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A BRIEF PROBLEM SOLVING INTERVENTION FOR CAREGIVERS OF CHILDREN  
WITH CANCER

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
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## **Abstract**

### **A BRIEF PROBLEM SOLVING INTERVENTION FOR CAREGIVERS OF CHILDREN WITH CANCER**

By Jennifer D. Lamanna, MA

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy at Virginia Commonwealth University

Virginia Commonwealth University, 2012

Major Director: Marilyn Stern, PhD,

Professor

Departments of Psychology, Pediatrics, and Social and Behavioral Health

**OBJECTIVE:** Pediatric cancer treatment is stressful for caregivers. Research has indicated that problem-solving coping reduces stress related to caregiving. The current study examines the effects of a problem-solving intervention (Parent Empowerment Program), based on Problem-Solving Therapy, for caregivers of children on active cancer treatment. It was hypothesized that participants who received the intervention would show decreases in caregiving stress and posttraumatic stress symptoms, and increases in problem-solving ability between baseline and post-test assessments compared to those who received an attention control.

**METHOD:** Thirty-nine caregivers (all parents; 48% participation rate) participated. The majority were mothers (90%), married or partnered (59%) and Caucasian (56%). Participants were randomly assigned to condition (intervention vs. attention control) after completing baseline questionnaires. Participants who received the intervention received one session of problem solving intervention and a follow-up session. Those in the attention control condition received

two general support sessions. Participants were assessed at baseline, one month after the second session, and three months after the second session. RESULTS: There were no effects of the intervention on any of the outcome variables when data for all participants was examined.

However, there was a significant effect of the intervention on problem-solving ability among participants of children between 4-16 weeks post-diagnosis. CONCLUSIONS: There were many factors that contributed to the lack of effect, including small sample size, variations in time since diagnosis, low participation rates, and limited number of sessions. Future studies should target parents who are under the highest levels of stress and increase the intensity of sessions.

However, the finding that the intervention has an effect on problem-solving ability early in the treatment trajectory replicates previous research and has potential clinical utility.

## A Brief Problem-Solving Intervention For Caregivers of Children with Cancer

Learning that one's child has cancer is a devastating, and often traumatic, experience for parents. For parents, this experience has been found to be as potentially traumatizing as crime victimization (Gudmundsdottir, Elklit, & Gudmundsdottir, 2006). During the initial period after diagnosis, the child is often hospitalized, undergoes invasive medical procedures, treatment plans are developed, and prognosis is determined. Even after the initial period, when the child is on routine treatment, the threat of both short-term and long-term medical complications, or in some cases, death of the child is ever-present for parents (Rabineau, Mabe, & Vega, 2008). According to a recently developed model of pediatric medical traumatic stress (Kazak, Kassam-Adams, Schneider, et al., 2006), in the weeks and months immediately following a child's cancer diagnosis, parents experience intense stress as a result of hospitalization, invasive medical procedures, and fears about the child's future health status. The consequences of this early traumatization often include high stress levels in parents (Eiser, Eiser, & Stride, 2005).

Evidence is mixed regarding how long after diagnosis increased levels of stress exist for parents. Some evidence suggests that stress levels decrease within six months of diagnosis (Dolgin, Phipps, Fairclough et al., 2007) while other evidence suggests that distress levels remain high well into the child's cancer remission or survivorship (Boman et al., 2003; Kazak, Alderfer, Rourke et al., 2004; Stoppelbein & Greening, 2007).

During cancer treatment, parents are faced with a number of challenges that require making difficult decisions. Research suggests that parents of children with cancer feel overwhelmed by the number of difficult problems they are required to solve. Mothers specifically are typically challenged with managing not only the needs of the patient, but of the associated disruption in the family and household. Varni, Sahler, Katz and colleagues (1999)

outlined the types of problems with which mothers specifically are presented. These categories include: 1) managing the ill child's needs; 2) managing the needs of other children and spouses; 3) personal psychological difficulties; 4) concern about personal physical health; 5) social problems; 6) financial and occupational problems; and 7) management of daily activities.

Because many of these problems suggested by Varni and colleagues are exacerbated by the stress of having a child with cancer, parents can feel overwhelmed with the number and severity of associated problems, and as a result, experience high levels of stress. Parents of children with cancer do not necessarily make poor decisions, but are required to make a large number of difficult decisions while under the ever-present stress of the child's illness. Having to make difficult decisions and solve challenging problems on a regular basis can be overwhelming for parents and cause additional stress. Therefore, there are a number of different sources of stress that are present for parents during treatment. Because the demands of problem solving can create additional stress, problem solving intervention is a viable solution for improving problem solving skills and reducing stress.

The purpose of the current study was to investigate the effectiveness of a brief problem-solving intervention for parents of children with cancer. It was presented as a program specifically designed for parents of children with cancer, and was called the ***Parent Empowerment Program***. The effectiveness of this intervention was examined in terms of 1) effectiveness on parents' problem-solving ability; 2) posttraumatic stress symptoms; and 3) caregiving stress. To provide a rationale for the current study, the literature on parental stress (including posttraumatic stress), problem solving therapy as an intervention for stress reduction, and the efficacy of problem solving interventions for caregivers is reviewed.

**Parental Stress** There is a large body of research which indicates that the diagnosis of cancer in one's child is acutely stressful for parents, particularly mothers (Wallender & Varni, 1998). Patino-Fernandez, Pai, Alderfer, and colleagues (2008) found that 51% of mothers and 40% of fathers experience acute stress symptoms within the first two weeks after diagnosis. One likely cause of the acute stress experienced by parents at the time of cancer diagnosis is the abrupt and unexpected nature of the diagnosis which leaves parents overwhelmed and feeling unprepared to cope with the catastrophic news. Interestingly, however, some have suggested that prognosis may not actually predict initial distress levels (Boman, Lindahl, & Bjork, 2003).

When children are suspected of having cancer, they are often quickly admitted to the hospital where they remain until their diagnosis. Often times, they also receive their initial treatments during their first hospitalization, so that the disease can be brought under control as quickly as possible. This initial time frame can be overwhelming for parents, as children receive frequent medical procedures such as scans, blood draws, and surgery. During this time, treatment plans, which include intense intervention such as chemotherapy, radiation, and bone marrow transplant or additional surgeries, are often discussed with parents. The consent process for these treatments is overwhelming and often stressful. In addition, some parents do not fully process the information provided to them during the consent process (Simon, Siminoff, Kodish, & Burant, 2004; Simon, Eder, Kodish, & Siminoff, 2006). When parents are able to take children home after the initial discharge, they are faced with the overwhelming task of caring for the child. Because children undergoing chemotherapy have compromised immunity, parents often need to take precautionary measures to protect the child from secondary infections that often results in drastic changes to daily activities and socialization.

**Posttraumatic Stress Symptoms.** There is evidence that hearing the news of one's child's diagnosis of cancer can contribute to Posttraumatic Stress Symptoms (PTSS) or Posttraumatic Stress Disorder (PTSD) in some parents. Research indicates that PTSS are common among parents of children newly diagnosed with cancer. Kazak and colleagues (2005) found that two months after the start of treatment, 68% of mothers and 57% of fathers reported moderate to severe levels of PTSS. Although few parents meet the full criteria for PTSD, their likelihood of developing PTSD is greater than parents of healthy children (Pelcovitz, Goldenberg, Kaplan, et al., 1996), suggesting that the potential for diagnosis to cause PTSD is quite real.

Intrusive thoughts, or the reliving in one's mind the circumstances under which they were informed of their child's diagnosis, is one common PTSS among parents of children with cancer (Norberg, & Boman, 2008). Another PTSS in parents of children with cancer is their tendency to avoid stimuli associated with the child's diagnosis (i.e., avoidance symptom; Norberg, & Boman, 2008). The avoidance symptoms of PTSS can be detrimental for the child's medical prognosis, as parents who experience this symptom may be non-adherent with medical appointments, medical procedures, and communication with the patient or medical staff (Rabineau et al., 2008). Although some (e.g., Rabineau et al., 2008) have speculated that the avoidance symptom may be detrimental to the child's medical prognosis, there currently is no extant literature that has found a link between avoidance and prognosis. Parents' vulnerability to stress during the time immediately following diagnosis can also negatively impact their ability to collaborate effectively with the child's medical care team (Norberg, & Boman, 2008). Even subclinical levels of distress can have an impact on the child's well-being and a parent's ability to care for the child (Rabineau et al., 2008).

**Stress levels across treatment trajectory.** Parents differ in their levels of distress in the weeks and months following a diagnosis of cancer. The literature suggests that distress levels are often most intense in the weeks immediately following diagnosis. In a large study of mothers of children newly diagnosed with cancer, Dolgin, Phipps, Fairclough and colleagues (2007) identified three different trajectories of maternal adjustment over time. One subset of mothers have low levels of distress that remain stable over time, another subset of mothers have moderate levels of distress that also remain stable over time, while a third subset of mothers have high initial distress that declines over time. The mothers with low levels of distress were characterized by low levels of neuroticism, high levels of extraversion, good problem-solving skills, and higher educational status. However, those with moderate or high initial stress levels were characterized by high levels of neuroticism, low agreeableness and extraversion, and poor problem-solving skills. These mothers were also more likely to be single parents and have a lower education level, compared with mothers with low levels of distress. Dolgin and colleagues found significant reductions in distress five months after diagnosis. However, the distress levels of mothers were significantly higher than normative distress levels.

Kazak, Boeving, Alderfer and colleagues (2005) found little relationship between PTSS and time since diagnosis, suggesting that the mere passage of time has minimal effect on symptomatology. Despite some evidence that distress levels subside over time (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998), there is also evidence that distress levels extend well past the initial diagnostic phase. Importantly, Mack, Wolfe, Cook, and colleagues (2009) found distress levels to be similar one month and one year after a child's cancer diagnosis. At one year post-diagnosis, 25% of parents are at risk for PTSS (Stoppelbein & Greening, 2007). Even more striking, some distress symptoms, such as uncertainty, disease-related fear, social isolation,

anxiety, loss of control, and sleep disturbance may still be present in parents years into their child's survivorship (Boman Lindahl, & Bjork, 2003). Kazak, Alderfer, Rourke and colleagues (2004) found that up to 99% of families had at least one member with PTSS, and 13.7% of mothers met the criteria for PTSD at the time of the study. In a study of parents of children with brain tumors (Hutchinson, Willard, Hardy, et al., 2009), those with children on treatment experienced more distress than those with a child off-treatment. However, even parents of children off-treatment still experienced high levels of distress, perhaps as a result of continued uncertainty and caregiver burden.

Overall, the literature on stress trajectories among parents of children with cancer suggests that although parents are at risk for the highest levels of stress in the peri-diagnostic phase, most parents also experience some level of distress throughout the treatment trajectory, and even into remission and survivorship. Therefore, monitoring PTSS and offering practical and effective interventions to treat parental stress throughout the treatment process is critical.

**Factors associated with increased risk for stress.** Research has identified some factors that make parents more susceptible to developing PTSS symptoms. These risk factors include poor social support (Pelcovitz, Goldenberg, Kaplan, et al., 1996; Rabineau et al., 2008), adverse experiences with child's medical procedures (Rabineau et al., 2008), parental beliefs about the treatment experience (Rabineau et al., 2008), problem-solving ability (Dolgin, Phipps, Fairclough, et al., 2007), and parental trait anxiety (Rabineau et al., 2008; Stoppelbein & Greening, 2007). As would be expected, parental history of prior traumatic life events has been found to be a predictor of PTSD subsequent to diagnosis (Pelcovitz, Goldenberg, Kaplan, et al., 1996; Stoppelbein & Greening, 2007). In addition, racial or ethnic minority status is associated with higher levels of PTSS near the time of diagnosis (Dolgin, Phipps, & Fairclough, 2007).



Existing life stressors associated with these demographic characteristics likely predispose parents to increased levels of PTSS when faced with the added stressor of having a child with a chronic illness.

**Problem-solving** The current study examines problem-solving as a means for ameliorating stress among parents of children with cancer. According to Nezu (2004), a problem is an actual or expected situation which requires an adaptive response from the individual, but for which no immediate effective coping mechanism is available. A solution is a coping mechanism that changes the nature of the problem and/or the individual's negative reactions to the problem. An effective solution is that which effectively meets these goals while also maximizes other positive consequences of the solution while simultaneously minimizing negative consequences.

The effectiveness of a problem-solving outcome is based on two dimensions: *problem orientation* and *problem-solving style* (Nezu, 2004). Problem orientation refers to one's attitude, or beliefs about their approach to problem-solving. Those with a *positive problem orientation* approach problems with an optimistic attitude. They accept that problems are inevitable and require work to solve, but perceive their ability to solve problems as strong. Those with a *negative problem orientation* take a pessimistic approach to problem-solving. They see problems as unsolvable, become frustrated or upset when faced with problems, and perceive that they have little or no ability to solve problems. Self-efficacy also is relevant with regard to problem orientation. Individuals may be optimistic that they can devise solutions, but pessimistic that they can carry out those solutions.

*Problem-solving style* is the set of thoughts and behaviors one uses to attempt to solve a problem. There are three main types of problem-solving style. First is the *impulsive/careless* style. Those who use this type of style want a quick solution to a problem, and therefore their

efforts are hurried or careless. Second is the *avoidance style*. Those who implement this style take few measures to address the problem. Instead they hope problems will work themselves out, procrastinate in making efforts to address the problem, or rely too heavily on others to devise solutions. Last is the *rational problem-solving style*. It involves the use of systematic steps to 1) define and formulate the problem; 2) generate possible solutions; 3) make a decision; and 4) evaluate the outcomes of the decision. These four steps are the primary components of Problem-Solving Therapy (PST).

**Problem-solving model of stress** The primary goal of the current study was to use PST as a means to moderate stress among parents of children with cancer. PST has been widely utilized as a moderator of stress (Nezu, Wilkins, & Nezu, 2004, p. 56-58). Nezu's (2004) problem-solving model of stress explains why failure or inability to solve problems effectively causes increases in stress.

Ineffective or maladaptive coping behavior in various contexts leads to psychological stress (Nezu et al., 2004, p.57). Stress can be conceptualized as a function of three variables (Nezu, 2004). First, stress can be caused by the interaction among stressful life events (both major negative life events and daily problems). Parents of children with cancer face both types of stressful life events. Stress is reciprocal for parents of children newly diagnosed with cancer because the diagnosis itself is a major negative life event, which sets the stage for daily problems and hassles. The impact of their child's serious or life-threatening disease is a major negative life event, and the disruption to normal family life, medical procedures, hospitalizations, clinic visits, financial issues, and many others are daily struggles. Second, stress is caused by negative emotional states such as anxiety and depression. Cancer diagnosis and treatment are anxiety-provoking for parents (Boman, Lindahl, & Bjork 2003; Norberg & Boman, 2008) and the long-

term struggles can lead to depression or symptoms of depression (Boman, Viksten, Kogner & Samuelsson, 2004; Norberg & Boman, 2008; Smith, Baum & Wing, 2005). Finally, problem-solving coping, when it is ineffective or non-productive, contributes to continued distress. Psychological distress can ultimately be caused by a number of different sources within the context of the problem (Nezu, 2004). These sources include 1) specific elements of the problem (e.g., pain or conflict); 2) one's appraisal of the problem (perceived vs. actual threat); and 3) the outcome of the problem-solving coping attempts. Figure 1 illustrates a graphical representation of the problem solving model of stress.

