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# Psychotherapeutic Modalities for Children with Cancer and Their Families

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## Introduction

Monumental changes have taken place in the field of pediatric cancer in the past three to four decades (Brown 2006) through dramatically improved and innovative treatments and improved survival rates with a greater focus on long-term survivorship and quality of life. Increasingly, efforts have been extended to better understand the short- and long-term adjustment of children with cancer and their families and, consequently, the means by which this adjustment may be facilitated by psychosocial interventions. With this in mind, the goal of this chapter is to highlight current psychotherapeutic modalities utilized in the treatment of youth with cancer and their families, including those with empirical support as well as those that are considered promising or have demonstrated support with other populations experiencing similar difficulties (e.g., heightened stress, depression, anxiety). Our focus will be on practical applications, with the goal of this chapter being a resource for clinicians working with

children with cancer and their families. Although this chapter will be arranged by specific therapeutic modalities, it should be taken into account that some of the work reviewed will describe interventions that are by design multimodal and multifaceted in nature. For an overview of the modalities described in this chapter, potential target symptoms and populations, and challenges to implementation, see Table 6.1.

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## Individual Therapy for Adolescents and Parents

Although we know very little about the actual practice patterns of clinicians in pediatric cancer centers, it is safe to say that individual psychotherapy broadly defined (e.g., supportive, nondirective, or eclectic) is a commonly delivered treatment modality for both parents as well as adolescents. This individual therapy probably takes many forms, depending upon the unique presentation of each individual, but it most often takes the form of crisis intervention (especially in the days and weeks following the initial diagnosis) or supportive psychotherapy, also referred to as Rogerian client-centered therapy (Rogers 1959). Key considerations in providing individual therapy would include (1) the development of a strong therapeutic alliance with the parent and adolescent and the establishment of trust; (2) “normalization” of the symptoms, fears, and

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**Table 6.1** Therapeutic approaches

	Key aspects	Symptom focus	Population	Challenges <sup>a</sup>
Traditional individual therapy	Tailored to individual needs, psychoeducation, crisis intervention, supportive psychotherapy, normalization of symptoms, and coping strategies	Premorbid psychiatric condition or adjustment difficulties	Adolescents and parents	Adolescent resistance/reluctance to participate. Multitude of modalities exist – previous experiences may influence interest to participate/seek services
Family and marital therapy cognitive behavioral therapies (CBT)	Tailored to family needs and may include medical family therapy, supportive care, family crisis intervention psychoeducation, encouraging expression of emotion, identifying automatic thoughts, thought logging, behavioral activation, relaxation strategies, and assertiveness and communication skills	Family conflict, family role relationships, marital conflict Maladaptive thoughts, feelings, and behaviors	Families and couples Children, parents, siblings	Resistance to discussing family problems and marital conflict. May require additional visits to clinicians Developmental level can be a barrier to engaging in the cognitive aspects of CBT, possible cultural and language barriers
Problem-solving therapy	Provide strategies to engage in effective problem-solving	Difficulties in making decisions and challenged in problem-solving	Parents and families	Best paired within a multimodal approach, difficult to implement just PST
Structured parent and family interventions	Psychoeducation, enhancing communication skills, problem-solving skills, Adversity-Belief-Consequence framework, self-talk, and reframing child's diagnosis and related concerns	Parent adjustment, coping, stress, and general psychological functioning	Parents and families	Scheduling sessions with families due to more time-consuming nature of treatment interventions
Play therapy	Play activities	Emotional difficulties	Younger children and siblings	Obtaining parent involvement and limited empirically supported evidence for efficacy of treatment
Art therapy	Drawing	Emotional difficulties and communication	Children and siblings	Obtaining parent involvement and limited empirically supported evidence for efficacy of treatment
Social skills training	Psychoeducation, modeling, and practice	Social skills	Children	Frequently provided as a group intervention which can be difficult to provide in more rural settings

**Table 6.1** (continued)

	Key aspects	Symptom focus	Population	Challenges <sup>a</sup>
Adherence to medical regimens	Psychoeducation, assess and overcome adherence barriers, and monitoring regimen	Nonadherence to medical regimen	Children, adolescents, young adults, caregivers	Monitoring adherence can be difficult due to the high cost of the devices. Some families have a difficult time navigating the use of these devices. Frequency of clinic appointments may limit opportunity to get blood assay levels and/or electronic downloaded of the adherence data device. Barriers to care (e.g., costs, transportation, access to care/information) can limit caregivers' ability to provide the appropriate resources for children/adolescents
Health promotion interventions	Psychoeducation, behavioral plans, problem-solving, assessing barriers, and coping skills	Health-risk behaviors (e.g., dietary choices, smoking cessation, and patient knowledge surrounding illness information)	Children and parents	Unwillingness to engage in behavior change and limited knowledge regarding the importance of certain health behaviors
Bibliotherapy	Psychoeducation, self-management, and coping skills	Anxiety related to procedures and treatments, uncertainty of cancer diagnosis and symptoms, and coping with distress	Children, parents, and siblings	May potentially confuse the patient or parent if material is too complex or arouses additional anxiety
Acceptance and commitment therapy	Engaging in acceptance, cognitive diffusion, being in the present moment, viewing the self as context, identifying and working towards the individuals' values, and committing actions	Psychological flexibility, acceptance of symptoms and diagnosis	Children and parents	Limited training opportunities and limited research support within pediatric cancer <sup>b</sup>
Mindfulness	Psychoeducation, focusing awareness, meditation, and nonjudgment	Anxiety and rumination	Children and parents	Ensuring mindfulness activities are age-appropriate and limited research support within pediatric cancer <sup>b</sup>

(continued)

**Table 6.1** (continued)

	Key aspects	Symptom focus	Population	Challenges <sup>a</sup>
Trauma-focused cognitive behavioral therapy	Psychoeducation, relaxation strategies, development of trauma narrative, repeated exposure to trauma narrative, and identifying and challenging maladaptive thoughts	Relieving PTSS related to cancer-specific procedures	Children and siblings	Limited research support within pediatric cancer <sup>b</sup>

*PTSS* posttraumatic stress symptoms

*Note*

<sup>a</sup>Common concerns across all treatment modalities include developing a therapeutic alliance with children and families, completing homework, and overcoming barriers to treatment

<sup>b</sup>As these emerging therapies become more prominent in the extant literature, it is likely that additional challenges specific to these treatment modalities will be identified and suggestions for management provided

concerns that characterize the cancer experience; (3) provision of resources and assessing the specific needs for the family, such as support groups, liaisons to other parents who are further past the initial diagnosis and who are in a good position to provide valuable insights; and (4) provision of coping strategies for dealing with negative emotions and the crisis at hand.

Many parents and adolescents diagnosed with cancer are individuals who could best be characterized as, “psychologically healthy” prior to the child’s diagnosis. For these individuals, the diagnosis is a major stressor to which, with time and appropriate support as described throughout this chapter, they will adjust. However, it is sometimes the case that a parent or adolescent presents with a challenging premorbid psychiatric condition. A small but significant subset of parents and adolescents will evidence a serious mental health problem that comes to the attention of the treatment team at some point after the diagnosis. These psychological difficulties can range from serious problems with drug and alcohol dependence to major mental illness such as bipolar disorder or obsessive-compulsive disorder. In each of these situations, the clinician must be prepared to either provide direct individual therapy services to the individual or refer to another mental health professional that can provide appropriate services.

Not surprisingly, in working with adolescents with cancer, a number of other unique challenges emerge in providing traditional individual ther-

apy. Establishing trust is essential in developing a therapeutic relationship and can be quite challenging with adolescents. In adolescents, the “typical themes” of the desire for increased independence and autonomy, the importance of peer relationships, and the emotional upheaval that can become magnified at the time of diagnosis and throughout the course of treatment usually emerge. The many physical changes that may occur including hair loss, fatigue, weight changes, and cushingoid facies can also contribute to increased distress and sense of “being different.” While some adolescents report that their friends lavish them with support, others find that they become estranged from their old friends. With these issues in mind, it is essential that clinicians do a careful, thorough assessment of the concerns of each adolescent and develop an appropriate treatment plan that addresses these issues.

