact the family's continued development. The therapist integrates two metaphors into the discussion, "The Family Survival Roadmap" and "Putting Cancer in its Place," to help parents/caregivers recognize their beliefs about the family's future, and share these beliefs with each other.

According to Gonzalez, Steinglass & Reiss (1998), "Putting Cancer in its Place" refers to the process of promoting family growth by having the family define the role the illness will have in family life. The concept of "Putting Cancer in its Place" supports the incorporation of the disease while diminishing its centrality in the family. Similarly, the metaphor of the "Family Survival Roadmap" is used to expand the theme of continuing the family's developmental course despite the uncertainty that cancer brings. In this session, parents/caregivers discuss the personal significance of the metaphors, as well as how they can modify their beliefs when necessary to "put cancer in its place" and promote family growth. Finally, the therapist prompts parents/caregivers to consider how they will incorporate what they learned in SCCIP-ND into family life.



The Video Family Discussion Group

The Video Family Discussion Group (VFDG) is one of the critical tools used in this intervention. Three video clips of a group of parents discussing cancer's impact on their families comprise the VFDG. Conceptually, the VFDG serves as an analogue to the Multiple Family Discussion Group (MFDG) model of Steinglass (1998), used in our previous research. In developing SCCIP-ND, we recognized the benefit of the MFDG for parents, but were also cognizant of the potential constraints of designing SCCIP-ND as a group intervention. Thus, we relied on technology as a proxy of participants' interactions with other parents in pediatric oncology.

The therapist shows a five-minute video clip in each session of the SCCIP-ND intervention. Some of the themes captured in the video clips includes discussion of parent's fears that their child might die; their anger and guilt feelings at not being able to protect their child from the cancer; physical and emotional exhaustion; and relationship changes and role conflicts with their spouse and family members. While the emotional content of these clips is intense; these clips are designed to normalize the parents' experiences by showing other parents processing common issues. The clips are also meant to provide a stimulus for further discussion about parents' beliefs, how their beliefs change, and how they think about the future. The manual provides guidelines for questions that may facilitate further conversation following the video. These include "Who did you connect with in the video?" and "What thoughts did you have as you watched the video?"



Therapist Training

During each session, a trained SCCIP-ND therapist meets with two caregivers of a child with cancer. The same therapist meets with each family for all three sessions. All therapists should have some experience providing psychotherapy and should participate in formal training on implementing the SCCIP-ND protocol. Training ensures that all SCCIP-ND therapists are familiar with key theoretical constructs, research findings, and methods for implementing the intervention, and are prepared for the strong emotional issues that can surface and might need to be worked through as part of the sessions (e.g. feelings of anger and guilt; fears that the child might die; relationship changes and conflicts). The training materials also provide guidelines for conducting role-plays where therapists can practice implementing SCCIP-ND and anticipate potential challenges that may occur during sessions. There are six two-hour modules that combine didactic presentations with role-playing exercises that are linked to key topics.

Treatment Fidelity

SCCIP-ND is currently being evaluated for treatment fidelity (adherence to the treatment manual and competence in providing the intervention) in a randomized clinical trial. Independent evaluations based on audiotapes of sessions are conducted with regard to basic goals and steps of the protocol. Further information about treatment fidelity will be available in subsequent reports of the outcome of the randomized clinical trial.



Logistics for Each Session.

The therapist should be familiar with the process of informed consent and with the specific consent documents that participants have signed.

A laptop computer is necessary for each session to play the VRDG. The following minimum specifications are recommended for the laptop: PC running Windows 98 or later or Macintosh running OS X or later; 8 speed CD drive capable of reading CD-R media; 400 mb free space on the hard drive; and Windows Media Player with an MPEG-2 Codec.

In order to assess the fidelity of the treatment, every SCCIP-ND session must be audiotaped. A high quality tape recorder is recommended.






Flexibility in Using a Manualized Intervention.

SCCIP-ND is an innovative program for families facing cancer. This Intervention Manual provides guidelines on how to learn and implement the components of the SCCIP-ND protocol. However, the protocol is meant to be flexible so that families, with the help of their therapists, may discover how the SCCIP-ND principles apply to the unique qualities of their families and their situations. Therapists are encouraged to be themselves and to get to know each family as part of SCCIP-ND. It is our hope that therapists and families find SCCIP-ND to be a useful complement to pediatric oncology care. We also hope that therapists and families enjoy the process of learning and using the SCCIP-ND principles


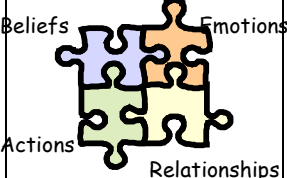

ICON INDEX



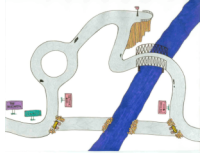

A number of icons have been included throughout this manual to remind interventionists about specific content or actions that should be addressed at that point during the sessions. While interventionists are not expected to repeat the script word for word, it is often helpful to be able to look down at your manual and quickly ascertain where you are and what you need to address next.