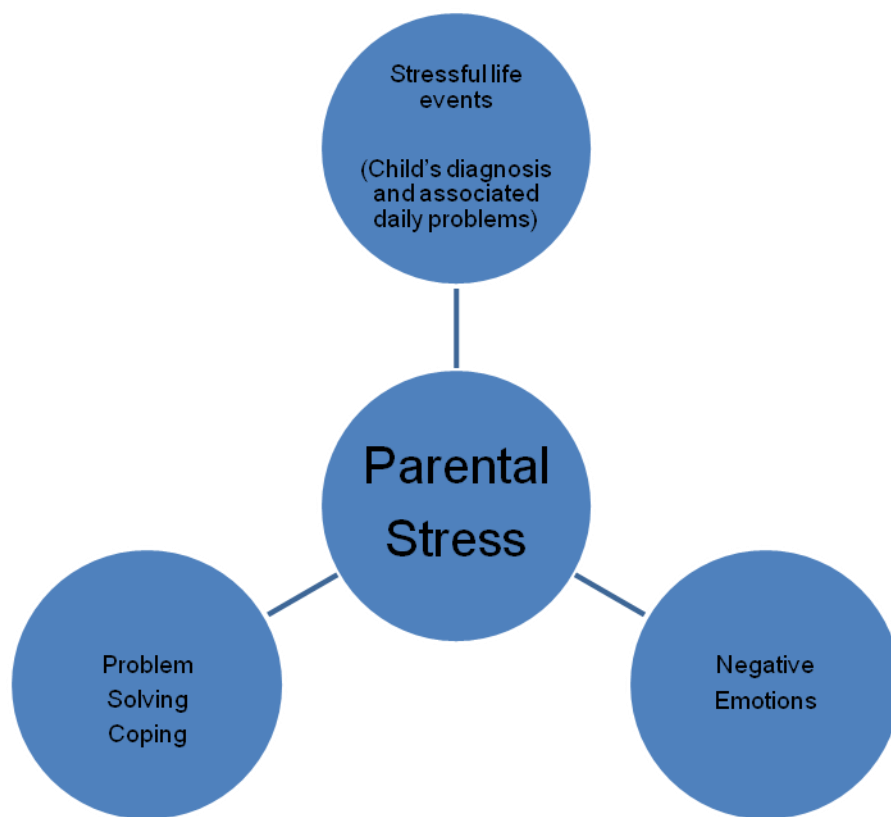


Figure 1 *Problem solving model of stress (based on Nezu, 2004)*

Over time, success in problem-solving may lessen the emotional distress that occurs as a reaction to a stressful event. In addition, PST promotes the likelihood of long-term positive outcomes (Nezu, 2004). Therefore, successful problem-solving may facilitate stress reduction over time. However, continued failure in problem-solving reduces the likelihood one will use problem-solving coping techniques to address future problems. In addition, the likelihood of negative long-term outcomes is increased (Nezu, 2004).

According to Nezu (2004), the stress-related variables (major negative life events, daily hassles/struggles, negative emotional states, and problem-solving coping) interact with one another to perpetuate the development of distress as a reaction to problems. Changing the final component (problem-solving coping) by utilizing the PST skills alters the interaction of these four stress-related variables. That is, by utilizing adaptive PST skills, an individual can change his or her approach to problem-solving, make overwhelming problems more manageable, and ultimately improve negative emotional states. The current study examined the effect of a problem solving intervention on three of these components: caregiving stress, posttraumatic stress symptoms, and problem solving ability.

**The effect of problem-solving on stress and psychological factors.** Stressful events are associated with psychological distress (D’Zurilla & Sheedy, 1991). Experiencing a stressful event may impair an individual’s problem-solving ability, and the failure to solve problems effectively adversely affects psychological adjustment (Bell & D’Zurilla, 2009). Having a large number of unresolved problems often contributes to a negative problem orientation, which in turn leads to unsuccessful problem-solving, and ultimately to higher levels of psychological distress (Kant, D’Zurilla, & Maydeu-Olivares, 1997). Therefore, effective problem-solving can reduce one’s number of stressful adjustment problems because individuals who solve problems

effectively perceive a sense of control over themselves and their environment (D’Zurilla & Sheedy, 1991). The problem-solving effectiveness examined in these studies is based on participants’ self-report of the success of their problem-solving ability, not on any objective measure. However, it may simply be that perceived success in problem-solving is associated with positive psychological outcomes.

Poor problem-solving ability has been found to have an effect on stress (D’Zurilla & Sheedy, 1991) and other psychological factors such as anxiety and depression (Bell & D’Zurilla, 2009). Consequently, effective problem-solving ability is associated with good psychological well-being (Chang, D’Zurilla, & Sanna, 2009). In addition, effective problem-solving ability can facilitate adjustment in those with high stress (Bell & D’Zurilla, 2009; Chang, et al., 2009). Of all the problem-solving components, problem orientation appears to have the strongest impact on stress (D’Zurilla & Sheedy, 1991). Positive problem orientation is associated with lower levels of distress (Bell & D’Zurilla, 2009) and increased psychological well-being (Chang, et al., 2009). However, negative problem orientation has consistently been found to be related to increased psychological distress (Bell & D’Zurilla, 2009; Chang, et al., 2009) and anxiety and depression (Kant, D’Zurilla, & Maydeu-Olivares, 1997). One’s problem orientation dictates the entire problem-solving process. Therefore, individuals with a negative problem orientation perceive problems pessimistically, and are unlikely to be able to solve problems effectively (Kant et al., 1997). In fact, those with a negative problem orientation have been found to perform poorly on problem-solving tasks (Shewchuk, Johnson, & Elliott, 2000). Shewchuk and colleagues explain that individuals with a negative problem orientation reduce their ability to solve problems flexibly while under stress because they tend to focus on their perceived inability to solve the problem and the likelihood of failure. In addition, an impulsive (i.e., making problem-solving

decisions without thinking through all the necessary facts) or avoidant (i.e., avoid solving the problem) problem-solving style is also associated with psychological distress (Bell & D’Zurilla, 2009; Chang, et al., 2009; Chang, Sanna, Riley, et al., 2007). Overall, the available literature on the effect of problem-solving ability, and problem orientation in particular, on stress and other psychological factors provide a rationale for the use of problem-solving therapy as a means to reduce stress among parents of children with cancer. This literature also suggests that it is especially important to promote a positive problem orientation in parents, as it appears to have the strongest relationship with stress and other psychological factors.

**Problem-solving among caregivers** Problem-solving among caregivers has been studied. As in previous research of the general population, positive problem orientation is associated with better adjustment in the caregiving role (Elliott & Shewchuk, 2003). Elliott and Shewchuk found that caregivers with a positive problem orientation have lower levels of depression and anxiety and better health than those with a negative problem orientation. In addition, those who perceive themselves as competent problem solvers report less distress associated with the caregiving role (Noojin & Wallender, 1997). However among family caregivers, a negative problem orientation has been found to be associated with fatigue, negative mood, and isolation (Elliott & Shewchuk, 2003).

**Problem-solving among parents of pediatric cancer patients.** Research has routinely found negative problem orientation to be associated with psychological distress (Bell & D’Zurilla, 2009; Chang, et al., 2009; Kant, et al., 1997), and this link has also been found among mothers of children with cancer. For example, research has found that a mother’s problem-solving orientation and style is related to her anxiety and depression symptomatology (Nelson, Gleaves, & Nuss, 2003) while children are undergoing stem cell transplant. Nelson and

colleagues further explain that a mother's negative problem-solving orientation may influence stress responses. Conversely, a parent's use of an active approach to problem-solving is associated with lower levels of distress. This tendency suggests that parents who use active problem-solving feel more in control, and therefore less distressed (Norberg, Lindblad, & Boman, 2005). A parent's problem-solving ability during the early phases of treatment has been found to predict distress levels in the peri-diagnostic phase and their rates of improvement over time (Dolgin, Phipps, & Fairclough, 2005).

Parents of children with cancer have consistently been found to experience PTSS, and there is some evidence to explain the role of problem-solving in the maintenance of PTSD (Sutherland & Bryant, 2008). Sutherland and Bryant found that individuals with PTSD take a less active approach to problem-solving. They further explain that the problem-solving ability in those with PTSD is impaired because they are impacted by memories of a traumatic event during the problem-solving process. Although there is no evidence to date that explains how PTSS impair problem-solving abilities or styles in parents of children with cancer, it is possible that parents have difficulty solving problems associated with their children's medical treatment because they are reminded of the traumatic nature of the diagnosis when attempting to solve these problems.

**Problem-Solving Therapy** Problem-Solving Therapy (PST) is a cognitive-behavioral skills training approach in which individuals are taught to use a set of steps to solve complex or distressing problems (Nezu, 2004). PST is skill-based and action-focused. It helps individuals to take concrete steps to solve problems that are distressing. The ultimate goal of PST is to improve coping ability, and thereby decrease stress and improve quality of life (Nezu, Nezu, Friedman, et al., 1998, p.3).

PST is comprised of five cognitively- and behaviorally-focused steps. Houts, Nezu, Nezu, and Bucher (1996) applied these five steps to PST for family caregivers of cancer patients. The first step is *problem-orientation*. This step refers to an individual's approach to viewing problems. It encourages a positive and optimistic outlook to problem-solving. Caregivers of cancer patients are encouraged to approach problems with optimism and hope, and to communicate this approach to the patient. In the second step, *problem definition and formulation*, the individual gathers all necessary facts related to the problem, interprets the problem in clear and unambiguous terms, and sets realistic problem-solving goals. As a part of this step, caregivers of cancer patients are encouraged to consult regularly with healthcare providers for information and guidance on problems that arise. The third step is *generation of alternatives*, whereby the individual brainstorms as many possible solutions to the problem in order to maximize successful outcomes. Again, caregivers are encouraged to consult with health care professionals. It is important for caregivers to devise only alternatives that do not interfere with health care professionals' instructions. In the fourth step, *decision making*, the caregiver conducts a cost-benefits analysis of each alternative, and carefully chooses the alternative that maximizes benefits while minimizing negative consequences. With problems that are exclusively medically-based, the caregiver is encouraged to defer to medical expertise. However, for other problems associated with cancer caregiving, caregivers are taught to use the cost-benefits analysis to arrive at the best solution for both the patient and themselves. In the final step, *solution implementation and verification*, the individual carries out the chosen plan and evaluates the results. Depending on the outcome of the plan, the individual either self-reinforces success, or determines why the plan was not successful, and returns to the decision-making process. At this step, health care providers need to give caregivers the necessary information to determine if



their problem-solving methods are effective and how quickly they can see results. Often in cancer treatment, progress is slow, and even successful problem-solving strategies may not show immediate results. Health care providers need to share with caregivers what types of indicators are signs of progress toward long-term goals.

**Problem-solving therapy for caregivers.** Much of the research on problem-solving skills training has been conducted with caregivers of adult cancer patients. For example, in a multi-faceted, six-session intervention program (Toseland, Blanchard, & McCallion, 1995), caregivers (primarily spouses) of adult cancer patients completed an intervention with problem-solving, support, and coping components. This intervention was not found to be effective for improving psychological distress or coping skills. However, results of the Toseland study likely have little impact on the potential for the current study for two reasons. First, they examined different outcomes than will be investigated in the current study. Second, their participants had low levels of initial distress, thus making it difficult to find significant changes as a result of intervention.

Several studies have been conducted on problem-solving interventions for caregivers of patients with acquired disabilities. In a problem-solving intervention for caregivers of individuals with spinal cord injuries (Elliott & Berry, 2009) caregivers received one session of problem-solving training and eight follow-up phone sessions. This intervention had an impact on problem-solving style, with fewer participants solving problems with an impulsive or avoidant style. In a similar study of caregivers of patients with traumatic brain injury (Rivera, Elliott, Berry, & Grant, 2008), caregivers had four individual problem-solving intervention sessions and eight follow-up phone sessions. A decrease in dysfunctional problem-solving style (impulsive or avoidant) depression, and health complaints was observed in these caregivers. This intervention

format also has shown improvements in constructive problem-solving style and decreases in depression among caregivers of women with disabilities (Elliott, Berry, & Grant, 2009).

Research on caregivers of adult patients has shown some promise for the effectiveness of one-session problem-solving interventions. Cameron, Shin, Williams and colleagues (2004) found that as a result of a one-session (60 minute) intervention focused on problem-solving skills, caregivers experienced a decrease in emotional tension. In another study of a one-session (90 minute) problem-solving intervention, caregivers reported significantly improved problem-solving ability (Bucher, Loscalzo, Zabora, et al., 2001). The literature on problem-solving interventions for caregivers of adult patients may likely be able to inform the current intervention, which aims to develop a brief intervention for caregivers of pediatric cancer patients.

**Problem solving therapy for parents.** There are a limited number of studies on the effects of PST-based interventions for parents. Two studies have examined the use of PST to help parents address child behavior problems. Kazdin and Whitley (2003) found that parents who took part in a five-session intervention demonstrated decreased parenting stress. In a study of parents of children with traumatic brain injuries, parents reported significant changes in family coping and child adjustment (Wade, Michaud, & Brown, 2006).

***Problem-solving therapy for caregivers of pediatric cancer patients.*** To date, PST has only been applied to caregivers of pediatric newly diagnosed cancer patients who are in the initial treatment phase. So far, none have evaluated PST for caregivers during the months (or years) of active treatment. Two studies have utilized problem-solving therapy approaches during the initial treatment phase. Sahler, Varni, Fairclough, and colleagues (2002) developed an eight-session program for mothers of children to begin two to 16 weeks post-diagnosis. Their

intervention was a variation of problem-solving therapy that focused on problem-solving skills specifically. They found that, compared to mothers who received the standard of care control condition, mothers who received the problem-solving intervention had significantly less distress up to three months after completing the intervention. Quite relevant to the current study, the authors hypothesized that the decrease in distress may be reflective of decreases in posttraumatic stress symptoms. In a larger study by the same group of authors, Sahler and colleagues (2005) found that the problem-solving skills training contributed to an improvement in problem-solving ability, and decreases in mood, depression, and the impact of the diagnosis. Although Sahler and colleagues have examined their PST intervention only in parents of newly diagnosed children, they indicate that the PST techniques can be applicable to parents whose children are at any stage of treatment (Sahler et al., 2005).

Overall, there are a limited number of studies examining the effectiveness of PST for caregivers, particularly for caregivers of pediatric cancer patients. In addition, there has been no comparison of treatment efficacy in terms of dosage level (i.e., number of sessions). Moreover, implementing a long-term intervention program (e.g., Sahler et al., 2002; Sahler et al., 2005), may not be feasible at all pediatric treatment settings, particularly small settings with limited psychosocial support staff. That is, there is currently no clear picture as to what number of sessions and PST application will be most widely disseminative. Therefore, the current study aims to develop a shorter intervention that will ideally be more manageable for health care providers to administer and for parents to receive.