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## Family and Marital Therapy Approaches

In the context of pediatric cancer, it is clear that the need often exists for supportive, crisis-oriented interventions to help the family as a whole or to help parents with issues in their marriage. This is particularly true in light of the many role changes and challenges to cohesiveness that can occur within the family system. Family and marital therapy interventions can often prove

helpful in these situations and can help restore homeostasis and reduce stress and conflict (see Chap. 9 for additional information on families of youth with cancer).

Family and marital therapy interventions of this type tend to be flexible and often do not necessarily follow an explicit protocol or manual. McDaniel and colleagues (McDaniel et al. 2002; Ruddy and McDaniel 2013) have written extensively about this approach, referring to it as medical family therapy (MFT). Using a biopsychosocial systems perspective (i.e., there are no psychosocial problems without biological features, and there are no biomedical problems without psychosocial features), MFT is designed to engage the patient and family and to actively collaborate between the family and the interdisciplinary team (Tyndall et al. 2012). In an effort to help families attenuate distress, the fundamental goals for this therapy are as follows:

1. Help the family identify which aspects of the disease are controllable.
2. Work to help families find sources of social support and avoid isolation. In this manner, the therapist attempts to encourage the family to not let the illness dominate their lives.
3. Help the family set new routines while continuing to meet the needs of others in the family, such as siblings.
4. Help the family to manage communication about the illness, particularly as it concerns balancing the amount of information given to the child about their illness and insuring that secrets about the disease are not being kept.
5. Help the family actively collaborate with the multidisciplinary team.

Specific to marriage, the stress of pediatric cancer clearly has the potential to take a toll, particularly if a marriage was fragile prior to the diagnosis. Financial pressures, time spent apart due to hospitalizations, changing role relationships, and disrupted family routines can result in a loss of closeness and intimacy as well as direct conflict. In some case, couples may seek help directly from the existing support team. Other couples may be reluctant, however, to bring up

marital concerns with the medical team, and therefore, it is important for personnel to be able to refer to marriage and family therapists in the community who are mindful of the themes that parents of youth with cancer face.

Traditional family therapy and marital therapy approaches clearly have a role in the context of pediatric cancer. MFT has been widely discussed in the health psychology literature and has been utilized extensively. Unfortunately, there are few studies that have evaluated its effectiveness in the context of pediatric chronic illness, specifically cancer, or adaptations that focus specifically on marriage and support for parents. Campbell (2003) has suggested that forms of MFT indeed have potential benefits for youth with cancer, asthma, cystic fibrosis, and cardiac disease. MFT and adaptations thereof that involve systemic interventions should continue to be evaluated as frontline interventions for families of youth with cancer.

## Cognitive Behavioral Approaches

Cognitive behavioral therapies (CBT) constitute a family of therapeutic interventions that have been applied to a wide variety of presenting problems with both adult and child populations. The fundamental basis or premise for the majority of CBT approaches is that cognitive factors, including cognitive schemas, belief systems, cognitive distortions, and dysfunctional or maladaptive beliefs, serve to predispose and or maintain various types of psychological distress. It is argued that targeting and altering these maladaptive cognitions or beliefs can alleviate distress. CBT also includes some interventions that may appear less “cognitive” and more behavioral, including behavioral activation (Kanter et al. 2010) and exposure techniques. CBT approaches have been applied to depressive disorders, anxiety disorders, general distress, sleep disorders, and somatoform disorders, among many others in literally hundreds of studies, and the evidence base for the efficacy of these interventions is considerable. CBT has targeted distress associated with medical conditions in adults and children, as well as in pediatric cancer populations.

In the 1990s, Hoekstra-Weebers et al. published one of the first studies examining CBT in parents of children newly diagnosed with cancer (Hoekstra-Weebers, et al. 1998). Cognitive behavioral strategies employed in the study included the encouragement of emotional expression, identification of distorted automatic thoughts, use of problem-focused coping skills, discussion of psychosocial impact on the family, and training in assertiveness and communication skills. Importantly, the intervention was tailored to meet the expressed needs of the parents and also took into account the developmental level of their child. Compared to standard care (which did include provision of psychosocial services from a social worker), few differences in outcomes were found. This may have been a function of the overall lack of intensity of the intervention or lengthy time periods between intervention sessions. Importantly, it may have also been the result of high-quality services delivered to the standard care group. However, it did appear that the intervention was both feasible and acceptable to the families and set the stage for future structured/semistructured psychosocial interventions.

Streisand and colleagues (2000) also piloted a brief (one 90-min session) stress management intervention using cognitive behavioral techniques with a small sample of parents of children undergoing bone marrow transplant (Streisand et al. 2000). This intervention included an educational component, the teaching of relaxation skills, and communication skills, augmented by handouts that reviewed the components of the program as well as a tape player and headset for them to practice their relaxation skills. Although no differences were found between the treatment and control group, the results did indicate that parents in the intervention group successfully learned and subsequently employed these strategies in their efforts to manage stress.

More recently, efforts have been made to pilot and test the potential effectiveness of CBT in conjunction with other therapies. Seitz and colleagues (2014) developed an Internet-based intervention called “Onco-STEP” for cancer

survivors who are off treatment (Seitz et al. 2014). Based in part on Pennebaker’s expressive writing disclosure task, this intervention consists of 10 writing sessions that involve standard text messages and instructions. “Onco-STEP” includes two essential treatment modules, one of which involves helping the individual reprocess traumatic experiences associated with their cancer experience and the second module focusing on developing coping skills for dealing with remaining fears related to their cancer. Although this was only a single arm study, the authors did find significant decreases in self-reported anxiety, posttraumatic symptoms, depressive symptoms, and fears of relapse. Notwithstanding the small sample size and control group, this work demonstrates the promise of CBT interventions delivered through electronic means and certainly warrants replication (see Chap. 20 eHealth).

Importantly, children undergoing treatment for cancer and survivors of childhood cancer have been identified as being particularly at risk for anxiety and somatic concerns. The Coping Cat is a well-established manualized cognitive behavioral treatment that assists children ages 10–17 years in (Kendall 1994; Kendall 2000; Kendall et al. 2005):

1. Identifying feelings and physical reactions to anxiety
2. Understanding and restructuring maladaptive cognitions and beliefs surrounding anxiety-provoking situations
3. Learning to develop a coping plan for situations and determining the most effective coping actions
4. Learning how to evaluate and alter coping strategies as needed

Techniques presented to children throughout each training session include modeling real-life situations, role-playing, relaxation training, and contingent reinforcement. In addition, therapists use social reinforcement to encourage and reward the child, who is then encouraged to verbally reinforce their own successful coping. The Coping Cat is comprised of 16 sessions; the first

eight sessions are training sessions in which each of the basic concepts is introduced individually and then practiced and reinforced (Kendall 1994; Kendall 2000). During the second set of eight sessions, the child practices the new skills in both imaginary and real-life situations varying from low stress/low anxiety to high stress/high anxiety situations, depending on their needs (Kendall 1994; Kendall 2000). Although there are currently no published studies available in the literature using the Coping Cat specifically with pediatric cancer patients, the strong empirical support for this approach in reducing anxiety in youth would argue for its use, particularly with youth who are experiencing significant symptoms of anxiety.

Similar to the strategies of the Coping Cat, a program targeting coping with cancer featuring a stuffed toy named “Cellie” was developed by psychologists at The Children’s Hospital of Philadelphia for children aged 6–12 years (Marsac et al. 2012). The Coping Kit includes “Cellie,” cancer coping cards, and a book for caregivers. The cancer Coping Cards, found hidden inside “Cellie’s” zippered mouth, provide children with strategies to deal with numerous cancer-related stressors, ranging from medical procedures and hospital visits to feelings of anxiety, distress, and uncertainty (Marsac et al. 2012). The “Cellie Cancer Coping Kit” is flexible and can be used in a number of settings including the home, clinic, and/or hospital (see <http://www.chop.edu/health-resources/cellie-cancer-coping-kit-prezi#>; Marsac et al. 2012). “Cellie” can also help families begin discussions surrounding difficult topics including care, treatment decisions, and managing hospital stays via the deck of Coping Cards. Once a problem has been identified, the child or caregiver finds the relevant Coping Card and takes the card(s) along wherever they go by placing and zipping them into “Cellie’s” mouth. In addition to providing support, “Cellie” also comes with a caregiver book that offers advice for dealing with common cancer-related challenges caregivers often face, such as caring for siblings and working with the medical team (Marsac et al. 2012). The acceptability and effi-

cacy of “Cellie” has been examined in families who have a child diagnosed with cancer, and all parents reported that Cellie was an engaging, helpful, and easy-to-use coping tool they would recommend to other parents of children with cancer (Marsac et al. 2012). Children reported using the “Cellie” Kit for multiple reasons, including it being a playtime activity as well as a way to express difficult topics surrounding their treatment and care.