The following icons provide short cuts to remembering these important actions:

1. Spend time at the beginning of each session (re)joining with the family.	
2. Remind participants of the reason for audiotaping the sessions	
3. Encourage discussion between participants, highlighting interpersonal beliefs and consequences.	
4. Encourage participants to ask questions.	
5. Introduce and play the video for that session.	

The following icons serve as reminders to address these key concepts:

1. Adversities – Beliefs – Consequences – known as the “ABC model.” A tool for helping participants identify and examine their beliefs and perceptions.	
2. Helping participants understand the interconnected role that their beliefs have on their actions, emotions, and relationships, using the ABC model.	
3. Reframing – a tool for helping participants change beliefs and consequences, and its four steps: 1) accept the uncontrollable; 2) focus on the controllable; 3) acknowledge your strengths; 4) use the positive.	

<p>4. The importance of using the video family discussion group to normalize participants' reactions, reduce their feelings of isolation, and help them connect with other families who have been through the cancer experience.</p>	
<p>5. The concept of cancer as the “unwelcome visitor that comes and stays” – a metaphor for helping families initially think about the role cancer plays in their lives.</p>	
<p>6. The concept of the “Family Survival Roadmap” – a tool for “putting cancer in its place” by helping families recognize their beliefs about the future and by helping them see (quite literally) where they are now and envision where they will be (and want to be) in the future.</p>	
<p>7. The recognition that families can grow as a result of their experience, by combining their unique strengths with what they've learned during the sessions, using the SCCIP-ND tools to help facilitate this.</p>	

SCCIP-ND Glossary



A-B-C Model

A tool that helps individuals to examine the relationship between their perceptions of an event and their feelings, actions and relationships. This tool is based on a cognitive-behavioral model developed by Ellis (2001). In this intervention, A refers to adversities, B refers to beliefs, C refers to consequences, which can be emotional, behavioral or interpersonal. Participants examine how B influences C, that is, how their beliefs influence their feelings, actions and interactions.

Collaborative therapeutic relationship

The shared understanding that the therapist and family will work together during a prescribed period of time, using a consensual approach in order to achieve desired goals.



Focusing on the family's strength and growth

One of the fundamental assumptions of SCCIP-ND is that parents and families are competent, able to adapt to adverse circumstances even as they sustain normal family functions, and will continue growing throughout the course of cancer treatment. Based on the interactions with the caregivers, the therapist is expected to identify, reflect and emphasize areas of strength for the family throughout the intervention, particularly strengths noted in the interactions between the parental/caregiver dyad. By focusing on family growth, the therapist helps parents/caregivers to consider life for the family over time, with cancer occupying a diminishing but ever-present role.



Joining

The ongoing process by which a therapist relates to parents/caregivers using acceptance, respect, curiosity and honesty (ARCH; Micucci, 1998). The therapist first seeks to establish trust with the parents/caregivers and to understand and accept the family's point of view. The therapist then integrates him/herself in the family's pattern of interactions to accomplish the specific objectives of the session.

Maintaining an interpersonal focus

The idea that the therapist will facilitate interactions and communication between caregivers throughout the intervention by encouraging caregivers to listen and respond to each other. When possible, the therapist will use opportunities to highlight how caregivers' beliefs impact their relationships within the family and within their social network.

Normalizing the family's experience

The therapist attempts to help parents/caregivers decrease feelings of isolation and feel connected to others. The therapist should communicate to the parents/caregivers that their reactions to their child's cancer are part of the wide range of responses that parents typically experience. When appropriate, the therapist relates the parents/caregivers' experience to that of parents in the video.



Reframing

A technique that helps individuals think about adversities differently. Expanding upon the A-B-C model, this technique focuses on altering beliefs in order to change emotional, behavioral and interpersonal consequences. The following four tools facilitate reframing: accept the uncontrollable; focus on the controllable; acknowledge your own strengths; identify the positive aspects of the situation.

Systemic focus

A framework for conceptualizing human development and behavior. Refers to the idea that people are best understood within the context of their environment. The environment is comprised of many subsystems (e.g., individual, family, school, neighborhood, socioeconomic strata). The relationships among subsystems are transactional, that is, individuals affect and are affected by others. It is thought that these relationships endure and change over time.

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