### **Development of the PST Adaptation for the Current Study**

**Psychosocial Interventions for parents of children with cancer.** Other types of interventions have been developed in recent years to address the issues parents face during this

critical time period. Intervention topics vary widely, but include expression of emotion interventions, cognitive-behavioral techniques, family issues during treatment (Hoekstra-Weebers, Heuvel, Jaspers, et al., 1998), coping skills (Hoekstra-Weebers, et al., 1998; Sahler, Fairclough, Phipps, et al., 2005), education, relaxation techniques, and communication training (Streisand, Rodrigue, Houck, et al., 2000). The number of intervention sessions also varies, from one (Streisand, et al., 2000) to eight (Hoekstra-Weebers, et al., 1998; Sahler, et al., 2005). Some studies strictly follow an intervention manual, while others tailor the intervention to a parent's needs. Sahler and colleagues (2005) adapted their intervention to mothers' specific needs and concerns, and found that their intervention improved overall problem-solving skills, avoidance style, mood, and the impact of diagnosis over the course of the intervention. Hoekstra-Weebers and colleagues (1998) reported no effect of their intervention. They indicate that their lack of effects may be attributed to their failure to address the specific needs of parents, and their intervention did not adapt to meet parents' changing needs. Streisand and colleagues (2000) utilized a one-session model for parents of children preparing for a bone marrow transplant (BMT). While their intervention yielded no significant effects, parents who completed the intervention did utilize the intervention techniques in the weeks both before and after the BMT. Because research designs vary widely, the effects of interventions on psychosocial outcomes are mixed.

**Calls for interventions.** Effective intervention at any point in the treatment trajectory can potentially contribute to decreases in stress and increases in adaptive functioning. Moreover, despite the fact that most families do cope well with their child's cancer diagnosis eventually, all families should receive some form of psychosocial care (Kazak, Cant, Jensen et al., 2003) because distress is normative in this population. Kazak, Rourke, Alderfer and colleagues (2007)

explain that psychosocial interventions should be provided to all families. They propose a “blueprint” for interventions based on both their Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006) and the Pediatric Medical Traumatic Stress Model (PMTSM; Kazak, Kassam-Adams et al., 2006). The PPPHM outlines three family populations based on the level of psychosocial support needed. The PPPHM was developed using the Psychosocial Assessment Tool (PAT2.0; Pai, Patiño-Fernandez, McSherry, et al., 2008), a measure that was also used in the current study. The *Universal* group encompasses the largest proportion, and requires general information and support. The *Targeted* group includes individuals (patients and family members) who are in acute distress and have psychosocial risk factors present. The smallest group, the *Clinical/Treatment* group has high levels of distress and high risk factors.

The PMTSM outlines three stages of PTSS response. The *peri-trauma* phase refers to the immediate time surrounding potentially traumatic events (PTE) related to the child’s medical care. The “*During Treatment*” phase occurs as the child endures treatment, and both the child and parent are exposed continually to PTEs. The final phase, “*long-term sequela*,” refers to families of a child who is no longer on treatment, but may still experience PTSS. Because research suggests that all parents, regardless of psychosocial risk or time point in the child’s treatment trajectory experience some level of PTSS (Kazak et al., 2005; Norberg, & Boman, 2008; Pelcovitz et al., 1996; Rabineau et al., 2008), Kazak and colleagues (2007) emphasize that psychosocial intervention should be available and disseminated to parents across all levels of psychosocial risk and treatment trajectory. Furthermore, Kazak and colleagues emphasize that, relevant to the current study, interventions must be cost-effective and readily disseminated. Therefore, it is necessary for researchers to develop feasible and brief interventions for parents, even those who experience sub-clinical levels of distress (Vrijmoet-Wiersma, van Klink, Kolk, et

al., 2008). It is proposed here that providing parents with skills to solve problems in a brief and focused format will reduce stress and ultimately lead to better long-term outcomes.

Research suggests that parents of children with cancer are receptive to brief mental health interventions that are presented in a systematic manner (Ljungman, McGrath, Cooper, et al., 2003). Parents do not generally pursue mental health treatment independently, but rather are identified by medical staff at the pediatric oncology centers (Rabineau, Mabe, & Vega, 2008). However, parents do perceive that they have greater needs for intervention than are currently provided (Ljungman et al., 2003). For these reasons, it is the duty of staff treating children with cancer to reach out to parents and to invite them to participate in intervention (Stoppelbein & Greening, 2007), as early intervention may prevent psychological complications as treatment progresses (Kazak, Boeving, Alderfer, et al., 2005). Specifically those at the highest risk for distress, such as parents with a child undergoing intense medical intervention, should be targeted for psychosocial intervention (Kazak, Boeving, Alderfer, et al., 2005).

Several literature reviews have made recommendations for future interventions. Pai, Drotar, Zebracki and colleagues (2006) suggest that future interventions need to be theory-driven. Specifically, outcomes, measures, and intervention techniques should be closely tied to theoretical models that can be tested. Based on a review of interventions for caregivers of adult patients, Harding and Higginson (2003) also encourage future interventions to be theory-based. In addition, they make the following suggestions: 1) to specifically target the needs of caregivers; 2) to address issues of feasibility and acceptability of interventions among caregivers; 3) have straightforward and non-complex aims; and 4) evaluate outcomes with rigorous methodological techniques (e.g., pre-post and experimental designs). The current study employs all of Harding and Higginson's suggestions.

The current intervention utilizes the principles of Problem-Solving Theory, because it closely follows the steps of Problem-Solving Therapy (Nezu et al., 1998). In addition, the targeted population is based on Kazak and colleagues' (2007) "blueprint" for parent psychosocial interventions which suggests that all parents, regardless of psychosocial risk or stage in treatment trajectory, should receive psychosocial intervention.

**The current study** The current study examined the effects of a problem-solving intervention for parents of children on treatment for cancer. This intervention is brief in order to minimize burden on parents, enhance participation rates, and be feasible for providers to administer. The current study had three primary aims: 1) To gain information on psychosocial functioning of parents of children on treatment for cancer; 2) to examine the effectiveness of a short, problem-solving intervention for parents that can be utilized during the cancer treatment process; 3) to examine the effects of this intervention on caregiving stress, posttraumatic stress symptoms, and problem-solving ability.

Parents received the Parent Empowerment Intervention or two support sessions (control). Parents who received the Parent Empowerment Intervention received one session of problem solving intervention and a follow-up session. Parents in the control condition received two general support sessions in which an interventionist provided information on how parents can help their children (patients) and other family members cope with the diagnosis and treatment. In the first session, parents were provided with materials from the Traumatic Stress Toolkit (Kassan-Adams, Schneider, & Kazak, 2009) designed to help their children cope with their illness and with hospitalization. The second control session reviewed these strategies.

It was hypothesized that parents of children who received the Parent Empowerment Intervention sessions would show decreases in caregiving stress and posttraumatic stress

symptoms; and increases in problem-solving ability between baseline and post-test assessments. Also, it was hypothesized that, compared to parents who received only the support sessions (i.e., control), parents who received the intervention would have lower scores on a measure of stress and a measure of the impact of the diagnosis; and higher scores on a measure of problem-solving skills.

## **Method**

**Participants** Parents (or other primary caregivers) of children on active cancer treatment at the Children’s Hospital of Richmond were eligible for the study. While any identified primary caregivers were recruited, all enrolled individuals were parents (hereafter referred to as “participants”). Participants were recruited no earlier than four weeks post-diagnosis. Sahler and colleagues (2005) report that caregivers are likely to be too overwhelmed to participate in an intervention that does not directly relate to their child’s medical care prior to four weeks post-diagnosis. Approximately 80 new cases of pediatric cancer are diagnosed each year at the Children’s Hospital of Richmond. Target participation was 34 participants, with 17 participants in each treatment condition (see power calculations). All primary caregivers of a child on active treatment for cancer were eligible for participation. However, some exclusion criteria were applied. First, caregivers had to be fluent in both spoken and written English. Second, any caregiver of a child in palliative or hospice care was not eligible for participation.

Eighty-one participants were recruited, and 48 consented. Parents who did not consent were not asked to provide a rationale for refusal. Of these 48 consented participants, 39 completed at least the initial questionnaires. The 9 participants who consented but did not complete the initial questionnaires (or any study activities) lost interest after consenting and withdrew (two had a spouse participate). These 39 participants came from 36 separate families



(three families had two parents participate). Thirty-three recruited participants did not consent. Twenty-seven parents asked to consider participation, and indicated that they would contact the researcher if interested. However, none of these 27 parents asked to be included in the study. Finally, six parents who were recruited declined participation immediately due to lack of interest.

Six participants withdrew from the study after completing baseline questionnaires for the following reasons: one participant discontinued care giving for the child with cancer, two participants had children pass away during the study duration, one participant's child was transferred to another medical facility for care, one participant had acute mental health needs of his own that prevented the completion of study activities and was referred to psychiatric services, and one participant was not available to meet for treatment sessions due to her employment schedule. The final total number of participants was 39.

The majority of the sample was either married or partnered (59%), while 18% were single (never married), and 23% were separated or divorced. Participants were on average 36.5 years of age ( $SD = 6.5$  years). The majority of the sample was Caucasian (55.6%), but there was a good representation of African Americans (25%), Latinos (5.6%), and Asian Americans (11%). One participant (2.8%) identified his/her race as "other." The majority of participants completed at least some college or vocational school (43.6%). Twenty-three percent of participants graduated from college or vocational school, 5% completed some professional or graduate school, while 18% completed professional or graduate school. A smaller proportion of participants did not complete high school (2.6%) or completed only high school/GED (5%). Finally, income for the sample varied widely. The yearly family income (before taxes) for 42.1% of the sample was \$75,000 or more. However, 23% of the sample reported a yearly family income of less than \$20,000. Income for the remainder of the sample was as follows: \$20,000-

\$30,000 = 8%; \$30,000-\$40,000 = 10.5%; \$40,000-\$50,000 = 2.6%; \$50,000-\$60,000 = 5.3%; and \$60,000 - \$75,000 = 8%.

The children of the participants (patients) ranged in age from two years to 16 years ( $M = 7.7$  years;  $SD = 4.9$  years). Time since diagnosis varied widely (5 to 115 weeks). Table 1 below compares data on times since diagnosis and diagnoses for children of parents who participated, those who consented then dropped out, and those who did not consent. A one-way analysis of variance revealed no differences in time since diagnosis ( $F [2, 69] = 1.58, p = .21$ ) among parents who participated in the study, as compared to those who consented and dropped out or those who did not consent. Overall, parents who did consent and participated in the study had children who were relatively similar to those who did not consent or who consented and then dropped out.

*Table 1.*

*Time since diagnosis and types of diagnosis*

	Participants (N = 39)	Consented, then dropped out (N = 9)	Did not consent (N=33)
Weeks since dx ( <i>M</i> ; <i>SD</i> ; <i>median</i> )	36.0; 30.5; 25	22.9; 9.5; 24	25.25; 26.6; 14*
Diagnoses (%)			
Leukemias (ALL, AML)	61.5	33.3	39.4
Lymphomas	5.1	11.1	24.2
Sarcomas	7.7	0	6.1
Neuroblastoma	7.7	22.2	12.1
Rhabdomyosarcoma	10.3	11.1	3.0
Central Nervous System Tumors	7.7	22.2	9.1
Solid Tumors	0	0	6.1

\* Data on time since diagnosis was available for only 24 children of parents who did not consent.

**Procedure** Parents were approached by a research staff member during an inpatient hospitalization or at an outpatient medical visit (see Appendix A). The study was presented as

*The Parent Empowerment Program.* Specifically, potential participants were informed that many caregivers feel stressed during the treatment phases and that meeting with a support staff member and discussing their challenges may be beneficial. Potential participants were informed that there are two different formats to the Parent Empowerment Program and that they would be randomly assigned to one of the two formats. They were informed that they would meet with a support provider and either be given the chance to discuss ways to help their child and family cope with the cancer diagnosis and the child's hospitalization (control), or talk about strategies to solve problems associated with treatment (intervention). All potential participants were informed that they would be required to fill out questionnaires prior to the intervention (baseline) and at 1-month and 3-months after the intervention.

Prior to the first intervention or control session, participants completed the psychosocial risk/demographics measure (PAT2.0), the Impact of Events Scale, Revised (IES-R), the Pediatric Inventory for Parents (PIP), and the Social-Problem-solving Inventory-Revised version (SPSI-R). Participants in both conditions completed the first session as soon as possible after completion of the baseline data ( $M = 19.9$  days,  $SD = 28.8$  days), and the second session within two to four weeks after the first session ( $M = 33.6$  days,  $SD = 26.7$  days). As close to one month ( $M = 25.0$  days,  $SD = 18.6$  days), and three months ( $M = 81.6$  days,  $SD = 51.5$  days), after the second session as possible, participants completed the IES-R, the PIP, the SPSI-R, and the recall form (see below).

**Parent self-report measures.** Participants completed the following measures.

**Demographics.** The Psychosocial Assessment Tool (PAT2.0; Pai, Patiño-Fernandez, McSherry, et al., 2008; see Appendix B) was used to gather information about family psychosocial characteristics. The PAT2.0 is a 15-item screening tool for psychosocial risk

developed for use with families of children with cancer. It assesses broad demographic information, as well as family functioning, child behavior symptoms, parent anxiety, and acute stress. The PAT2.0 has been found to have strong internal consistency and validity (Pai et al., 2008). It was standardized on parents of children with cancer within two weeks of diagnosis. An item asking parents to report their yearly income was added to the PAT2.0.

***History of traumatic events.*** The Life Events Checklist (LEC; Gray, Litz, Hsu, & Lombardo, 2004) is a 17-item measure of potentially traumatic events (see Appendix C). For each potentially traumatic event, respondents indicate if the event happened to them personally, if they witnessed the event, if they learned about the event happening to someone close to them, if they are not sure the event happened to them, or if the event did not occur for them. The LEC has good inter-item correlation ( $\alpha > .60$ ) and test-retest reliability ( $r = .82$ ). The LEC was standardized on university college students as well as combat veterans.

***Posttraumatic Stress Symptoms.*** The Impact of Events Scale (IES-R; Weiss & Marmar, 1997) is a 22-item self-report measure (see Appendix D). Its three subscales: Intrusion, Avoidance, and Hyperarousal, assess symptoms associated with trauma experience. The IES-R is scored in two steps. First, the subscales are computed by averaging the items that load onto each subscale. Then, the total score is computed by summing the averages of the three subscales. Weiss and Marmar found the IES-R subscales to have good internal consistency (Intrusion:  $\alpha = .87$ , Avoidance:  $\alpha = .86$ , Hyperarousal:  $\alpha = .79$ ). The IES-R has also been found to have excellent internal consistency in studies of the traumatic stress in parents associated with a child's cancer diagnosis ( $\alpha = 0.93$ ; Norberg, & Boman, 2008).