Another unique intervention that employs a cognitive element is the game “Shop Talk” (Wiener et al. 2011). “ShopTalk” is a therapeutic game with versions in Spanish and English, designed for children ages 7–16 diagnosed with cancer. It also can be used with children and youth who have been diagnosed with other types of serious medical illness (Wiener et al. 2011). “ShopTalk” can be used in individual or group therapy sessions to assist in starting conversations about difficult emotional issues related to the child or adolescent’s medical illness and the impact their illness has in various situations (e.g., school, home, peer relations). During the game, “ShopTalk” players visit ten different “shops” around the board, choosing one of six “gifts” from each store to place in their individual shopping bag when they choose to answer the question. One example of a “shop” that is visited during the game is a pet store called “Unconditional Love,” that provides a series of questions pertaining to aspects of the child’s life that are accepting, supportive, and helpful in addition to assessing for fears of rejection and/or abandonment. Another shop visited during game play is a sports store called “Balls in Your Court,” which provides a series of questions examining different social scenarios that can occur throughout the course of treatment and then specific ways to handle these situations. “ShopTalk” is an effective tool in identifying a multitude of psychological adjustment issues, such as family relationships, sadness, peer relationships, and self-esteem (Wiener et al. 2011). Two additional versions of “ShopTalk” are now available. A sibling version can be obtained through (<http://www.alexislemonade.org/campaign/supersibs>) and a version for children

whose parents have cancer is available through the National Cancer Institute ([http://pediatrics.cancer.gov/scientific\\_programs/psychosocial/educational.asp](http://pediatrics.cancer.gov/scientific_programs/psychosocial/educational.asp))

Cognitive behavioral interventions have become a mainstay treatment for many psychological disorders, including the distress associated with a diagnosis of pediatric cancer. Although studies evaluating the impact of CBT have not always shown significant improvement in symptoms above and beyond standard care, it is worth noting that there have actually been very few studies that have attempted to deliver CBT as a stand-alone, intensive intervention. The existing studies involved very brief interventions and used personnel with limited training in use of these techniques. Indeed, it may also be that these studies included a significant number of individuals who evidenced relatively low levels of depression and anxiety, both of which are traditional targets of CBT interventions. Thus, CBT may be best suited for individuals with higher levels of distress.

As will be seen later in this chapter, some clinicians have integrated CBT techniques with other modalities (e.g., family therapy, communication training) and have witnessed stronger findings. Indeed, a strength of CBT is the ease in which it can be integrated into other psychotherapeutic approaches (e.g., family therapy, mindfulness training, acceptance and commitment therapy), as well as its strong empirical underpinnings. For more information on CBT and its implementation, see *Cognitive Behavior Therapy: Core Principles for Practice* (O'Donohue and Fisher 2012), *General Principles and Empirically Supported Techniques of Cognitive Behavior Therapy* (O'Donohue and Fisher 2009), as well as *The Case Formulation Approach to Cognitive Behavior Therapy: Guides to Individualized Evidence Based Treatment* by Jacqueline Persons (Persons 2012).

### Case Vignette

Paul, a 16-year-old adolescent with non-Hodgkin Lymphoma, approached a physician's assistant (PA) during a regular clinic visit 3 months after his diagnosis and asked if he could get a prescription for his

“nerves.” After asking a few follow-up questions about his specific complaints and history, the PA referred him to the mental health clinician for additional assessment and possible treatment. Apparently, Paul had experienced a number of significant stressors in the year prior to his diagnosis, including the loss of his grandmother from breast cancer, feelings of separation from his friends, and anxiety surrounding his performance in school. To Paul, his diagnosis was “the last straw.” He reported increased sadness and irritability, avoidance of activities that typically brought him pleasure, significant weight gain, and sleep problems. He agreed with the clinician to try short-term cognitive behavior therapy to address what appeared to be a major depressive disorder. The counselor began by having Paul self-monitor his mood and thoughts via the 3-column technique (situation-thought-feeling relationships) as a means of identifying his cognitive beliefs and schemas. Over the first few sessions, it appeared that he was harboring rather significant negative beliefs related to his self-worth (“I am useless unless I am valedictorian,” “I am a loser now because I don’t have as many friends as I had before I got sick”) as well as to his future (“bad things are going to continue to pile up in my life and I’ll never get past them”). Paul’s counselor helped him to begin to understand how his cognitions and beliefs contributed to his depressed mood, and slowly he was asked to assess the validity of these beliefs through Socratic questioning. Cognitive coping strategies were shared with Paul such that he could address his cognitive distortions on his own (“what evidence do I have that other bad things are actually going to happen or that I can’t cope with them?”). In addition, Paul was asked to increase the frequency of his activities, particularly those activities that he had previously enjoyed. Over the course of 10–12 sessions, Paul reported decreasing depressive symptoms and improvement in mood.



## Problem-Solving Therapy

Problem-solving therapy (PST), a well-established model of intervention, has considerable empirical support for a wide range of psychosocial issues. Originally, this therapeutic modality was developed to help clients solve “real-life” problems and was not necessarily targeted at psychopathology per se. Problem-solving therapy involves teaching the client a very broad, general strategy that is designed to address any given problem situation and involves the following steps: (1) teach the patient to identify and clearly define the problem, (2) establish all available strategies that will address or solve the problem, (3) evaluate the specific pros and cons of each possible solution to the problem, (4) select a solution and take action, (5) evaluate the effectiveness of that action, and (6) determine whether another option or course of action is needed in order to effectively solve the problem (Nezu et al. 2013) (Table 6.2).

Problem-solving therapy has received considerable attention as an effective treatment for parents of youth with pediatric cancer. In a programmatic series of studies, Sahler and colleagues

(2002, 2005) and Varni and colleagues (1999) evaluated the effectiveness of PST with mothers of children newly diagnosed with cancer. The problem-solving intervention utilized was called “Bright IDEAS.” The term “bright” was meant to convey a sense of optimism to the parents as they approached the problem-solving process. The acronym *IDEA* refers to:

1. Identify the problem.
2. Determine the options available.
3. Evaluate the options and choose the best possible solution.
4. Act on the solution.
5. See if the solution worked, thus mirroring the problem-solving process outlined above.

Eight one hour therapy sessions were conducted in either the clinic or hospital setting, so that parents need not travel back to the hospital for additional meeting times. Parent worksheets facilitated the problem-solving process, and homework tasks were included as part of the intervention to help parents continue to practice problem-solving skills outside of the clinic and hospital setting.

**Table 6.2** Example steps in problem-solving therapy

1. Identify and clearly define the problem	“I have no childcare options for my healthy child when I have to take my child with cancer to the clinic for their outpatient visits”
2. Establish all available strategies that will address or solve the problem	“Check with the social worker at the hospital to see what options might be available at the hospital itself” “Look in the yellow pages for affordable childcare options” “Check with my friends at church to see who might be available”
3. Evaluate the specific pros and cons of each possible solution to the problem	“Checking with the social worker would be easy and I would know very quickly if there are such services. But my child would be with folks they don’t know well” “The yellow pages would have lots and lots of options, but I’d have to call around, investigate their safety, and it would be expensive” “Checking with the church would be easy and affordable, and my child would be with someone they know. Having someone who can be flexible in their schedule is the biggest challenge”
4. Select a solution and take action	“I think I’m going to call the church and see if they can help. I’m going to call tomorrow”
5. Evaluate the effectiveness of that action,	“The church has agreed that they are going to send out an immediate message to all members and have assured me that they will identify a group of individuals who can watch my child in my home on the days that I have to go to the hospital”
6. Determine whether another option or course of action is needed in order to effectively solve the problem	“No other solution is necessary. A list of members was established and volunteers were scheduled to help for the next 4 clinic visits”

Importantly, this study found considerable support for its efficacy in reducing what has been referred to as “negative affectivity” (e.g., anxiety, depression, and posttraumatic stress symptoms) as well as improvement in overall problem-solving skills. Additionally, this intervention was particularly effective for younger, single mothers, as well as for Hispanic mothers. PST has also been incorporated into other multimodal treatments in the context of pediatric cancer. Sahler et al. (2013) later compared the “Bright IDEAS” problem-solving intervention to a more active treatment (nondirective supportive therapy) and concluded that PST is not only effective in reducing symptoms of distress but also in eliciting improvements that continue over time. These positive long-term changes are most likely due to the acquisition of active coping skills.