***Caregiving Stress.*** The Pediatric Inventory for Parents (PIP; Streisand, Branietcki, Tercyak, & Kazak, 2001) is a 42-item measure of the parenting stress caused by events

associated with the care of a chronically ill child (see Appendix E). It assesses four sources of parenting stress: Communication, Medical Care, Emotional Distress, and Role Functioning. Parents rate the frequency (PIP-F) in which they experience each event on a five-point scale from 1 = never to 5 = very often. They also rate the difficulty (PIP-D) of their experience with each event on a five-point scale from 1 = not at all to 5 = extremely. Both domains of the PIP have strong internal consistency: PIP-F = .95, PIP-D = .96; and the subscales all have acceptable internal consistency ( $>.80$ ; Streisand et al., 2001). The PIP was standardized on parents of children who were both on active treatment as well as off active treatment.

***Problem-solving.*** The Social-Problem-solving Inventory, Revised (SPSI-R; D'Zurilla & Nezu, 1990) was used to measure change in problem-solving abilities over time (the SPSI-R is a copyrighted measure and not included in the appendices). The SPSI-R is a 52-item measure of problem-solving ability. It has five scales: Positive Problem Orientation (PPO), Negative Problem Orientation (NPO), Rational Problem-Solving (RPS), Impulsivity/Carelessness Style (ICS), and Avoidance Style (AS). The RPS has four subscales: Problem Definition and Formulation (PDF), Generation of Alternative Solutions (GAS), Decision Making (DM) and Solution Implementation and Verification (SIV). The SPSI-R has good test-retest reliability and internal consistency (D'Zurilla & Nezu, 1990).

***Recall form.*** At post-testing only (1 month and 3 months post-intervention), participants were asked how often they used information discussed during the treatment session, how helpful they found the information, and the effect they believe that the treatment session had on their distress level. Participants were also asked about their satisfaction with the treatment, and were invited to provide feedback (see Appendix F).

***Chart review measures.*** The following measures were completed by the research staff via review of the children's medical charts.

***Medical chart review.*** A review of medical charts was completed in order to ascertain information on the child's age, diagnosis, treatment modalities (e.g., chemotherapy, radiation, surgery, bone marrow transplant), and treatment duration (see Appendix G).

***Additional utilization of services.*** The Division of Pediatric Hematology/Oncology at the Children's Hospital of Richmond also provides regular support services (e.g., psychological, social work, chaplain/spiritual, and child life) to parents. Participants in the current study often received additional services during the time between intervention and follow-up data collection. However, additional contact with a support provider during this time period may have introduced bias, and would essentially constitute additional intervention. To help control for this bias, the researcher recorded the number of additional visits with support staff during the time between baseline questionnaire completion and the 3-month follow-up (see Appendix H).

***Treatment fidelity.*** To ensure that the intervention was delivered in a systematic and consistent fashion to all participants, efforts were made to promote treatment fidelity. All intervention sessions were audio-recorded and coded for consistency across sessions. Undergraduate research assistants reviewed the audiotapes of the intervention sessions and verified that critical topics were covered (see Appendix I). Because all ratings were performed on a dichotomous scale (i.e., yes vs. no for the presence of each point), the most efficient way to reach sufficient reliability was to have a third rater rate the audiotapes to clear up the discrepancy. Each item with a discrepancy was examined by hand, and the third rater's ranking was used as a tie breaker. Because all items in the treatment fidelity for both conditions had

dichotomous rating options, the third rater's codes were sufficient for a tie breaker. In further analyses, the inconsistent rating of the three raters was dropped.

**Design** A mixed-model multivariate experimental design was implemented to examine the effect of the problem-solving intervention on posttraumatic stress symptoms, caregiving stress, and problem-solving ability. The intervention is the between-subjects variable (problem-solving intervention vs. control), and time is the within-subjects variable (baseline vs. 1-month vs. 3-months). All participants were assessed at baseline ( $T_1$ ). Next, participants in the intervention condition received two problem-solving sessions, and participants in the control session received two support sessions. All participants were then re-assessed twice; 1 month after the end of the intervention ( $T_2$ ) and 3 months after the end of the intervention ( $T_3$ ). Figure 2 provides a graphical representation of the study design. Participants were compensated with a \$15 store gift card for completing the 1-month follow-up questionnaires, and a \$10 store gift card for completing the 3-month follow-up questionnaires.

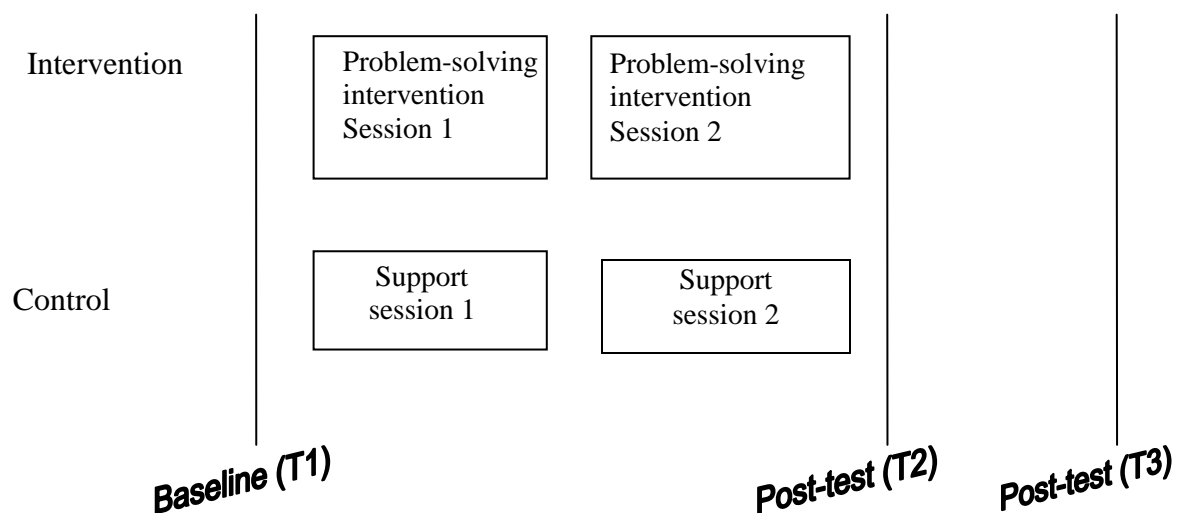


Figure 2 *Study design*

**Staffing** The researcher (JL) administered both the intervention and control conditions. A manual was utilized for both sessions of the intervention condition. The researcher was supervised by a licensed clinical psychologist.

**Randomization** Participants were randomized to either the intervention or control condition after completing baseline questionnaires. Randomization was conducted according to the randomization plan outlined in Appendix J. An online random number generator (Haahr, 2010) was used to assign participants to treatment condition. First, a chart was created that listed participant identification numbers from 1 to 50. Next, the random number generator was programmed to randomly select 25 numbers between 1 and 50. The numbers generated by the random number generator were the participant identification numbers assigned to the intervention condition. The other 25 participants' identification numbers were assigned to the control condition. Participants were assigned to treatment condition after they were consented and completed the baseline measures. For example, the first parent to consent for participation complete the baseline measures was assigned identification number "01."

**Intervention** The intervention format followed a manual designed specifically for the current project (see Appendix K). It is based on a problem-solving approach originally designed for caregivers of adult patients (Nezu, Nezu, Friedman, et al., 1998). The intervention consisted of two sessions. The first session included a manualized intervention approximately 60 minutes in length. The length of intervention session one ranged from 35.5 minutes to 95.5 minutes, but the mean length (68.5 minutes, SD = 16.2 minutes) was close to the goal time of 60 minutes. This session taught parents the five problem-solving steps. The steps were taught the skills in the context of a difficult problem the participants had at the time of participation. Each participant was also provided with a workbook (see Appendix L) of worksheets with information on each



problem-solving step as well as a worksheet that helped them apply each step to a specific problem. Also, participants were provided with a small index card with the five problem-solving steps that could be used as a quick reminder of the steps (Appendix M).

A second, follow-up session was conducted approximately two to four weeks after the completion of the first session, at a time that was convenient for the participant. During the follow-up session, the interventionist reviewed the problem-solving steps discussed in the first session. In addition, the interventionist discussed the participant's current problem-solving progress, and discussed any difficulties participants had in implementing the problem-solving approach. Appendix N outlines the topics discussed in the follow-up session. The target time for session two was 30 minutes. Intervention session two ranged in length from 8 minutes to 33.5 minutes, and the mean length (18.1 minutes,  $SD = 6.9$  minutes) was somewhat shorter than the goal time of 30 minutes. Over the course of the study, the interventionist gained experience in delivering the intervention, and thus later sessions tended to be shorter. Also, all sessions were audio recorded and checked for content. Shorter sessions were no more likely than longer sessions to have missed intervention points.

**Control** An attention control condition was implemented as a comparison condition. Participants in the control condition also received two sessions of treatment. Pai and colleagues (2006) suggest that this type of control condition is preferable over the commonly used wait-list control or standard of care conditions. They explain that, by having an attention control condition, the results of an intervention study can be more directly accounted for by the treatment, rather than by simple interaction with a therapist.

In the control condition, participants also met for two sessions with the interventionist. These sessions utilized literature from the Center for Pediatric Traumatic Stress (Kassam-Adams,

Schneider, & Kazak, 2009) on coping with illness and hospitalization (see Appendix P). The interventionist reviewed this literature with participants and helped them to apply the information to their family. Participants were provided literature focused on helping the child (Appendix P.1 - child aged 12 or under; Appendix P.2 - child age 13 to 18) or the family (Appendix P.3) adjust to the cancer diagnosis. Finally, they were provided with information to help their child adjust to life at home after a hospitalization (Appendix P.4). The length of control session one ranged from 12.5 minutes to 69.5 minutes ( $M = 37.8$ ,  $SD = 19.3$ ). Session two among the control condition ranged from 6.5 minutes to 51.0 minutes ( $M = 21.0$ ,  $SD = 13.0$ ). While the goal was to make these sessions similar lengths to the intervention sessions (session 1 = 60 minutes; session 2 = 30 minutes), the lack of a standard treatment manual made a specific time frame difficult.

## **Results**

**Power Analysis** A power analysis was conducted prior to data collection to determine appropriate sample size. According to Cohen (1988), the power to detect a significant effect of the problem-solving intervention ( $IV_1$ ) over a 3-month time period ( $IV_2$ ) on caregiving stress, posttraumatic stress symptoms, and problem-solving ability (DVs) depends on a number of parameters. These parameters include:

1. Sample size ( $N$ )
2. The proportion of variance in the outcome measures (DVs) accounted for by type of treatment (IVs) ( $R^2_{XY}$ )
3. The number of independent variables ( $k_x = 3$  [ $k_{x1}$ : intervention;  $k_{x2}$ : time])
4. The total number of levels of each independent variable ( $k_A = 11$  [ $k_{A1}$ : treatment vs. control;  $k_{A2}$ : pre-test vs. 1-month follow-up vs. 3-month follow-up])

5. The number of dependent variables ( $k_y = 3$ )
6. Estimate of population standard deviation ( $\sigma = 2.6$ )
7. The effect size index ( $f^2 = 0.3$  for large effect size)
8. The non-centrality parameter ( $\lambda = 1 - R^2_{XY}$ )
9. The numerator degrees of freedom ( $u = k_x k_y$ )
10. The denominator degrees of freedom ( $v = [\lambda / f^2] - u - 1$ ) ( $v = 15.5/0.3 - 9 - 1 = 41.67$ )

The non-centrality parameter ( $\lambda$ ) is derived from values of the significance level ( $\alpha = 0.05$ ), numerator degrees of freedom, and the desired power level (0.8). Therefore,  $\lambda$  is the value that takes into account the desired power level and significance level. According to Cohen (1988), given these above parameters, the sample size (N) required to achieve a power level of 0.8 can be solved with the following equation:

$$N = \frac{1}{\sigma^2} (v + \frac{u}{2} - 1) + \frac{(k_y + k_x + 3)}{2} + \max(k_C, k_A + k_G) = N = \frac{1}{\sigma^2} (41.67 + \frac{9}{2} - 1) + \frac{(3 + 3 + 3)}{2} + \max(0, 11)$$

$$N = 32.87$$

According to Cohen (1988, p.471),  $k_C$  refers to further sublevels of each DV, and  $k_G$  refers to covariates. Because each DV only has one level, and there are no covariates considered in this a priori analysis, both  $k_C$  and  $k_G$  are set at 0. Therefore, a total of 33 participants were required to achieve a power level of 0.8. Because 33 cannot be evenly randomized between the two conditions, 34 participants was the target recruitment number.

**Intent-to-treat analysis** For all outcome measures (caregiving stress, posttraumatic stress, and problem-solving ability), an intent-to-treat analysis was conducted for all participants who completed at least the baseline questionnaires. The intent-to-treat analysis is a statistical procedure commonly used in randomized clinical trials to account for missing follow-up data

(Lachin, 2000). Specifically, it reduces the type 1 error rate posed by attrition of participants. It allows for full analysis of all participants, regardless of whether or not they complete all phases of the study. In the current study, for participants who dropped out after completing the baseline questionnaires, their data was “brought forward” and also analyzed as 1-month and 3-month data. The same principle was used for participants who completed the 1-month follow-up but not the 3-month follow-up. Also, there were a few participants whose 1-month data collection was so delayed that their 1-month questionnaire packet had to be considered the 3-month follow-up. In these cases, the baseline data was “brought forward” as the 1-month data. Chi square analyses were conducted to determine if there is a relationship between treatment condition and attrition. There was no relationship between treatment condition and attrition,  $\chi^2(1) = .037, p = .847$ . That is, those in the control condition were no more likely than those in the intervention condition to drop out of the study.

### **Descriptive analyses**

**Baseline data.** Participants completed five measures at baseline: 1) the Psychosocial Assessment Tool 2.0 (PAT2.0); 2) the Life Events Checklist (LEC); 3) the Impact of Events Scale Revised (IES-R); 4) the Pediatric Inventory for Parents (PIP); 5) and the Social Problem Solving Inventory Revised (SPSI-R).

The average psychosocial risk as measured by the PAT 2.0 for mothers in the current sample ( $M = 1.15, SD = 0.74$ ) was similar to the profile of mothers in the standardization sample ( $M = 1.11, SD = 0.81$ ; Pai et al., 2008). The psychosocial risk reported by fathers in the current sample ( $M = 1.05, SD = 0.35$ ) was higher than that found in the standardization sample by Pai and colleagues ( $M = 0.85, SD = 0.53$ ). Therefore, mothers in the current sample report that their families are at around the same psychosocial risk as found in other studies, but fathers report that

it is higher than in other studies. Pai and colleagues report that a PAT2.0 score of 1.0 or higher suggests that a family may require increased psychosocial support. In the current sample, 51% of participants had a score of above 1.0, suggesting that there is a strong need for psychosocial support.

History of potentially traumatic life events was assessed by the Life Events Checklist. Of 17 potentially traumatic life events listed on the checklist, participants reported experiencing a small number of events (mothers:  $M = 2.35$ ,  $SD = 2.19$ ; fathers:  $M = 3.2$ ,  $SD = 3.11$ ).

**Repeated measures data** Participants completed the Impact of Events Scale – Revised (IES-R) at baseline, 1-month follow-up and at 3-month follow-up. At baseline, participants reported relatively low posttraumatic stress symptoms related to their child’s diagnosis compared to posttraumatic stress of parents in other studies as measured by the IES-R. Mothers in the current study reported an average of 3.53 ( $SD = 2.59$ ) at baseline, 3.13 ( $SD = 2.54$ ) at 1-month follow-up, and 3.20 ( $SD = 2.29$ ) at 3-month follow-up. Fathers in the current study reported an average of 4.88 ( $SD = 2.24$ ) at baseline, 3.20 ( $SD = 3.15$ ) at 1-month follow-up, and 3.18 ( $SD = 3.08$ ) at 3-month follow-up.

Weiss and Marmar (1997) suggest that the total score of the IES-R should be the sum of the three subscales. Each subscale is the average of the item scores that load onto each subscale. In the current study, IES-R scores are calculated in this manner. However, other studies of parents of children with cancer appear to use the sum of each individual item. For the purposes of comparison, the total items sums for the IES-R in the current study are listed here. Mothers in the current study reported an average of 25.71 ( $SD = 19.27$ ) at baseline, 22.44 ( $SD = 19.01$ ) at 1-month follow-up, and 22.71 ( $SD = 17.02$ ) at 3-month follow-up. Fathers in the current study reported an average of 36.00 ( $SD = 16.16$ ) at baseline, 23.67 ( $SD = 20.55$ ) at 1-month follow-up,

and 23.67 ( $SD = 20.00$ ) at 3-month follow-up. These findings are much lower than Kazak and colleagues (2005) found in parents of children at various stages of treatment (mothers:  $M = 43.6$ ,  $SD = 14.0$ ; fathers:  $M = 32.6$ ,  $SD = 21.5$ ), suggesting that participants in the current study had less severe posttraumatic stress symptoms than in the Kazak and colleagues study. Calculations based on Weiss and Marmar's suggestions for the total IES-R sum were used for the data analyses so as not to deviate from the proper scoring method of the IES-R.

Participants completed the Pediatric Inventory for Parents, a measure of caregiving stress, at baseline, 1-month follow-up and at 3-month follow-up. At baseline, participants' reported frequency of experiencing caregiving requirements ( $M = 113.0$ ,  $SD = 26.9$ ) was somewhat higher than the standardization sample ( $M = 94.0$ ,  $SD = 33.3$ ). Frequency of caregiving requirements was also higher than the standardization sample at one-month follow up ( $M = 111.63$ ,  $SD = 30.27$ ) and three-month follow-up ( $M = 109.33$ ,  $SD = 31.56$ ). However, the difficulty that these caregiving requirements posed at baseline ( $M = 101.7$ ,  $SD = 30.1$ ) was somewhat lower than that of the standardization sample ( $M = 112.4$ ,  $SD = 35.1$ ). Difficulty of caregiving requirements continued to be less than the standardization sample at one-month follow-up ( $M = 100.5$ ,  $SD = 34.45$ ) and three-month follow-up ( $M = 96.74$ ,  $SD = 31.76$ ).

Finally, participants completed the Social Problem Solving Inventory Revised (SPSI-R) at baseline, 1-month and 3-month follow-ups. Mean total score for participants at baseline was 13.25 ( $SD = 2.8$ ). This score was similar to the average SPSI-R baseline score found by Sahler and colleagues (2005) in a similar study ( $M = 13.7$ ). Scores remained steady at one-month follow-up ( $M = 13.45$ ,  $SD = 2.84$ ) and at the three-month follow-up ( $M = 13.17$ ,  $SD = 3.05$ ). The SPSI-R is scored using scaled scores to take into account age norms. Scaled scores were used in the SPSI-R analyses.

**Parent self-reported use of strategies** At the one-month and three-month follow-up data collection time points, participants in the intervention condition were asked to indicate how often they used the PEP problem-solving materials (manual and mini strategy card) and how often they used the strategies (Five problem-solving skills) without looking at the materials. Table 2 below illustrates parent self-reported use of the intervention strategies and materials at the one-month and three-month follow-ups.

Table 2.

*Participant usage of intervention materials and skills*

Frequency of Use	One-month follow-up		Three month-follow-up	
	Material Use	Strategy Use	Material Use	Strategy Use
<b>Never</b>	20%	6.7%	17.6%	0%
<b>1-2 times per month</b>	33.3%	33.3%	47.1%	52.9%
<b>3-4 times per month</b>	20%	26.7%	11.8%	11.8%
<b>1-2 times per week</b>	13.3%	20%	11.8%	23.5%
<b>3-4 times per week</b>	6.7%	6.7%	0%	0%
<b>More than 4 times per week</b>	6.7%	6.7%	11.8%	11.8%

Analyses of variance (ANOVAs) were conducted to determine if PEP material or strategy use had an effect on the outcome variables. The Bonferroni correction was used to account for multiple comparisons. The statistical significance level ( $\alpha$ ) was set at .003. Table 3 demonstrates the results of those ANOVAs.

Table 3.

*Effect of PEP material and strategy use on the outcome variables*

Outcome variable (measure name)	Data							
	One-month material use		Three-month material use		One-month strategy use		Three-month strategy use	
	<i>F</i>	<i>p</i>	<i>F</i>	<i>p</i>	<i>F</i>	<i>p</i>	<i>F</i>	<i>P</i>
<b>Posttraumatic stress symptoms (IES-R)</b>	2.193	.092	1.391	.255	2.193	.092	.638	.699
<b>Difficulty of caregiving stress (PIP-D)</b>	2.357	.069	.837	.580	1.384	.274	1.410	.252
<b>Frequency of caregiving stress (PIP-F)</b>	1.357	.287	.293	.961	.490	.808	.476	.819
<b>Problem-Solving (SPSI-R)</b>	.664	.715	3.492	.009	.507	.795	.525	.784

Usage of PEP materials (workbook and mini strategy card) on problem-solving ability at the three-month follow-up trended toward significance. At the one month follow-up, participants in both conditions were asked feedback questions on the quality of the intervention. All questions were responded to on a five-point likert scale ranging from 1 (Strongly disagree) to 5 (Strongly Agree). Overall, participants enjoyed participating ( $M = 4.1$ ,  $SD = 1.16$ ), felt comfortable with the interventionist ( $M = 4.4$ ,  $SD = 1.17$ ), and found that the session content was relevant to their concerns ( $M = 4.16$ ,  $SD = 1.14$ ). Parents also provided written feedback on what they found most helpful and least helpful (see Tables 4 and 5 below), as well as suggestions for program improvement (see Table 6 below).



Table 4.

*Participant feedback on what they found most helpful*

<b>Intervention Participants</b>
Talking with [interventionist] about the Parent Empowerment problem solving strategies and going through all of the steps.
Talk to someone and have them explain how these steps can be used every day.
Writing down my problem and finding out my solutions while thinking of consequences.
Writing down the problems/points on paper so I could focus more on how to solve them.
The problem solving tool was most helpful for me.
Having something in writing to refer to when making decisions.
Helping to stop and write down my issues so I can look at them objectively.
I am a feeler by personality; the [Parent Empowerment] program nudged me to <u>think</u> for a solution.
How did my solution work? Evaluation of strategy gives it a chance for reproducibility.
Presentation of the problem-solving strategies as separate strategies that work together.
The tools provided were helpful to me and my husband. We actually use some of the techniques- just not the way they were constructed in the booklet.
Mapping out the problem and then finding the answer.
Helped me realize the way to approach problems/issues with my child's diagnosis. And concerns that accompany it. Would like to talk to other parents and see how they approach similar problems.
Talking out the program and brainstorming with the counselor. Just reading it would not be enough.
Learning how to deal with family members.
Speaking with [interventionist] and my husband. It was like a little therapy session and really helped me hear my husband.

<b>Control Participants</b>
It was most helpful handling discipline at home.
I enjoyed talking about my situations and having someone else's opinion.
Discussions about my child's emotions and reactions to her treatment and the effects thereof.
Honesty and being able to relate with people who have been through same circumstances.
It helped just being able to sit down and talk over some of the problems that have occurred since my child's diagnosis, and [the interventionist] went over some things that I could work on, on trying to make things better.
This questionnaire helped to pinpoint some of my uneasy feelings that I had not been able to figure out.
To actually see my issues/concerns of how I was handling my son's diagnosis on paper in black and white.
Identifying the methods.
The disciplining skills were most helpful. All of it was relevant.
Being able to clearly identify and discuss thoughts and feelings related to [child]'s diagnosis and treatment and also how the situation affects his siblings.
Being able to air some of the concern I was dealing with in making sure my child was on the right path.

Table 5.

*Participant feedback on what they found least helpful*

<b>Intervention Participants</b>
Format in which it was put in the book, felt like I was being talked down to.
I wish this was available when my child was first diagnosed.
Sometimes was not sure of the problem solving method, the right direction.
The questionnaires, my moods change somewhat and I get bogged down in slight changes

or subtleties so I find it hard to answer the questions.
How do I see the problem? A problem if conceptualized as such is a hindrance anyway, no matter how I see it.
Mini strategy card was not needed.
Too many handouts and paperwork.
<b>Control Participants</b>
I felt the need for a more private place [to conduct the session].
The questionnaire, although I realize it's used to collect data.
This process would've been more effective if we had done it closer to diagnosis instead of about halfway through [treatment].

Table 6.

*Participant suggestions for improvement*

<b>Intervention Participants</b>
Give better examples.
Maybe have a list of all the different ways other parents solved their children's problems. Can be anonymous. But it should list problems and how they solved it and it can just be handed out to other parents or posted in the clinic.
Make these strategies available to non-cancer families that have to make difficult decisions and problems that come up in treatment. It could even be helpful in parents making serious medical decisions, such as tubes for chronic ear infections, etc.
I think it is a wonderful program.
While keeping "problem" a concept applicable to several current/future hindrances. Provision of case studies likely to apply to target respondents may be effective in igniting or maintaining specific interest.
Maybe group discussions.

Control Participants
If the program can have more direct questions with yes/no answers it would alleviate the length of the questionnaires.
Summer version of the program and meet [twice per month] in Jan, March, May, Aug, Oct, Dec. Because holidays can be a difficult time to have a sick child
Focus groups and then have parent answers recorded as oppose to have parents fill out extensive forms.

**Treatment Fidelity** To ensure treatment fidelity across the intervention sessions, each session was audio recorded. Trained raters (undergraduate Psychology students) reviewed each session and checked for accuracy. Session one was divided into 23 distinct points that was checked for treatment fidelity (see Appendix I). Session two was divided into 15 distinct points (see Appendix S). Two raters reviewed each session audio recording. Among session one audio recordings, the interventionist correctly addressed all 23 points in 53% of sessions; at least 22 points in 65% of sessions; at least 21 points in 98.5% of sessions; and at least 19 points in 100% of sessions. Among session two audio recordings, the interventionist correctly addressed all 15 points in 31% of sessions; at least 14 points in 63% of sessions; at least 13 points in 88% of sessions; and at least 12 points in 100% of sessions.

The control sessions were audiotaped and reviewed as well by trained raters (undergraduate Psychology students). These raters were different individuals than the raters for the intervention sessions. Because the control sessions were unscripted, the raters were not evaluating adherence to a manual as in the intervention sessions. To ensure that the interventionist delivered the control sessions in an equally enthusiastic manner, the control sessions were reviewed for two therapeutic factors: interest and empathy (see Appendix T). The interventionist demonstrated interest in discussing concerns with the parent in 100% of session

one, and 93% of session two. The interventionist demonstrated empathy in 88% of session one, and 93% of session two.

To assess for contamination of intervention problem-solving skills into control sessions, trained raters also determined if the interventionist addressed any of the problem-solving skills. For each problem-solving skill, the percentage of times they were addressed in the control sessions is as follows: 1) Problem Orientation (Session 1: 6%; Session 2: 7%; e.g., encouraging participants to be optimistic about their ability to address the issue; helping participants to be hopeful about their ability to address the issue); 2) Problem Definition and Formulation (Session 1: 0%; Session 2: 0%); 3) Generation of alternative solutions (Session 1: 25%; Session 2: 0%; e.g., assisting parents in devising various strategies to address the issue; encouraging participants to take multiple approaches to addressing an issue); 4) Decision Making (Session 1: 12.5%; Session 2: 0%; e.g., assisting participants in making decisions about how to address issues; teaching them to weigh pros and cons of different approaches); and 5) Solution Implementation and Verification (Session 1: 12.5%; Session 2: 7%; e.g., encouraging participants to evaluate their approaches to dealing with issues). The interventionist demonstrated continuity across the two sessions and followed-up on concerns address in session one in 83% of follow-up sessions (session two).

**Inter-rater reliability** Two trained raters rated each intervention session for treatment fidelity. For session one, inter-rater reliability was good ( $\kappa = 0.73$ ), but for session two treatment fidelity was poor ( $\kappa = 0.43$ ). The reason for the large difference in inter-rater reliability between session one and session two is not clear, but may have to do with the fact that some of the raters for session one were different individuals than session two. Undergraduate research assistants were used as raters. Some of the raters who had rated session one were no longer a part of the study

team when session two audiotapes were rated. A measure of treatment fidelity was used for the control condition as well. For both sessions one and two of the control condition, raters rated whether or not the interventionist showed interest and empathy, as well as whether or not the interventionist discussed the five problem-solving skills taught in the intervention condition. Evaluation of avoidance of teaching the five problem-solving skills was done in order establish a measure of treatment contamination. Overall, inter-rater reliability for the control sessions was poor (Session one  $\kappa = 0.47$ ; Session two  $\kappa = 0.40$ ). However, the rating criteria were vague, making consensus among raters difficult. Because inter-rater reliability was generally poor, discrepancies between the two raters were identified for each point and a third rater coded sessions with discrepancies. Among the intervention sessions, 33.3% of session one audio recordings had at least one discrepancy and required a third rater, and 28.6% of session two required a third rater. Larger proportions of the control sessions had discrepancies (Session one: 58.8%; Session two: 42.9%). A third rater rated all audiotapes with discrepancies. After this process was implemented, inter-rater reliability reached  $\kappa = 1.0$ .

## **Outcome Analyses**

**Analysis of Variance (ANOVA).** The initial analyses included a series of ANOVAs was conducted without considering covariates to examine the effects of the intervention on the outcome variables. First, the effects of the intervention were analyzed for posttraumatic stress symptoms, as measured by the Impact of Events Scale, Revised (IES-R). Analyses were completed for the total scale and the significance value was set at  $\alpha=.05$ . Because there were no changes in the IES-R total score over time, the subscales were not analyzed. Overall, neither the intervention, the passage of time, nor the interaction had an impact on posttraumatic stress symptoms.

Next, the effects of the intervention were analyzed for caregiving stress symptoms, as measured by the Pediatric Inventory for Parents (PIP). Because data on the PIP falls into either the difficulty (PIP-D) or frequency (PIP-F) domain, two separate ANOVAs were conducted. The significance level was again set at  $\alpha=0.05$ . Data analyses failed to detect any significant results for the effects of the intervention, passage of time, or the interaction. Again, because no significant results were found for the overall scores, the subscales were not examined.