Problem-solving therapy appears to have great promise in the pediatric cancer setting. Such an approach is very easily taught to both older children and parents, is cost-effective in terms of the number of sessions needed to teach these skills, can be delivered in virtually any setting by a number of modalities (e.g., outpatient clinic, hospital room, by phone or Skype), and is acceptable to diverse populations (Nezu et al. 2013). PST is also a strategy that can be readily incorporated with other cognitive behavioral intervention tools. Law et al. (2014) recently concluded in their meta-analysis that PST is one of the few interventions with considerable demonstrated research support as an effective treatment for parents of children with a medical condition. An excellent resource for clinicians on problem-solving therapy is “Problem-Solving Therapy: A Treatment Manual” by Arthur and Christine Nezu et al. (2013).

## Structured Parent and Family Interventions

In light of the fact that cancer affects the entire family, structured interventions have been developed to broaden the focus of psychological support to encompass the parent and the family system of the child with a diagnosis of cancer.

These interventions are structured to provide education and psychological skills, which are typically provided within a CBT framework.

Mullins and colleagues (2012) developed an interdisciplinary intervention to provide support for mothers of children with newly diagnosed pediatric cancer (i.e., within 6–12 weeks following the initial diagnosis), which was tested as part of a randomized controlled trial. This intervention focused on illness uncertainty as a mechanism for reducing parental stress. Six modules were developed as part of the standardized intervention, including (1) understanding the nature of uncertainty in the context of pediatric cancer, (2) enhancing communication with medical staff, (3) training in cognitive coping skills (i.e., CBT), (4) problem-solving training, (5) learning how to garner social support, and (6) consolidating all of these skills (Mullins et al. 2012). Sessions were led in clinic by a psychologist, followed by a nurse interventionist contacting mothers by phone to provide additional support and reinforcement related to each module topic. The intervention was designed to allow mothers to meet with the psychologist on odd weeks and receive follow-up care from the nurse interventionist on even weeks.

Mothers reported high levels of satisfaction with the overall protocol and with each individual intervention session. For all measures of distress, consistent significant effects or trends in favor of the intervention were found. Such results suggest that the intervention can reduce maternal psychological distress, posttraumatic stress symptoms, and burden. It was also interesting to note that several mothers in the treatment as usual group showed *worsening* scores over time, a pattern not observed in mothers in the intervention group. One possible interpretation is that the intervention served a preventive or buffering function for those mothers who were at risk for worsening symptoms over time.

Other structured parent and family interventions have similarly been developed. “The Surviving Cancer Competently: An Intervention Program (SCCIP)” was a pilot study designed by Kazak and colleagues (1999). SCCIP is a 1-day, 4-session intervention that incorporates both

CBT strategies and family therapy in order to reduce symptoms of distress and posttraumatic stress. During the intervention, families meet all together and in four separate groups. These four groups include (1) the child with the cancer diagnosis, (2) siblings, (3) mothers, and (4) fathers. Families received psychoeducation, practiced self-talk and reframing, and discussed beliefs about cancer.

The SCCIP study was later adapted to the Surviving Cancer Competently Intervention Program – Newly Diagnosed (SCCIP-ND; Kazak et al. 2005). This protocol was developed for caregivers of newly diagnosed cancer patients. This specific intervention consists of 3-sessions lasting 45 min each conducted during the first month after the child’s cancer diagnosis. During Session 1, the goal is to develop a collaborative relationship with caregivers and introduce an A-B-C framework for identifying concerns about cancer-related difficulties or concerns and examining thoughts, feelings, behaviors, and relationships. Session 2 provides psychoeducation, modeling, and practice for caregivers to change their maladaptive thoughts in order to produce different behaviors. Specifically, these cognitive strategies examine the relationship between thoughts or beliefs and behaviors that result in negative consequences for the family. Caregivers are given tools to be able to identify maladaptive thoughts and then identify new beliefs that address: (1) accepting events related to their child’s illness that cannot be controlled, (2) turning their attention on events that can be controlled, (3) bringing their attention and efforts towards utilizing and maximizing their strengths, and (4) focusing on positives. The third session is aimed at encouraging caregivers to nurture the growth of their family beyond the cancer diagnosis. Tools the psychologist provided in order to accomplish this included “The Family Survival Roadmap” and “Putting Cancer in Its Place.” The Family Survival Roadmap is a visual map that caregivers utilize to plan a course of action for themselves and their family as they maneuver through the cancer diagnosis and plan for resuming a more typical course in light of the uncertainty their child’s illness may cause. Putting

Cancer in Its Place helps caregivers to incorporate their child’s cancer diagnosis into the family structure while also providing boundaries so the diagnosis does not take over all aspects of family life. Studies suggest that the SCCIP-ND is both useful to families and that caregivers in the intervention group show reduced posttraumatic stress. Importantly, the Intervention Manual for SCCIP-ND is available at [https://www.health-caretoolbox.org/images/pdf/sccipnd\\_info.pdf](https://www.health-caretoolbox.org/images/pdf/sccipnd_info.pdf).

**Case Study** Tracy, a 25-year-old single mom, requested psychological services through the Pediatric Hematology/Oncology Clinic in order to help her cope with her daughter Melissa’s new diagnosis of leukemia. During the initial session, which was conducted in clinic following Melissa’s appointment to see her physician, Tracy and the clinical psychologist, Dr. Smith, first discussed Tracy’s concerns and goals for therapy. Tracy reported that she felt completely overwhelmed by Melissa’s diagnosis; had stopped going to work because she was so nervous about Melissa’s care, even though Tracy’s mother typically watched Melissa during the day while she went to work; and was not sleeping well. Tracy completed several measures to assess her current mood, including the Beck Depression Inventory and the Beck Anxiety Inventory, the results of which placed her in the moderate range of clinical depression and anxiety. Tracy indicated that she would like to gain skills to better manage her stress surrounding Melissa’s leukemia diagnosis and treatment.

The following week, Tracy again saw Dr. Smith after Melissa’s appointment in the Pediatric Hematology/Oncology Clinic. During this session, Dr. Smith provided psychoeducation about the Adversity-Belief-Consequence (A-B-C) framework to identify concerns about Melissa’s cancer diagnosis and examine the impact of subsequent thoughts, feelings, behaviors, and relationships, as in:

1. Adversity: Tracy identified Melissa’s leukemia diagnosis as a significant Adversity for her and worrying about Melissa’s health had taken over most of her thoughts.

2. *Belief*: Tracy was also able to identify the Belief that if she was not there to care for Melissa, something bad would happen and Melissa would likely get sicker.
3. *Consequence*: As a Consequence, Tracy had not gone to work in 3 weeks; she was spending most of her time worrying about Melissa and was sleeping only 3 to 5 hours per night. Dr. Smith and Tracy worked together to reframe Tracy's concerns related to her daughter's diagnosis. For example, Tracy was able to change her belief that her going to work would affect Melissa's health in light of the fact that her mother was a wonderful caregiver and completely competent to take care of Melissa during the day.

The following week, Tracy indicated that she had started back to work, beginning with a 2-day trial. Due to this success, Tracy felt she could continue to attend work on more regular basis. Tracy also stated that she thought therapy had been helpful but no longer needed services. Dr. Smith reiterated the importance of the A-B-C framework and encouraged Tracy to follow-up with her if she needed support in the future.

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## Play Therapy with Children

Play therapy as a modality for treating children's emotional difficulties has been in existence for almost a century, with reports of its use going back to the early 1900s. Play therapy was specifically designed for younger children whose capacity for abstract thought has yet to be developed. In this regard, play is utilized as a substitute for verbal expression; it is argued that through their play activities, children can express negative emotions, achieve conflict resolution, and ultimately a resolution of symptoms and psychological distress. Many forms of play therapy exist including filial, patient-centered, ecosystemic, prescriptive, and sand therapy. A thorough review of all of these modalities is beyond the scope of this chapter (see Bratton and colleagues 2005 for an excellent overview and meta-analysis of play therapy outcomes). Although not formally stud-

ied, it is safe to say that play therapy can be utilized for children with cancer, particularly those whose capacity for verbal expression and learning of coping skills may be limited.

Although there has been some debate about the effectiveness of play therapy in general, Bratton et al.'s (2005) results suggest that play therapy can result in positive and significant outcomes, particularly if parents are involved in the play therapy training. Philips (2010) argues that some of the best evidence for play therapy comes from work with children with health conditions, including those who are facing needle sticks and medical procedures.

In the medical setting, play therapy has been utilized to ease children's fears and help them adjust to stressful and challenging situations. Providing puzzles, pictures, or other fun activities can help children ease into a therapeutic atmosphere. These approaches can be combined with other modalities (e.g., relaxation training, cognitive coping strategies) to facilitate child adjustment.

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## Art Therapy with Children

For many years, art therapy has been used consistently with children who experience both acute and chronic medical conditions (Prager 1995), such as pediatric cancer (Coucil 1993; Sourkes 1991). Specifically, art therapy is the use of drawing to allow an individual to communicate about or explore a particular situation they are experiencing. Having a child with a pediatric cancer diagnosis engage in art therapy allows them to express their feelings related to their illness and treatments. Additionally, it can be useful in developing a therapeutic alliance and sense of support for the child. This practice has been linked to improvements in the patient's sense of self and quality of life (Madden et al. 2010). Sourkes (1991) used structured art therapy techniques with pediatric cancer patients and their siblings in order to facilitate the expression of emotions. Techniques used included (1) mandalas, (2) the change-in-family drawing, and (3) and scariest drawing. While the child is engaged

in drawing, the therapist asks specific questions related to the subject of the drawing. In examining the mandala of a 12-year-old boy, Sourkes stated that “a black triangle indicates endlessness, a yellow one has gratefulness for being alive, pink for hating the feeling of having no control, and mauve for invasion of his privacy which is part of hospital life” (Chester 1998 p. 1). Art therapy with pediatric cancer patients can be used in both individual and group settings. Additionally, this technique can be used in conjunction with other treatments, such as cognitive behavioral therapy.

### **Social Support Groups**

Support groups have a long history in the context of pediatric cancer as well as other health conditions, including those developed for the child with cancer, parents, and siblings. Support groups are based on the fundamental principle that social support buffers the impact of highly stressful life events, for which there is considerable scientific evidence. The setting for scheduling support groups is flexible, but typically they take place in the hospital, clinics, in the community setting, or online. While some are highly structured and consist of a series of informative lectures about coping with cancer followed by open discussion, others are much less formal and primarily revolve around allowing members to voice their individual concerns with facilitation from a group leader. Some support groups are led by trained professionals with a mental health background, while others are led by parents or survivors or a combination of both.

In an effort to evaluate the needs of adolescent cancer survivors, Cassano and colleagues (2008) described a number of themes that emerged for youth who were involved in a support group. The importance of being able to speak to other youth with the same experience, share inspirational messages, and have fun as a normal teenager were common threads of conversation. Other topics that have been the focus of discussion in teen support groups include the responses of healthy peers to the diagnosis of cancer, reintegration

into school, dealing with medical staff, improving communication between teenagers and parents, inclusion in medical decision-making, and positive communication between the physician and the teenager (Orr et al. 1984; Palmer et al. 2000). The importance of having support groups for siblings of youth with cancer has also been underscored, with efforts made to help siblings reduce their own anxiety and fear about the cancer experience (Houtzager et al. 2001). Additionally, support groups have been effective for parents of children with pediatric cancer (Foreman et al. 2005).

For both parents and children, the American Childhood Cancer Organization (ACCO) provides links to online support groups, email support groups, and listserves meant to connect children, parents, and siblings to other individuals experiencing similar difficulties. The online support group resources can be found at <https://www.inspire.com/groups/american-childhood-cancer-organization/>. It is also recommended that families be encouraged to ask their oncology provider what support groups are available in the hospital and in their community.

Support groups are a long-standing tradition in the care of youth with cancer and their families. They appear to be widely available to families, and resources typically can be found in pediatric cancer centers, in the community, through professional foundations, and electronically.

### **Social Skills Training**

Pediatric cancer survivors, specifically those diagnosed with brain or central nervous system (CNS) tumors, can potentially experience significant deficits in social functioning. Problems with social interactions in these youth have been noted throughout the literature across self, parent, and teacher reports. It has been hypothesized that social deficits are related to concomitant declines in executive functioning (Wolf et al. 2013). Due to these deficits, interventions have been developed in order to provide support and encourage the strengthening of social interactions for children and adolescents with pediatric

cancer. Social skills interventions involve providing children with tools to better maneuver their social interactions. Gaining these skills is achieved through (1) psychoeducation, (2) modeling, and (3) practice.

Social skills interventions have been created to help children with a new diagnosis of pediatric cancer reintegrate into the classroom (Varni et al. 1993). Children engaged in social cognitive problem-solving, assertiveness training, and ways to manage teasing and name-calling. Specific to problem-solving, children as young as 5 years old were taught to approach problems as if they are solvable, outline the importance of identifying specific problems, identify antecedents of the problem, brainstorm potential solutions, and plan solutions and assess outcomes. Children were provided with information about asserting their concerns, wishes, and thoughts to their parents, teachers, medical staff, and peers. Furthermore, assertive, passive, and aggressive behavior was defined. Children were also given skills for managing teasing and name-calling due to changes in their appearance from cancer.

More recently, Schulte and colleagues (2014) developed an 8-week social skills group intervention with pediatric brain tumor survivors. The intervention was developed to enhance skills related to (1) making friends, (2) cooperation, (3) dealing with bullies, (4) resolving conflicts, (5) empathy, and (6) assertiveness. Psychoeducation, modeling, and practice were interwoven with activities that helped participants practice intervention skills. The introduction of social skills and practice took place during the first 6 sessions of the intervention. Session 7 focused on reviewing all skills learned in the previous sessions, and the final session enabled children to practice their skills and share what they had learned throughout the study with their families. Children in the control group experienced significant increases in social problems from pre- to post-intervention per parent report, compared to children in the intervention group, whose social problem levels remained stable. Additionally, children in the intervention group reported a significant improvement in social functioning, compared to the control group who experienced no change.

Social skills training can be an integral aspect of providing psychosocial support for children with a diagnosis of pediatric cancer and their families. The negative cognitive outcomes associated with a cancer diagnosis and treatments as well as the social isolation that comes from missing school due to treatment speak to the importance of social skills training in this population.

## Adherence to Medical Regimens

Adherence to medical regimens has been a major focus for improving pediatric outcomes for over 30 years. Adherence has been defined as “the extent to which a person’s behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice” (Haynes 1979). Adherence rates vary tremendously depending on specific disease factors (e.g., severity, length of illness, etc.), complexity of the treatment regimen (e.g., number of medications, varying times per day medication is required, intravenous versus oral ingestion), and the method of monitoring adherence (e.g., pill count, daily diary, electronic monitoring). In general, across studies and disease groups in which adherence rates have been extensively assessed, estimates for adherence in children and adolescents are typically below 50 % (Rapoff 2010; La Greca and Bearman 2003). Specific to cancer, Kondryn and colleagues (2011) reviewed the literature on treatment non-adherence to oral medications in adolescents and young adults (AYA) and found that there are only four studies focusing on nonadherence with rates ranging from 27 to 63 %. The cost of this nonadherence is extremely serious for the individual. Failure to adhere to medication regimens can result in drug resistance, unexpected adverse medical events (e.g., negative drug reactions), increased rates of relapse, as well as morbidity and mortality and can lead to unnecessary increased dosages or discontinuation of a medication due to the belief that it is ineffective for the individual (Bhatia et al. 2012; DiMatteo et al. 2002). Therefore, it is clear that nonadherence is

a significant but understudied problem among pediatric cancer patients.

Patients with behavioral or emotional problems are less likely to adhere to regimens for cancer, diabetes, and renal disease (Rapoff 2010). Additionally, ambiguity within the family context of who is in charge or has primary responsibility of monitoring regimen tasks (e.g., making sure the medication was taken and completing refills) also tends to be associated with lower adherence (Rapoff 2010). Specifically related to effective treatments, behavioral interventions and multicomponent interventions with a treatment focus on the individual, family, and broader community within which the family operates have been identified as the most effective in improving treatment adherence (Butow et al. 2010). Adherence in younger children may also be affected by inability to or aversion to swallowing pills. Strategies for pill swallowing are described in Chap. 13, Stem Cell Transplantation.