Finally, the effects of the intervention were analyzed for problem-solving ability, as measured by the SPSI-R. The table below illustrates the results of the ANOVA for problem-solving ability. Alpha was set at .05. No significant differences were found for condition (between subjects-effects), across time points (within-subjects effects) or for the interaction. As in previous analyses, because no significant effects were found for the overall SPSI-R, no subscales were considered. Effect sizes (partial  $\eta^2$ ) were also computed for all ANOVAs. All effect sizes were below Cohen's (1988) standard of 0.10 for a small effect size (see table 7).

Table 7.

*Results of Analyses of Variance*

Outcome variable	Between Subjects Effects				Within Subjects Effects				Interaction Effects			
	df	F	p	Partial $\eta^2$	df	F	p	Partial $\eta^2$	df	F	p	Partial $\eta^2$
Post-traumatic Stress Symptoms (IES-R)	1, 37	2.094	2, 74	.054	2, 74	.456	.636	.012	2, 74	.456	.636	.012
Frequency of Caregiving Stress (PIP-F)	1, 37	.577	2, 72	.016	2, 72	.471	.626	.013	2, 72	.471	.626	.013
Difficulty of Caregiving Stress (PIP-D)	1, 33	.717	2, 66	.021	2, 66	.541	.585	.016	2, 66	.541	.585	.016
Problem-Solving (SPSI-R)	1, 37	.237	2, 74	.006	2, 74	1.190	.310	.031	2, 74	1.19	.310	.031

**Covariates** Next, variables other than the main factors under study that might have a significant effect on the outcome variables were examined. Potentially confounding variables included participant history of traumatic life events (measured by Life Events Checklist); number of additional support sessions from psychosocial providers (Psychologist, Social Worker, Chaplain, Child life specialist); time since diagnosis; and child age. Correlations between these variables and baseline, 1-month, and 3-month data were conducted. Participant history of traumatic life events was not related to posttraumatic symptoms (measured by Impact of Events Scale-Revised; IES-R), and was therefore not considered a covariate. Also, child age was not related to the outcome variables, and was not included as a covariate. However, time since diagnosis and number of additional support sessions were related to the outcome variables, and both were considered as covariates.

Variables related to the timing of the delivery of the sessions and data collection time points were considered as well. For example, some participants did not complete data questionnaires exactly 1-month or 3-months after session two. Therefore, the time between the due date and actual collection date was considered as a covariate. In addition, participants typically could not complete the baseline data packets and participate in the first session on the same day. Therefore, the number of days between baseline data completion and session one was considered a covariate. Also, not all participants were able to complete session two exactly two weeks after session one, therefore, the number of days between session one and session two was also considered a covariate. These variables related to the timing of the delivery of the sessions and data collection time points were related to outcome variables and were used in analyses.



**Analyses of Covariance** To examine the effects of the intervention on outcomes, three separate analyses of covariance (ANCOVA) were conducted, one for each outcome variable of interest (caregiving stress, posttraumatic stress symptoms, and problem-solving ability). The ANCOVA had two independent variables, treatment (intervention vs. control) and time (baseline vs. 1-month follow-up vs. 3 month follow-up). The following covariates were included: time since diagnosis, number of additional sessions with hospital psychosocial services providers (psychologist, social worker, chaplain, child life specialist), and variability in study timing (number of days between: 1) Baseline questionnaire completion and session 1; 2) Session 1 and session 2; 3) Session 2 and 1-month follow-up; 4) Session 2 and 3-month follow-up). None of the ANCOVAs yielded significant results. Therefore, data are not examined here.

**Examination of effects of psychosocial functioning on outcomes** Another set of ANOVAs were conducted to determine if the intervention had a greater effect for participants with higher levels of psychosocial risk as measured by the PAT2.0 (Pai et al., 2008). Pai and colleagues suggest that a PAT2.0 cutoff score of 1.0 differentiates among parents of children with cancer in need of additional psychosocial support. ANOVAs were conducted to examine the additional effects of psychosocial functioning on the outcome variables. The data set was split to examine participants in “high” and “low” categories of psychosocial risk across both intervention and control conditions. No differences in outcome variables were found when psychosocial risk was considered. Therefore, the intervention has not been found to be any more effective for those with higher levels of psychosocial risk than those with lower psychosocial risk. Effect sizes (partial  $\eta^2$ ) were also computed for all ANOVAs when psychosocial risk was considered. All effect sizes here were also below Cohen’s (1988) standard of 0.10 for a small effect size. Results of the ANOVAs are summarized in Table 8 below.

Table 8.

*Effects on outcome variables with psychosocial risk (PAT2.0) included*

Outcome variable (measure name)	Degrees of freedom	PAT2.0 x condition x time interaction			PAT2.0 x time interaction		
		<i>F</i>	<i>p</i>	Partial $\eta^2$	<i>F</i>	<i>p</i>	Partial $\eta^2$
Posttraumatic Stress Symptoms (IES-R)	2, 70	1.106	.337	.031	.579	.563	.016
Frequency of Caregiving Stress (PIP-F)	2, 68	.581	.562	.017	.857	.429	.025
Difficulty of Caregiving Stress (PIP-D)	2, 62	.474	.625	.015	1.204	.307	.037
Problem-Solving (SPSI-R)	2, 70	.892	.414	.025	1.226	.300	.034

**Examination of effects based on time since diagnosis** Previous studies have found significant effects for problem-solving interventions for parents of children between four and 16 weeks post diagnosis (Sahler et al., 2002; 2005). Analyses on the outcome variables were also conducted for this subset of participants in the current study ( $N = 16$ ). Table 9 below depicts those results.

Table 9.

*Effects on outcome variables where child is between 4-16 weeks post-diagnosis*

Outcome variable	Between Subjects Effects				Within Subjects Effects				Interaction Effects			
	<i>df</i>	<i>F</i>	<i>p</i>	Partial $\eta^2$	<i>df</i>	<i>F</i>	<i>p</i>	Partial $\eta^2$	<i>df</i>	<i>F</i>	<i>p</i>	Partial $\eta^2$
Posttraumatic Stress Symptoms (IES-R)	1, 14	.445	.516	.031	2, 28	.650	.530	.044	2, 28	.775	.470	.052
Frequency of Caregiving Stress (PIP-F)	1, 13	.125	.730	.010	2, 26	.093	.911	.007	2, 26	.486	.620	.036
Difficulty of Caregiving Stress (PIP-D)	1, 12	.016	.901	.001	2, 24	.473	.629	.038	2, 24	.628	.542	.050
Problem- Solving (SPSI-R)	1, 14	.922	.353	.062	2, 28	.584	.564	.040	2, 28	3.583	.041*	.201

\* $p < .05$

For this sub-sample, the interaction between condition and time was significant, suggesting that the intervention does have an effect on problem-solving ability for this sub-sample. No significant results were found for other variables. Covariates were also included in a separated analysis. No new significant results emerged when covariates were considered, and thus those results are not reported here.

**Analysis of baseline data** Exploratory analyses were also conducted on the baseline data. First, correlations were analyzed to investigate relationships among the outcome variables. Results of the correlation analysis were promising and yielded several significant correlations among variables. Results indicated that the stronger the problem solving skills, the lesser the stress in caregiving frequency and difficulty, as well as the lesser the posttraumatic stress symptoms. Also, relationships between maladaptive problem-solving variables (Negative Problem Orientation, Impulsivity/Carelessness Style, Avoidance Style) and caregiving and posttraumatic stress were found. Correlations among the total scale scores of the outcome variables are listed in table 10, and correlations between subscales scores and total scale scores are summarized in table 11.

Table 10.

*Correlations among total scale scores at baseline*

Total Scales	Problem-Solving (SPSI-R)	Caregiving Frequency (PIP-F)	Caregiving Difficulty (PIP-D)	Posttraumatic Stress Symptoms (IES-R)
Problem-Solving (SPSI-R)				
Caregiving Frequency (PIP-F)	-.430**			
Caregiving Difficulty (PIP-D)	-.406*	.827**		
Posttraumatic Stress Symptoms (IES-R)	-.460**	.581**	.537**	
Psychosocial Risk (PAT 2.0)	-.242	.441**	.458**	.474**

$p < .05$  \*;  $p < .01$  \*\*

Table 11.

*Correlations between total scale scores and subscale scores at baseline*

Total Scales	Subscales	TOTAL SCALES				
		Problem Solving	Caregiving Frequency	Caregiving Difficulty	Post-traumatic Stress Symptoms	Psycho-social Risk (PAT 2.0)
Problem-Solving Subscales	Positive Problem Orientation		-.128	-.117	-.120	-.062
	Negative Problem Orientation		.399*	.558**	.482**	.246
	Decision Making		.060	-.041	.110	.110
	Solution Implementation and Verification		.020	-.059	-.043	-.102
	Generation of Alternative Solutions		-.127	-.089	.003	-.029
	Rational Problem Solving		-.028	-.055	.041	.004
	Impulsivity/Carelessness Style		.299	.185	.511**	.148
	Avoidance Style		.498**	.344*	.468**	.307
	Problem Definition and Formulation		-.013	.031	.104	.049
Caregiving Difficulty Subscales	Communication Difficulty	-.354*			.574**	.454**
	Medical Care Difficulty	-.359*			.404*	.306
	Emotional Distress Difficulty	-.371*			.463**	.368*
	Role Function Difficulty	-.359*			.551**	.591**
Caregiving Frequency Subscales	Communication Frequency	-.384*			.504**	.296
	Medical Care Frequency	-.256			.354*	.203
	Emotional Distress Frequency	-.484**			.590**	.459**
	Role Function Frequency	-.368*			.587**	.555**
Post-traumatic Stress Symptoms	Avoidance	-.348*	.476**	.430**		.381*
	Intrusion	-.474**	.514**	.497**		.412**
	Hyperarousal	-.439**	.610**	.556**		.513**

 $p < .05$  \*;  $p < .01$  \*\*

## **Discussion**

The goal of the present study was to examine the effectiveness of the Parent Empowerment Program (PEP) as a problem-solving intervention for parents of children with cancer. The main purpose was to determine if the PEP could effectively improve parents' problem-solving ability while reducing posttraumatic stress symptoms and decreasing stress associated with caregiving. While the hypothesized effects were not found, the implementation of this study was successful. Initial power estimates required 33 participants (rounded-up to 34 for even randomization). Thirty-three participants completed both sessions as well as at least one follow-up session. Data were available for a total of 39 participants. In addition, parent engagement was evidenced by good retention rates and positive parent feedback.

The current study followed Kazak and colleagues' (2007) guidelines to develop interventions for parents of children with cancer that are brief and cost-effective, and therefore feasible in real-world clinical settings. The original aim of the study was to determine the effectiveness of a problem-solving intervention throughout the treatment trajectory. No significant effects were found when testing the original hypotheses. Sahler and colleagues (2002; 2005) have found significant effects of problem-solving therapy on parental posttraumatic stress symptoms, depression, and problem-solving ability for parents of children between two and 16 weeks post-diagnosis. When the sub-sample of parents of children between four and 16 weeks post-diagnosis was investigated for the current sample, a significant effect of the intervention was found for problem-solving ability, but not caregiving stress or posttraumatic stress symptoms.

Sahler and colleagues' intervention used an eight-session format, which was far greater than the number used in the current study. Although an eight-session intervention format is

effective, it is likely not to be feasible in most clinical settings. The results of the current study are promising because a two-session problem-solving intervention for parents in the peri-diagnostic phase was shown to improve problem-solving ability. The goal of the current study was to improve problem-solving ability in order to reduce parent stress, both in caregiving and posttraumatic stress. Unfortunately, these reductions were not found in the current study. However, Sahler and colleagues did find decreases in parent stress. Therefore, while the current study did demonstrate that problem-solving improvements can be accomplished for parents in the peri-diagnostic phase in only two sessions, it fell short in finding actual changes in parent stress. It appears that at this point, further research needs to be conducted to determine the optimal dosage level that balances the goals of effectiveness and feasibility. Regardless of the types of interventions developed it seems that the needs of parents are so great, and the access to intervention so limited, that there is a great potential for developing efficacious programs.

Significant effects were only found for problem-solving among parents in the peri-diagnostic phase. The aim of the current study was to examine the effectiveness of problem-solving therapy among caregivers across the treatment trajectory. Analyses of the entire sample that tested the study hypotheses failed to find significant changes in problem-solving ability, caregiving stress, or posttraumatic stress symptoms. There are a number of factors which may have contributed to lack of significant findings. First, the consent rate was approximately 59%, meaning that around 41% of recruited caregivers did not consent to participate. Of the 59% who did consent, 9 participants (18.8% of all who consented), did not complete any part of the study, resulting in a 48% participation rate. While attrition is to be expected in any study, it may be that in this particular study, the most “stressed” caregivers declined participation or dropped out after consenting, due to feeling overwhelmed with caregiving responsibilities. If this is the case, then

caregivers who were the least stressed of the entire potential pool actually participated, perhaps because they felt they could take the time to focus on a study and participate. Because the intervention is designed to address parenting stress in the context of caring for children with cancer, if only the least stressed actually participated, there may not have been much room for the constructs of interest to change.

Data on psychosocial risk collected from the Psychosocial Assessment Tool (PAT2.0) provides some insight into the stress level and risk of parents at the beginning of the study. Pai and colleagues (2008) report that a PAT2.0 score of 1.0 or higher suggests that a family may require increased psychosocial support. In the current sample, only slightly more than half of participants (51%) had a score of 1.0 or higher, meaning that the other half of the sample was in need of only minimal psychosocial support. It would have been interesting to know what the level of psychosocial risk (as measured by the PAT2.0) would have been for those participants who either did not consent or dropped out of the study. It is possible that the PEP is only beneficial for those caregivers with the greatest amount of psychosocial risk. However, participants in the current study had similar psychosocial risk scores as reported by Pai and colleagues (2008), suggesting that the current sample is largely representative of the average pediatric cancer patient caregiver population. Psychosocial risk was examined in the current study to determine if it had an effect on the outcomes. These results ultimately indicated that the PEP intervention was no more effective for parents with higher psychosocial risk than those with lower psychosocial risk.