In one approach to remedying nonadherence in AYAs, AYAs were given a mini-PC computer that contained either the intervention game (“Re-Mission”) and/or the commercial game (i.e., “Indiana Jones and the Emperor’s Tomb”) and were asked to play the game(s) for at least 1 hour per week during the 3-month study period (Kato et al. 2008). “Re-Mission” (HopeLab 2015) addresses issues of cancer treatment and care for teenagers and young adults. The game includes missions such as destroying cancer cells and managing common treatment-related effects (e.g., bacterial infections, nausea, constipation) by using chemotherapy, antibiotics, and stool softeners as ammunition. Players are also encouraged to use relaxation techniques to reduce stress, and eat healthy foods to gain energy. During any point in the game, neither the Nano-Bot nor any of the virtual patients “die.” If players fail to complete a mission or level at any point in the game, then the Nano-Bot powers down and players are given the opportunity to try the mission again. Players must complete missions successfully prior to moving to the next level. Importantly, Kato et al. (2008) found that individuals who played the game evidenced improved levels of adherence to treatment protocols, increased self-

efficacy, and higher levels of cancer-related knowledge compared to those that did not.

Currently, “Re-Mission 2” has open access to six games, “Nano-Bot’s Revenge,” “Stem Cell Defender,” “Nano Dropbot,” “Leukemia,” “Feeding Frenzy,” and “Special Op” online (<http://www.re-mission2.org>), which allows players to engage in different tactics to defend the body against mutant cells. It also provides access to information regarding research supporting the game platform and resources for families to become engaged in “Re-Mission 2.” This is one example of an innovative intervention that incorporates multiple approaches to the management of treatment adherence in the context of pediatric cancer.

A significant gap in the literature still exists for proven interventions to improve adherence in adolescents and young adults undergoing treatment for cancer (Butow et al. 2010). Numerous pediatric cancer researchers (e.g., La Greca and Schuman 1995; Gray et al. 2014; McGrady et al. 2014; Pai and Drotar 2010) have suggested general approaches to the management of treatment adherence as interventions that primarily emphasize (1) learning new skills and behaviors specific to adherence, (2) providing supervision and/or feedback, (3) providing incentives for improved treatment adherence, (4) enhancing family support and/or problem-solving, and (5) offering conventional psychiatric treatment. Pediatric interventions that include a multitude of these modules are likely to be most beneficial in assisting the patient and their family with adherence issues. For example, interventions may need to include one-on-one psychoeducation instruction surrounding specific disease management techniques, medical education (e.g., knowledge of medication side effects), problem-solving techniques, and adherence feedback (e.g., medical bioassay levels and/or MEMsCaps®), coupled with nurse consultation in order to be maximally effective. With the advent of new technology (e.g., Medication Even Monitoring System® (MEMSCap®; © 2002, 2003, 2005 by AARDEX® Ltd., Untermüli 6, CH-6302 Zug); Maya Pill Dispenser (MedMinder™ © 2014); MedFolio Pillbox (©

MedFolio 2014)), adherence to medical regimens has become an integral part of many interventions within the context of pediatric cancer treatment. Each of these technological devices provides the clinician, patient, and/or family members the ability to track adherence, set phone, text message, and/or email reminders to take medication. These devices can be excellent resources for providing additional assistance to children and families having significant difficulties with adherence to medication.

## Health Promotion Interventions

Similar to adherence interventions, which focus on a multitude of constructs (e.g., behavior, cognitive functioning, psychosocial functioning) to improve outcomes, health promotion interventions target modifiable behaviors such as dietary choices, smoking cessation, and patient knowledge surrounding illness information. Health-risk behaviors, such as smoking, drug use, sun exposure, and sedentary lifestyles can place individuals at risk for maladaptive psychosocial and physical outcomes (Hudson and Findlay 2006). Pediatric cancer and subsequent treatments can place patients at even greater risk for morbidity secondary to engaging in the same risky behaviors as their peers without cancer (Hudson et al. 1997; Mertens et al. 2002). Several interventions to motivate the practice of health behaviors have been a focus of childhood cancer research (Nathan et al. 2009); however, little is currently known regarding the use of health promotion behaviors to optimize health status and decrease cancer-related health effects (Hudson and Findlay 2006) in children who have undergone pediatric cancer treatment.

One area of health promotion literature examines the importance of physical activity. In the adult literature, research on exercise interventions during cancer treatment is well established (Knols et al. 2005), yet very few studies exist in children. Despite methodological limitations and small sample sizes, existing evidence strongly suggests that exercise is not only safe and feasible during cancer treatment, but that it can also improve physical functioning, quality of life, and

potentially cognitive functioning (Knols et al. 2005; Schmitz et al. 2005).

A recent study involving pediatric patients with a malignant bone tumor investigated the effects of individualized exercise interventions versus a control condition during their inpatient stays (Winter et al. 2013). Due to varying degrees in exercise history and disease severity, exercise plans were tailored individually to each participant to include different exercise elements such as strength, endurance, coordination, and flexibility exercises as well as games and relaxation training. Overall, the physical activity intervention group increased in overall physical activity, yet differences decreased after the cessation of the intervention. While no durable significant differences were observed, this is an important intervention program which gives pediatric cancer patients individualized exercise knowledge and education about healthy activity levels.

What have sometimes been referred to as “psychoeducational” interventions are another type of health promotion intervention that can be implemented by pediatric healthcare providers. This approach addresses informational transactions, discussions of problem-solving techniques and/or concerns surrounding the individual/illness/family, and use of coping skills training and psychosocial support. While this was briefly discussed in the adherence section regarding knowledge of medication and disease prognosis, the role of psychoeducational interventions in facilitating adaptation to chronic disease has received growing recognition, especially with the development of patients and families advocating for greater involvement in their own care (please see Chap. 24 for additional information on Advocacy).

According to the systematic review of informational interventions designed to influence knowledge among pediatric cancer patients, the development of health-related knowledge in children is best accompanied by information transfer methods that are highly interactive and individualized (Bradlyn et al. 2003), such as interactive multimedia formats. Lastly, an online interactive website including webisodes and chat rooms, created by HopeLabs and the StarLight Children’s



Foundation, called *Coping With Chemo*, is another resource for children and families (<http://chemo.starlight.org/>). Webisodes include information about the diagnosis, telling your friends you have cancer and making decisions about your treatment.

Other psychoeducational interventions have focused on reduction of secondhand smoke exposure among children with cancer. Secondhand smoke exposure is carcinogenic and can lead to significant health consequences such as respiratory illness, ear infections, and reduced pulmonary functioning (United States Department of Health & Human Services 2006). This is particularly worrisome for children who are diagnosed with cancer as it may increase vulnerability to health risks associated with their diagnosis (Tyc et al. 2013). A recent innovative intervention attempted to decrease secondhand smoke exposure in children undergoing active cancer treatment. This intervention involved three individual, face-to-face, biweekly 1 hour sessions followed by three 25-minute telephone sessions with parents with the goals of reducing children's exposure to tobacco smoke, increasing parental self-monitoring of smoking around the child, and problem-solving barriers to smoking around the child and social reinforcement for success (Tyc et al. 2013). Overall, the intervention was successful in significantly reducing parent-reported child secondhand smoke exposure. While no significant changes in cotinine levels were observed, overall parents reported a willingness to participate. While Tyc and colleagues (2013) provided a significant first step in assessing secondhand smoke in children with pediatric cancer, more studies are needed to assess interventions for secondhand smoke exposure.

It is essential that effective interventions are implemented and embedded within multidisciplinary care in addition to including a multitude of formats (e.g., electronic, web-based) in order to maximize positive health outcomes for children, adolescents, and their parents. These interventions will also need to take into account different learning styles (e.g., auditory versus visual, desire for written materials versus electronic modalities) and take into account developmental levels.

### Case Vignette

Gus, a 14-year-old male who was diagnosed with acute lymphoblastic leukemia (ALL), was referred to the psychologist due to staff concern about his nonadherence with his medical regimen, which was interfering with his recovery and ability to attend school. Gus was withdrawn, depressed and anxious about medical complications, and felt little control over his treatment and disease. The psychologist arranged an initial care conference that included Gus, a social worker, the primary nurse coordinator, nutritionist, and the psychologist.