Second, the fact that there was a wide range of time since diagnosis was also likely a problematic factor. Parents were recruited anywhere from four weeks past their child's diagnosis through 75% of the expected treatment protocol. In addition, parents of children with

any cancer diagnosis were recruited, meaning that these time parameters had different meanings for different diagnoses. For example, a child diagnosed with Acute Lymphoblastic Leukemia has a 2.5 to 3 year treatment protocol (Ching-Hon & Evans, 2006). For these parents, at four weeks past diagnosis, the child is usually in the intensive induction phase of treatment, and one can reasonably assume that the parent is under tremendous stress navigating the medical needs of the child, fearing for the health and wellbeing of the child, and learning to adapt family and occupational needs to a new schedule. However, by the time the child is 75% completed with treatment, he or she is generally well into the maintenance phase of treatment, and is receiving less intensive chemotherapy. At this time, the medical and caregiving demands are much less intensive, generally making the parent less “stressed.” However, for a child with Hodgkin’s Lymphoma, who has a 6 to 9 month treatment protocol (Hudson & Donaldson, 1999), the demands of medical treatment and caregiving remain largely stable throughout the duration of treatment, because the treatment schedule does not change over the duration of treatment. Research findings with regard to how long after diagnosis stress persists are mixed. Some evidence suggests parents experience a decrease in stress over time (Dolgin, Phipps, Fairclough, et al., 2007; Hoekstra-Weebers et al., 1998), while other evidence suggests that stress levels remain similar throughout the treatment trajectory (Kazak, Boeving, Alderfer, et al., 2005; Mack, Wolfe, Cook, et al., 2009). It is possible that the current sample exemplified this discrepancy in the literature: that some parents’ distress lessened overtime, while others’ remained stable. This pattern likely contributed to the overall lack of significant effect of the intervention. When only parents of children in the peri-diagnostic phase (4 to 16 weeks post-diagnosis [41% of the sample]) were evaluated, the PEP intervention actually did have an effect



on problem-solving ability. This finding suggests that the intervention works best for parents in the early stages of treatment, consistent with previous research (Sahler et al., 2002; 2005).

The inconsistency in timing of data collection introduced statistical variance that limits the assumptions that can be made about the impact of the intervention one month and three months post-intervention. For example, some participants completed the first intervention session on the day they completed the baseline questionnaire packet, but for most it was two to three weeks before they received the first intervention session. Also, participants did not always complete questionnaire packets at exactly one and three months post-intervention. In addition, the inconsistency in timing of intervention sessions also introduced statistical variance. Most participants completed the second intervention session two to four weeks after the first session, but for some participants, the length of time between sessions was several weeks. Variations in the timing of participant completion of questionnaires and session completion were expected. Throughout the course of the study, efforts were made to coordinate questionnaire completion and session participation with the child patients' clinic visits, thus reducing the burden on parent participants and improving participation rates. While it is likely that this coordination did facilitate the completion of study procedures, it should be noted that there was likely some unfortunate impact on the validity of the timing of both questionnaire and intervention session completion.

Finally, there is the issue of treatment fidelity. Session one of the intervention condition was divided into 23 distinct points to be addressed, and only 53% of sessions addressed all 23 points. Session two was divided into 15 distinct points, all of which were addressed in only 31% of sessions. This problem with treatment fidelity was likely caused by the interventionist's tendency to tailor the sessions to the participants needs at the time of the session. That is, if a

particular participant did not seem to require a discussion of a particular intervention point, it was skipped in order to focus on the intervention points that were determined to be more important. This failure to address all pertinent points in all sessions prevented some participants from getting important information. However, there was no specific point that was consistently missed, so it is likely that poor treatment fidelity did not introduce a large amount of bias. In addition, some of the problem-solving steps were alluded to in the control sessions, potentially causing treatment contamination.

Also, initial inter-rater reliability of the audio recording ratings was poor. Better training of raters should have been implemented. Each rater was individually trained. However, group trainings could have been done to help the raters work to code the audiotapes consistently. Better examples of codes could have also been presented. Most of the coding was done after the majority of the sessions had been completed. When audiotape ratings showed that some critical points in the intervention were missed, the interventionist could have been more diligent in addressing all points in future sessions.

There were also no effects of the intervention on parental posttraumatic stress symptoms. Several studies have found parents of children with cancer to experience posttraumatic stress symptoms (PTSS; Kazak et al., 2005; Norberg, & Boman, 2008; Pelcovitz et al., 1996) and there have been recent calls for interventions to address parental PTSS (e.g., Kazak et al., 2007). This study aimed to address global stress via problem-solving intervention. The intention was that if parents could cope better with problems related to their child's diagnosis and treatment, perhaps the impact of the diagnosis and treatment (i.e., PTSS) would be ameliorated. The focus of the intervention sessions was on problem-solving, not on posttraumatic stress symptoms per se. However, as with many other measured constructs, parental posttraumatic stress symptoms were

minimal, as measured by the Impact of Events Scale. This overall low posttraumatic stress pattern may be a product of the wide variability in time since diagnosis. That is, a large number of parents simply may have experienced a reduction in PTSS before their participation in the study. Also, the sample of participants may have represented those with already low levels of PTSS, and perhaps those who refused participation or dropped out had higher levels of PTSS. If these parents who did not participate did have PTSS, the avoidance symptom may have prevented them from addressing problems by participating in an intervention. Future studies could be conducted that identify parents with high PTSS, and develop interventions that incorporate elements of traditional psychotherapeutic treatments for posttraumatic stress, such as Prolonged Exposure Therapy or Cognitive Processing Therapy.

Improvements in problem-solving ability were detected when only parents of children 4-16 weeks post-diagnosis were evaluated. When the entire sample was evaluated (to test the study hypotheses), there were no effects on problem-solving ability. This lack of effect was likely due to the brief nature of the intervention, that there were simply not enough sessions to teach the skills in a manner that the participants could develop a sufficient understanding of the skills to use on a regular basis. In addition, the lack of effect in problem-solving skills may have stemmed from the study design. That is, the control condition that was created for this study may not have been sufficiently different from the intervention condition. Treatment fidelity issues were two-fold. First, although a relatively minimal issue, coding suggested that some problem-solving skills were delivered to the control condition participants. Second, in the intervention sessions, there was a lack of sufficient adherence to the manual. To summarize, some of the control participants received problem-solving skills, while some of the intervention participants did not receive all of the problem-solving skills. However, because significant effects were found for

those with a child 4-16 weeks post-diagnosis, time since diagnosis appears to be the factor that determines for whom this problem-solving intervention is effective.

The original intention of the intervention was to teach participants the problem solving skills in the context of a problem they were currently having. Some participants actually had a difficult time defining a problem. This point relates back to the hypothesis that the sample consisted of participants with less stress (because they consented to be in the study) than those who did not consent to participate. If this is the case, perhaps these participants were biased toward already having some level of problem solving ability. The second session was intended to reiterate the problem solving steps, but often because participants did not necessarily apply the steps to new problems, the second session was more of a “check-in” of how their previous problem-solving session helped them to address the particular problem at hand.

Also, there was some level of contamination in that problem-solving skills were accidentally addressed with the control condition participants. While the number of control participants with whom the problem-solving skills were addressed was small, there is some likelihood that this contamination contributed to the lack of significant difference in problem-solving skill ability between the intervention and control conditions. This point is particularly relevant given the small sample size. Finally, the problem-solving skills were taught in a way that was specific to caring for a child with cancer, but the problem-solving outcome measure (SPSI-R), was not cancer-specific. It is possible that the measure was not sensitive enough to detect these changes.

The effect of participant usage of the PEP materials (workbook and mini strategy card) on the three outcomes of interest trended toward significance for problem-solving. Although not significant, this finding suggests that there may be some effect of remaining engaged in the study

materials on ability to problem-solve. If this relationship does exist, this finding may suggest that the face-to-face intervention with a therapist may not actually be necessary, and providing only written materials on problem-solving may be sufficient. In fact, if future studies could demonstrate that providing written materials does have a significant effect, this type of literature could be provided to parents at diagnosis as part of the standard of care.

The lack of any significant change in caregiving stress is disappointing, given that the primary research question of the current study was to examine whether teaching problem-solving skills to participants would have an effect on caregiving-associated stress. Stress reduction is the main goal of problem-solving therapy (Nezu, et al., 1998, p.3) and previous literature has found problem-solving skills to reduce care giving stress (Bucher et al., 2001; Cameron et al., 2004; Elliott & Berry, 2009; Elliot et al., 2009; Kadzin & Whitley, 2003; Rivera et al., 2008; Sahler et al., 2002; Sahler et al., 2005; Wade et al., 2006).

The caregiving stress measure (Pediatric Inventory for Parents [PIP; Streisand et al., 2001]) examines both the frequency and difficulty of caregiving demands. Compared to the standardization sample of the PIP, participants in the current sample reported less difficulty with caregiving demands. It is reasonable to hypothesize that if parents do not see caregiving demands as particularly difficult, they may also not see them as problematic. This pattern could explain one reason then why problem-solving skills training did not impact caregiving stress.

Another reason for the lack of significant effects in caregiving stress was the wide time variation in children's treatment protocols for various diagnoses, as well as the wide range in time since diagnosis. Parents of children at the early, middle, and late stages were all included. Parents of children in middle or late stages may have developed coping strategies by this time, and did not benefit from new strategies. Also, caregiving demands for some diagnoses decrease

as treatment continues. This point is especially true for Acute Lymphoblastic Leukemia (ALL), of which parents completed the majority of the sample. That is, parents of children in the maintenance phases of ALL treatment simply do not have the day-to-day caregiving requirements as parents of children in the induction or consolidation phases. In addition, parents of children from birth to 17 years were eligible for participation (actual age range: 2-16 years). Naturally, caregiving requirements vary by age, with younger children requiring more caregiving than older children. Unfortunately, the caregiving stress measure (PIP) does not adjust for child age. However, preliminary analyses indicated that child age was not related to the outcome variables. When only parents of children 4 to 16 weeks post-diagnosis were evaluated, there were also no effects of the intervention on caregiving stress. It could be that for this sub-sample, the effects observed in problem-solving ability did not translate to effects in caregiving stress.

Despite the disappointing overall lack of effect of the PEP for the entire sample, it was well-received by the parents who participated as evidenced by their feedback. Participants in the control condition perceived their participation as helpful, even though they did not receive specific problem-solving skills. At study consenting, the two conditions were presented to caregivers as equal interventions, and participants in the control condition did not know they were not receiving the intervention of interest. This approach likely contributed to good retention rates in the control condition. Overall, participants enjoyed participating and felt comfortable discussing concerns with the interventionist. These qualitative findings suggest that, given that participants perceived the intervention so positively, that all caregivers are in need of psychosocial support. In addition, the PEP was well-received by the staff of the Children's Hospital of Richmond Division of Pediatric Hematology/Oncology.

Exploratory analyses were conducted on the baseline data to determine if problem solving ability, posttraumatic stress symptoms, and caregiving stress are related. Several significant correlations were found. Results indicated that the stronger the problem solving skills, the lesser the stress in caregiving frequency and difficulty, as well as the lesser the posttraumatic stress symptoms. Also, relations between maladaptive problem-solving variables (Negative Problem Orientation, Impulsivity/Carelessness Style, Avoidance Style) and caregiving and posttraumatic stress were found. These significant correlations are quite promising in that they indicate that those with good problem-solving skills have lower caregiving stress and posttraumatic stress symptoms. In addition, those with maladaptive problem-solving tendencies, have greater caregiving stress and posttraumatic stress symptoms. These results are consistent with previous findings. For example, Nelson, Gleaves, and Nuss (2003) found that mothers' negative problem orientation influences stress responses. Norberg, Lindblad, and Boman (2005) had found that active problem-solving is associated with lower distress levels, while Dolgin, Phipps, and Fairclough (2005) found that problem-solving skills predict parental adaptation over the treatment trajectory.

**Limitations** There were a number of factors that limited this study and may have contributed to the overall lack of significant findings. First, the sample size was rather small. Although the sample was large enough to meet the requirements determined by the power analysis for a significant effect, a larger sample would have perhaps had a higher likelihood of detecting an effect. With a larger sample size, small to moderate effect sizes could have been detected. With the small sample size of the current study, only a large effect size could be detected. In the power calculations, a large effect size (0.3) was assumed. Actual effect sizes were calculated and reported in order to aid future researchers in determining sample size for similar studies. Also,

the actual effect size was used to estimate the number of participants that would have been needed to detect these small effects. Using the smallest effect size detected (.012 for caregiving stress), a sample size of 510 participants would be required (see power calculation equation on pages 32-33). A sample size that large would have been impossible given the scale of the current study.

Second, data were collected from only one clinical site (Children's Hospital of Richmond Division of Pediatric Hematology/Oncology), and therefore the results are not generalizable to sites in other geographic areas. However, having additional sites would have introduced additional variability. With other major issues to address in future studies (i.e., improved treatment fidelity; modification in study design), the issue of generalizability is rather insignificant. Third, there was only one interventionist for both the intervention and control conditions. The interventionist knew the study aims, and this fact may have introduced bias. In addition, this point may have been the reason for the small degree of contamination of the control sessions with intervention skills. Despite the drawbacks of having only one interventionist, this created a degree of "self-control," in that there was no need to control for differences between interventionists. On that note, if the current intervention were to be disseminated to a clinical setting, it is likely that only one provider would deliver the intervention. Next, there were issues with treatment fidelity, in that not every intervention point was addressed with every participant. Also, some of the intervention skills were inadvertently addressed with the control participants. In addition, there was a wide range in time duration of intervention and control sessions, largely due to variations in participant engagement in sessions. Finally, the treatment fidelity criteria for the control sessions were rather vague, making consistent ratings difficult to achieve.



**Recommendations** Changes to the current study's approach could be considered in future research. First, the number of sessions should be extended. Sahler and colleagues (2002, 2005) found significant effects in problem-solving, but also in other distress variables (posttraumatic stress, depression) with eight sessions. Teaching and reviewing problem-solving skills for a longer period of time would allow parents to not only learn problem-solving skills, but also allow for time for their problem-solving abilities to have a measurable effect on their distress. However, an eight-session intervention is not easily translatable to a clinical setting. Future studies should work to determine the fewest number of problem-solving intervention sessions to achieve improvements in problem-solving skills. Second, as an extension to the previous point, an effort to utilize a more homogenous population should be made. There is a great deal of variability in the amount of stress parents experience based on time since diagnosis, length of treatment protocol, type of diagnosis, and age of the child. Therefore, a study that examined parents at either similar phases of treatment (e.g., peri-diagnostic period; or maintenance chemotherapy), diagnostic group (e.g., ALL vs. lymphomas), or child age (e.g., toddlers vs. school age) would provide the homogeneity necessary to avoid the wide variability.

While the current study did adhere to Pai and colleagues' (2006) recommendations for intervention studies to utilize an attention control comparison condition, future studies should explore modifications to the control comparison. One option is a waitlist control condition, in which certain participants first contribute to a control condition while waiting to receive the intervention after the conclusion of the study. The drawback of this option is that it would extend the time since diagnosis time frame, as children would continue with cancer treatment while the parent remained on the waitlist. Another option is to have the control participants receive only written materials, and not interact with a therapist. However, the best likely control condition

would be a “standard of care” control, in which parents receive only the services already in place at a particular clinical site. The standard of care control condition would be preferred to the attention control condition because an attention control condition is not different enough from the intervention to detect significant differences in the outcome variables of interest.

Next, subsequent studies should utilize separate interventionists for the intervention and control conditions that are blind to study hypotheses. This procedure will enhance treatment fidelity and reduce contamination of the intervention skills to the control condition. Also, reliability in the coding of audiotapes could be improved by better training of raters. Raters should be trained as a group so that they all code audiotapes in a consistent fashion.

Also, efforts should be made to improve the timing of data collection and session delivery. For example, baseline questionnaire packets should be completed as close as possible to the day of session one, session two should occur as close to two week after session one as possible, and follow-up questionnaires should be collected as close to one month and three months after session two as possible.