The team began by trying to increase Gus' sense of control by informing him about painful procedures at least 3 days in advance and choosing which days of the week he preferred to receive his chemotherapy. The team also worked to improve Gus' activity in support groups, provided him additional knowledge of his illness via interactive forums (i.e., video games and interactive videos), and implemented electronic monitoring with text messaging reminders sent to both Gus and his parents to improve adherence.

While the team worked with Gus, it became clear that Gus' parents experienced significant conflict surrounding his care and would often yell at each other during clinic visits. His parents were seen together for one session to negotiate who would bring Gus to clinic visits and to identify communication difficulties. To address Gus' exposure to his father's secondhand smoke, the psychologist implemented a behavioral smoking cessation intervention (e.g., nicotine replacement therapy products) for Gus' father. After two months, Gus' parents were successful in decreasing Gus' exposure to secondhand smoke, as measured by oral cotinine levels and exhaled carbon monoxide. In addition, Gus increased his school attendance, improved his adherence with his treatment regimen, and became more social in school activities.

## Bibliotherapy

From a formal perspective, bibliotherapy has been defined as the “use of written materials to gain understanding and engage in problem-solving” (Goddard 2011). Bibliotherapy can be particularly useful in settings where engaging in a therapeutic treatment protocol that requires multiple sessions would simply not be feasible (e.g., with families living in rural setting; Elgar and McGrath 2003). Bibliotherapy has four components, including:

1. Identification
2. Selection
3. Presentation
4. Follow-up (Pardeck 1992)

Identification involves working with the family and patient to pinpoint their specific psychosocial needs. The process of selection consists of selecting materials that coincide with the family and patients identified needs. Presentation involves the clinician giving the selected information to the patient in a manner that is appropriate to their specific developmental level. Finally, follow-up involves the clinician checking in with the patient to ensure they understood the information given, offer the opportunity for the patient to explain the information they found helpful, and address or elaborate on any questions. Pardeck (1992) suggests that bibliotherapy with patients is a process whereby the clinician is involved directly with the patient during therapy, as opposed to the patient reading materials on their own without the presence of the clinician. Additionally, bibliotherapy can be used in sessions with the clinician and patient as a means of modeling of skills and generating discussion.

Bibliotherapy and multimedia such as film and short stories have a long history of clinical utilization in the pediatric context. Numerous books are available for both parents and children whose lives have been affected by pediatric cancer (see Chap. 25 for additional resources). These books include those written for parents that cover material relevant to diagnosis and treatment (see Nancy Keene’s series of books on a variety of

topics specific to pediatric cancer) to books that specifically help children cope with negative feelings and fears. Many resources for parents can be found on the Internet.

As mentioned previously, bibliotherapy has been widely used to provide psychoeducational support for pediatric cancer patients, but rarely has it been investigated from a research perspective (Schneider et al. 2013). Schneider and colleagues (2013) completed a bibliotherapy intervention with 21 pediatric cancer patients. A social worker read *Nikki’s Day at Chemo*, a book developed for the study to facilitate discussions of coping strategies, emotions, diagnosis, and treatment, to the cancer patient and then asked pointed questions in order to assess the child’s understanding of the book. The child was asked how the story might be applicable to their own cancer diagnosis and treatment, using specific examples from the book to prompt the child. The discussion of the use of the tools provided in the book typically lasted about 15 minutes. They found that it helped to improve interpersonal functioning and was also rated as a satisfying activity by both patients and families. There was also an improvement in intrapersonal functioning several months post-intervention compared to pre-intervention. Bibliotherapy has also been suggested as a useful tool for psychologists, educators, physicians, other healthcare providers (Elgar and McGrath 2003) and school counselors when working specifically with pediatric cancer patients (Karayanni and Spitzer 1984). Bibliotherapy can be a helpful tool in providing support when used within the context of a larger treatment protocol (see Chap. 25).

## Emerging New Therapies

Acceptance and commitment therapy (ACT), mindfulness, and trauma-focused cognitive behavioral therapy (TF-CBT) are three relatively new therapeutic approaches that may be used within the pediatric cancer population. The main focus of ACT is to increase psychological flexibility by engaging in acceptance, cognitive defusion, practicing being in the present moment,

viewing the self as context, identifying and working towards the individual's values, and committing actions (Hayes et al. 2006). Mindfulness is the "awareness that emerges through paying attention, purposefully and nonjudgmentally, to the unfolding of experience moment to moment, including one's thoughts, feelings, and body sensations" (Jones et al. 2013). TF-CBT within pediatric cancer is aimed at alleviating posttraumatic stress symptoms resulting from disease-related procedures in order to elicit improvements in quality of life and psychosocial adjustment.

There is limited research examining the effectiveness of ACT within a pediatric cancer population. Masuda and colleagues (2010) developed a protocol of eight 60-minute family sessions within the context of sickle-cell disease. Sessions were broken into 3 sections. The first section, lasting 5–10 minutes, involved the patient and family discussing the patient's activities throughout the week and any medical concerns the patient or family had. The second section, about 30–40 minutes long, was comprised of utilizing ACT tools to address the concerns of the patient and family. These included acceptance, values clarification, and mindfulness. The final section, lasting 10–15 minutes, was geared towards having the patient and family develop specific values-based goals for the coming week. Additionally, Burke and colleagues (2014) developed the Take a Breath Intervention for parents of children with life-threatening conditions (i.e., parents of youth with cancer or cardiac disease). This intervention involved five 90-minute sessions. During these group sessions, parents participated in the use of metaphors, experiential exercises, and self-reflection, all elements of ACT. Parents also worked to identify personal values and then utilized those values to help enhance problem-solving skills. From pre- to post-intervention, parents reportedly experienced decreases in posttraumatic stress symptoms and impact of illness scores and increases in psychological flexibility and mindfulness. Parents also reported an improvement in access to emotional resources.

Mindfulness involves both elements of psychoeducation and practice. Patients practice

observing their external surroundings and internal thoughts and sensations as ever changing while refraining from identifying with or reacting to these stimuli (Jones et al. 2013). Mindfulness also typically involves setting an intention. This is typically related to showing compassion and kindness towards the self and others. It has been suggested in the literature that using these skills will help pediatric cancer patients shift their cognitive focus from uncertain future-oriented thoughts to focusing on the present moment through a nonjudgmental lens. Lagor and colleagues (2013) developed a mindfulness-based intervention for children with various chronic illnesses. There were six group sessions that provided psychoeducation through interactive exercises and metaphors and practice. Sessions towards the beginning of the intervention focused on making patients aware of their environment. An example of this would be mindful touching, where patients were asked to describe a mystery object that was in a paper bag using nonjudgmental words. Sessions towards the end of the intervention focused on patients practicing mindfulness of their internal experiences. These sessions were aimed at using visual imagery and playful curiosity in order to practice mindfulness. An example of visual imagery was being mindful of thoughts by sorting them into boxes (Lagor et al. 2013).

Although there is no data on the use of TF-CBT in pediatric cancer, a review completed by Nenova and colleagues (2013) found that with adult cancer patients, cognitive behavioral strategies can alleviate cancer-related posttraumatic stress symptoms (PTSS). Results from the adult literature suggest that cognitive behavioral strategies may be effective in reducing PTSS, but more research is needed to better understand the implication of trauma-focused interventions within pediatric cancer samples. As with all psychotherapeutic modalities, there can be barriers that arise in providing TF-CBT effectively. These include, but are not limited to, the developmental and cognitive level of the child, resistance to homework, and cultural considerations. Therefore, it is important for the clinician to consider these potential barriers when engaging in treatment.

ACT, mindfulness, and TF-CBT are emerging therapies that have the potential to be clinically useful tools when working with children with chronic illness. Within the pediatric cancer population, additional research needs to be done before we can understand the implications of these interventions within this population; however, preliminary work thus far seems promising.

### **Case Study** *Background*

Brock, a 5-year-old boy, was referred for psychotherapy by his pediatric oncologist and multidisciplinary team following his recent diagnosis of acute lymphoblastic leukemia (ALL). Brock had been diagnosed at a regional hospital in a rural part of the state and had been medically evacuated to the pediatric cancer center in a university teaching hospital approximately 160 miles from his home. Ten weeks into his treatment protocol, he began to show signs of withdrawal and sadness. Notably, his mother had also begun to show signs of depression, isolating herself from the other parents, asking minimal questions to the medical team, and experiencing significant weight loss.

The treatment team noticed that the vast majority of hospitalizations and outpatient visits involved only Brock and his mother; rarely did visits occur with Brock's father and two siblings. Brock's mother was found sobbing in the bathroom one morning, stating that she was completely overwhelmed by everything that she had to deal with. She also stated concerns about the uncertainty surrounding Brock's illness, including his long-term prognosis and possibility of late effects, stating "even if he does survive, what will his future be like?" She noted that the family was excessively burdened by the increased financial and logistical demands (e.g., travel to the hospital, childcare for their other children, and management of business needs) and that her husband felt compelled to work even harder in order to keep them financially afloat. Although Brock's paternal grandmother was able to provide some childcare, his dad had considerable new responsibilities being the primary care provider for Brock's siblings managing two other small children on a daily basis.

### *Intervention*

In a meeting with the pediatric oncology psychologist, Brock's mother revealed her own history of episodic depressive episodes, triggered by major stressors in her life, for which she had successfully sought treatment through a local mental health provider. The psychologist proposed conducting weekly family sessions that would coincide with Brock's treatment, and Brock's father would call in if he were unable to attend.

During the subsequent three sessions, a number of potential problem areas were identified using a medical family therapy approach. Both parents underscored how difficult communication between them had been, in part due to the physical distance between home and hospital and also due to their desire not to stress each other further. Apparently, both individuals were "conflict-avoidant," and the diagnosis of cancer had further accentuated that pattern. In addition, both acknowledged the considerable uncertainty they felt. On the one hand, they acknowledged the good prognosis their son had and their trust in the treatment team, and yet they were both experiencing the "what if" phenomenon, (i.e., "what if he doesn't respond to chemotherapy," "what if his port gets infected"?). They both voiced their concerns for Brock's siblings as well, believing that they were "short-changing them" and worried in particular that Brock's older brother would be resentful about the attention Brock was receiving and the additional chores that he was being asked to assume. The therapist attempted to "normalize" yet legitimize their concerns while offering support and continuing to develop the therapeutic relationship. She also reframed their conflict-avoidant style intended to protect one another as potentially causing detriment in the long run.

In later sessions, it appeared that both parents were experiencing a sense of relief and a new commitment to maintaining communication. Brock's father was reassured that they could discuss these issues without his wife plunging further into depression. In order to further support the mother's coping with her depressive symptoms, the therapist implemented CBT approaches such as having her monitor symptoms through a

daily thought diary and increasing social interactions, which had been helpful to her in the past.

A *problem-solving approach* (PST) was taken to address the family's financial concerns, including (1) checking with his insurance coverage to determine what treatment is covered, (2) consulting with a financial advisor to further determine their actual financial status and the long-term impact on his business, and (3) consulting with the social worker at the hospital to see if funds were available to support them. Through each of these efforts, they were able to determine their financial needs, and while not a specific goal of therapy, a number of fundraisers were held in their home community.

Additional visits were conducted with Brock to assess his level of distress. Not unlike many 5-year-old boys, his preference was to talk about toys and his favorite superheroes. Although Brock initially appeared somewhat sad, his mood slowly lifted as he talked about his various interests. When the therapist asked him in the third meeting what he worried about the most, he very quickly said "my mom" and changed the topic. The therapist continued to keep the topic "light" over the next few sessions while continuing to meet with his mother and father. As the mother's mood lifted, so did Brock's, indicating that his "depression" was in large part a reflection of his mother's challenges in coping.

When the family was seen 10 weeks later, the therapist reviewed their progress. Brock's parents were concerned about his reintegration into the school environment and the questions his friends may have about his treatment and health status. Fortunately, the treatment center had a well-established school reintegration tool kit they had developed, with an array of informational pamphlets and handouts for teachers and schoolmates. A release was obtained and the reintegration coordinator contacted the school, offering to visit with the staff and students. The parents also agreed to schedule a meeting with Brock's teacher, principal, and special education director to discuss these issues further.

Approximately 6 months into Brock's treatment, his parents described being "in a much better place," both individually and as a couple. They

reported that although they still experienced uncertainty and knew that their son had a lot of treatment remaining, they felt they had the skills to manage their fears. They did not think they needed more sessions with the therapist, but wanted to make sure they could "touch base" should the need arise. Additionally, the therapist spoke with Brock's treatment team to obtain their perspective on the family's adjustment and ensure that the family was coping more effectively and was appropriately engaged in oncology treatment.

This case study illustrates a multicomponent cognitive behavior therapy and problem-solving therapy (PST) approach in the context of a family systems intervention. Such a case demonstrates the integration of empirically supported strategies but in the context of a flexibly instituted family systems framework. In this treatment approach, the therapist took care to (1) assess the family dynamics, including their strengths and weaknesses prior to the diagnosis of cancer, role definitions, and role shifts that had occurred; (2) clearly assess how the family defined their greatest stressors/challenges, including how they were coping with uncertainty; (3) establish multiple therapeutic plans at different systems levels (e.g., parent, child, sibling, medical team) for enhancing their coping; (4) subsequently implement the plan; and (5) evaluate its effectiveness. Care was taken throughout the course of treatment to establish and maintain the therapeutic alliance, assess for cultural issues, integrate procedures/resources with the multidisciplinary team, and assess for barriers. A basic assumption at all times was that *all families seek to do the very best they can under extraordinary circumstances* and that the role of the therapist is to facilitate the process of coping while hopefully mitigating maladaptive responses.

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## Future Directions

A wide array of approaches and techniques have been utilized to address the needs of children with cancer and their families. These range from broad and general strategies aimed at alleviating family distress to very specific and targeted therapies aimed at reducing pain or enhancing

adherence or exercise. Clinicians now have the ability to employ various interventions depending on the needs of a given family.

In light of the current state of intervention science, where do we need to go from here? First, it appears that while a wide range of psychotherapeutic modalities are available, many of these modalities would benefit from continued empirical scrutiny. Some of the interventions that have been employed to date actually have limited support from a research perspective in children with cancer (e.g., CBT, Coping Cat) compared to treatment as usual. Although randomized clinical trials are time-consuming and expensive, it remains important to find ways to document “best practices” if we are to provide the best possible care to our families. Additionally, although a number of emerging therapies have been identified as effective with adult cancer patients (e.g., ACT, mindfulness, and TF-CBT), the utility of these interventions should be explored within pediatric cancer in order to provide patients with cutting-edge empirically supported psychological treatments.

Second, it is clear that the movement towards electronic dissemination of interventions has great potential for utilization in pediatric cancer centers around the country (see Chap. 20). Families can already access an immense amount of information online, including coping resources, support groups, and education about treatment, side effects, and new developments in the field. Such interventions may be particularly helpful for those families who live in rural areas or who have limited resources to travel for additional psychotherapeutic services. This technology is already available, and both patient and parent can track cognitive (e.g., thoughts and beliefs), emotional (e.g., depressive and anxiety symptoms), and physical variables (e.g., activity levels and exercise) electronically with relative ease and low expense. Although there are issues of confidentiality to contend with, technology such as Skype allows for real time face-to-face intervention from virtually any location (including around the world). Such technology may be the primary means by which we can enhance the delivery of services to families whose lives are often fragmented by the diagnosis of cancer.

### Clinical Pearls

- Resiliency is the norm! However, there are those subsets of families that need support and who are at risk for various types of psychological distress (e.g., anxiety, depression). Each family should be approached through a unique lens to provide the appropriate and necessary psychological assistance.
- Use a multidisciplinary team approach to benefit the family. Such a team can provide resources, assist with care management decisions, and implement interventions in several settings (e.g., hospital, home, school), which will help to improve psychosocial functioning.
- When you have worked with one family with a child with cancer, you have worked with one family with a child with cancer. Do not assume they are all the same and will fit neatly into a single conceptual framework.
- The best predictor of child adjustment is parent adjustment. All psychotherapeutic endeavors should attempt to involve the parents and the entire family system in some form or fashion.
- We cannot provide all resources to all parents, but with careful assessment, we can address their most pressing needs.
- Craft interventions to the needs and desires of the families. Some families may want to problem solve and share openly with other families; other families may want to be listened to and desire privacy. Continual assessment of the family needs over time is important, as needs may well change over the trajectory of survivorship.

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