Finally, because the participants who were enrolled in the study may have had better coping skills than those who refused participation, efforts to enroll those with more psychosocial stressors and poorer coping skills should be made. One possibility is for problem-solving to be integrated into parent training that is offered as standard of care. It could be tailored to be relevant to parents with children at various stages of the treatment process (e.g., after diagnosis, entering survivorship) or for parents of children with a high level of need such as those with rare diagnoses, disease relapses, or requiring bone-marrow transplantation. Another possible way to accomplish this recommendation would be to use the PAT 2.0 as a screening tool to determine who is at greatest risk, explain the risk, and encourage participation. While the PAT 2.0 is a

validated measure of psychosocial risk, it does not evaluate parental coping with the demands of caregiving or with the emotional impact of the cancer experience. It cannot be assumed that high psychosocial risk is related to poor coping strategies. In fact, those with high psychosocial risk may have developed good coping skills through experiencing other stressful life circumstances. Therefore, the PAT 2.0 has limited ability to detect those parents who are coping poorly with their child's cancer treatment, and thus has poor ability to detect those who would most greatly benefit from intervention. Nevertheless, the PAT 2.0 offers a wealth of information on psychosocial risk. As more research is completed on the PAT 2.0, it is likely that it will become an even more sensitive measure of psychosocial risk, and perhaps inform new interventions in a consistent manner.

It would also be helpful to determine why some parents refuse participation. Identifying the true reasons that parents declined participation (e.g., lack of interest; feeling too stressed/overwhelmed; lack of trust in the research process) would inform changes in consent procedures or the study itself to improve participation rates.

**Clinical Implications** While the findings of this study are limited, problem-solving training has the potential to be a viable intervention, specifically for parents during the peri-diagnostic phase. Despite the notion that problem-solving could be effective during various stages of treatment, this study supported previous research in that it is effective early in treatment. One possibility is for psychosocial providers in pediatric oncology clinics to integrate problem-solving into the standard of care for newly diagnosed families. Two sessions appears sufficient for teaching problem-solving skills, but more research needs to be done to determine the minimum number of sessions required to impact parental distress. Also, given the problems with treatment fidelity in this study, psychosocial providers should strive to stricter adherence to an intervention manual.

**Conclusions** The goal of the current study was to examine the efficacy of a two-session problem-solving intervention to ameliorate care giving stress and posttraumatic stress symptoms in care givers of children with cancer. It was a randomized controlled trial with an attention control. The study failed to yield significant results on the outcomes of interest (problem-solving ability, care giving stress, and posttraumatic stress symptoms). However, the study did show that intervention participant usage of the intervention materials led to improvements in problem solving ability at the three-month follow-up. In addition, participant feedback in both the intervention and control conditions was positive, suggesting that any psychosocial intervention for care givers of children with cancer is well-received and beneficial. Limitations in study design, particularly limited number of intervention sessions and small sample size, likely contributed to the lack of effect. However, this study represents an important step toward developing psychosocial interventions for care givers that are both efficacious and manageable to conduct in a pediatric hematology/oncology setting.

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## Appendix A

### Parent Recruitment Script Inpatient/Outpatient recruitment script

Hello \_\_\_\_\_ (parent name), my name is \_\_\_\_\_ and I am part of a new program for parents of children with cancer that was designed here at the Pediatric Hematology/Oncology Clinic at VCU Medical Center. This program is called *Parent Empowerment* and it is designed to help parents deal with the many struggles that come up during cancer treatment. Do you have a few minutes to talk, so that I can tell you about the program and see if you might be interested in participating?

*(If parent says, yes, then continue.)*

The *Parent Empowerment* program is a joint effort between the VCU Division of Pediatric Hematology/Oncology and the VCU Department of Psychology. It is a brand new program designed specifically for parents of children with cancer that addresses the stress and problems associated with diagnosis and treatment. This program is also be part of a research study that we are conducting to see how best to help parents solve difficult problems. If you decide to be a part of this program, you will be asked to attend two individual sessions with a counselor. The second session will occur 2 weeks after the first session. There are two different versions of the *Parent Empowerment* program, and you will be randomly assigned to one of the two versions. In one of the versions, the counselor will talk with parents about helping children and families cope with cancer and the child's hospitalization. In the other version, the counselor will talk with parents about solving problems. This session will be conducted either in the Pediatrics inpatient unit (Main Hospital, 7<sup>th</sup> floor) or in the ASK Pediatric Hematology/Oncology Clinic.

In addition to attending the parent session, we will ask you to fill out some questionnaires about you and your family at three time points: right before the first session, 1 month after the second session, and 3 months after the second session. We will also ask for your permission to access your child's medical records for information about his or her diagnosis and treatment and to keep track of the number of sessions you and your child receive from the Division of Pediatric Hematology/Oncology support staff. This includes the psychologist, social worker, chaplain, and child life specialist.

As a thank you for participating in this study, we will give you a \$15.00 gift card for completing the second set of questionnaires, and a \$10.00 gift card for completing the third set of questionnaires. There is no compensation for completing the first set of questionnaires.

Do you have any questions? Does this project sound like something you would be interested in participating in?

*(If no, discontinue. If yes, continue.)*

Thank you. If you would like to set up a time to participate in the program, we can do that now. Otherwise, I can contact you to find a time that is convenient for you. Do you have any questions?

(If yes, answer them; if no say): Thank you again for your interest in the program. We look forward to working with you!

## Appendix B

### Psychosocial Assessment Tool 2.0

ABOUT YOUR CHILD (THE PATIENT):			
Patient's Name: First MI Last	Today's Date: Month Day Yr		
Date of Birth: Month Day Yr	Patient's Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female		
Diagnosis:	Date of Diagnosis: Month Day Yr		
Patient's Ethnicity (CHECK ALL THAT APPLY): <input type="checkbox"/> Hispanic <input type="checkbox"/> Asian <input type="checkbox"/> Black/African Amer. <input type="checkbox"/> White <input type="checkbox"/> Other (specify):			
ABOUT YOURSELF:	Family Member Completing Form: <input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Other (please specify):		
Ethnicity of person completing form (CHECK ALL THAT APPLY): <input type="checkbox"/> Hispanic <input type="checkbox"/> Asian <input type="checkbox"/> Black/African Amer. <input type="checkbox"/> White <input type="checkbox"/> Other (specify):			
Highest Education Completed:	<input type="checkbox"/> Less than high school <input type="checkbox"/> Some college/ vocational school <input type="checkbox"/> Some professional/graduate school <input type="checkbox"/> Graduated High School/GED <input type="checkbox"/> Graduated college/vocational school <input type="checkbox"/> Graduate of professional/graduate school		
Do you consider yourself part of a faith-based or spiritual community? <input type="checkbox"/> No <input type="checkbox"/> Yes			

1. PLEASE TELL US WHO LIVES IN YOUR HOME: (PLEASE INCLUDE THE PATIENT AND YOURSELF)							
	Relationship to Pt.	First and Last Name	Age		Relationship to Pt.	First and Last Name	Age
1	<b>Patient</b>			4			
2	Person completing form			5			
3				6			

2. IS ANYONE IN THE HOUSEHOLD PREGNANT OR PLANNING TO ADOPT?	<input type="checkbox"/> No	<input type="checkbox"/> Yes
--	-----------------------------	------------------------------

3. PATIENT'S PARENTS'/GUARDIANS' RELATIONSHIP STATUS: (PLEASE CHECK ONE)	
<input type="checkbox"/> Single	<input type="checkbox"/> Married/Partnered <input type="checkbox"/> Separated/Divorced <input type="checkbox"/> Other (describe):

4. WHO CAN YOU COUNT ON TO PROVIDE THE FOLLOWING: (PLEASE CHECK ALL THAT APPLY)							
	Spouse/ Partner	Patient's Grand- parents	Other extended family	Friends	Work Associates	Other (describe)	No One
a. Childcare/Parenting							
b. Emotional Support							
c. Financial Support							
d. Information							
e. Help with everyday tasks (i.e. meals, errands, transportation)							

5. HOW WILL YOU GET TO YOUR APPOINTMENTS? (PLEASE CHECK ALL THAT APPLY)	
<input type="checkbox"/> Own Car	<input type="checkbox"/> Rides from Others
<input type="checkbox"/> Public Transportation	<input type="checkbox"/> Not Sure /Don't Know

6. PATIENT'S CURRENT HEALTH COVERAGE: (PLEASE CHECK ALL THAT APPLY)	
<input type="checkbox"/> None	<input type="checkbox"/> Low cost/limited coverage <input type="checkbox"/> COBRA
<input type="checkbox"/> Medicaid	<input type="checkbox"/> Insurance (private/through employer)

<b>7. IS YOUR FAMILY CURRENTLY EXPERIENCING ANY FINANCIAL DIFFICULTIES?</b> (PLEASE CHECK ONE)	No	We have some financial problems	We have many financial problems	It's hard to meet our basic needs
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>8. IN WHAT AREAS ARE YOU CURRENTLY EXPERIENCING FINANCIAL DIFFICULTIES?</b> (PLEASE CHECK ALL THAT APPLY)
<input type="checkbox"/> None <input type="checkbox"/> Phone/Utility bills <input type="checkbox"/> Rent/Mortgage <input type="checkbox"/> Buying food <input type="checkbox"/> Vehicle-related (upkeep/gas/insurance) <input type="checkbox"/> Medical Expenses

<b>9. DOES YOUR CHILD KNOW S/HE HAS CANCER?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No, too young to know <input type="checkbox"/> No, have opted to not tell him/her
---	---

<b>10. PLEASE TELL US ABOUT YOUR CHILD'S CURRENT SCHOOLING:</b> (CHECK ALL THAT APPLY)	<input type="checkbox"/> Too young for school → SKIP to #11
<input type="checkbox"/> Head Start <input type="checkbox"/> Preschool/Pre-K <input type="checkbox"/> K-12; Grade? _____ <input type="checkbox"/> College/Vocational <input type="checkbox"/> Home schooling <input type="checkbox"/> Homebound <input type="checkbox"/> Gifted <input type="checkbox"/> Special Education <input type="checkbox"/> Dropped out <input type="checkbox"/> Completed Formal Education <input type="checkbox"/> Not attending school by parent's choice <input type="checkbox"/> Not currently receiving school or homebound services	

<b>11. In general, does your child (the patient):</b> (Please check one box for each question) →				<b>12. Is this a concern for a Sibling?</b> <input type="checkbox"/> N/A	
	Never Been a Concern	Sometimes a Concern	Currently Receiving Help	No	Yes
a. Change moods quickly?					
b. Act younger than his/her age?					
c. Get upset about going to the doctor/dentist?					
d. Act overly active? (i.e. hyperactivity)					
e. Have attention difficulties/ADHD?					
f. Cry easily or become upset easily?					
g. Seem easily distracted?					
h. Worry?					
i. Have learning or school difficulties?					
j. Appear sad or withdrawn?					
k. Use drugs, alcohol or other substances?					
l. Have developmental concerns or delays?					
m. Act shy or cling to you/other familiar adults?					
n. Have difficulty making and keeping friends?					
o. Have a pre-existing medical condition? (Describe)					
p. Been a victim of violence?					
q. Another psychological concern? (Describe)					

<b>13. THINKING ABOUT THE ADULTS (CAREGIVERS) IN THE PATIENT'S HOME, PLEASE CHECK ONE BOX FOR EACH QUESTION:</b>		
	No	Yes
a. Has anyone experienced periods of excessive worry, fear and/or anxiety?		
b. Has substance use ever caused problems for anyone in the family?		
c. Has anyone experienced periods of prolonged sadness or depression?		
d. Does anyone have difficulty focusing, concentrating and/or have a history of an attention deficit disorder?		
e. Have there been marital difficulties, conflict or discussion of separation?		
f. Has anyone been (or currently is) incarcerated/in jail?		
g. Has anyone ever been told that s/he drinks too much?		

h. Have there been any difficulties with child custody disputes?		
i. Does anyone have a serious or chronic medical illness/condition? (Describe)		
j. Does anyone have a psychological condition not described above? (Describe)		
k. Have you experienced the death of a family member within the past year?		
l. Other family stressors? (Describe)		

<b>14. SINCE DIAGNOSIS . . . (PLEASE CIRCLE ONE FOR EACH ITEM BELOW)</b>	Not at All	Sometimes	Often	Very Much
a. Have you had bad dreams or nightmares about your child being ill?	0	1	2	3
b. Have you become jumpy since your child came to the hospital?	0	1	2	3
c. When you are reminded of your child being ill, do you sweat or tremble, or does your heart beat fast?	0	1	2	3

<b>15. How much do you believe. . . (Please check one box for each item below)</b>				
	Not at all true	Just a little bit true	Pretty much true	Very true
a. The doctors will know what to do				
b. My child will be in a lot of pain				
c. Our family will be closer because of this				
d. Our marriage or family will fall apart				
e. This is a disaster				
f. We can make good treatment decisions				
g. People will pull away from us				
h. We're going to beat this				
i. Cancer is a death sentence				
j. Everything happens for a reason				

### **Additional Demographic Items**

**Please indicate your household's total yearly income before taxes:**

**More than \$75, 000** \_\_\_\_\_

**\$60, 000 - \$75, 000** \_\_\_\_\_

**\$50, 000 - \$60, 000** \_\_\_\_\_

**\$40,000 - \$50, 000** \_\_\_\_\_

**\$30,000 - \$40, 000** \_\_\_\_\_

**\$20,000 - \$30, 000** \_\_\_\_\_

**Less than \$20, 000** \_\_\_\_\_



## **Appendix C**

### **Life Events Checklist**

Listed below are a number of difficult or stressful things that sometimes happen to people. For each event, check one or more of the boxes to the right to indicate that: (a) It *happened to you* personally, (b) you *witnessed it* happen to someone else, (c) you *learned about it* happening to someone close to you, (d) you're *not sure* if it applies to you, or (e) it *doesn't apply* to you.

Mark *only one* item for any single stressful event you have experienced. For events that might fit more than one item description, choose the one that fits best.

Be sure to consider your *entire life* (growing up, as well as adulthood) as you go through the list of events.

<i>Event</i>	<i>Happened to me</i>	<i>Witnessed it</i>	<i>Learned about it</i>	<i>Not Sure</i>	<i>Doesn't apply</i>
1. Natural disaster (for example, flood, hurricane, tornado, earthquake)					
2. Fire or explosion					
3. Transportation accident (for example, car accident, boat accident, train wreck, plane crash)					
4. Serious accident at work, home, or during recreational activity					
5. Exposure to toxic substance (for example, dangerous chemicals, radiation)					
6. Physical assault (for example, being attacked, hit, slapped, kicked, beaten up)					
7. Assault with a weapon (for example, being shot, stabbed, threatened with a knife, gun, bomb)					
8. Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm)					
9. Other unwanted or uncomfortable sexual experience					
10. Combat or exposure to a war-zone (in the military or as a civilian)					
11. Captivity (for example, being kidnapped, abducted, held hostage, prisoner of war)					
12. Life-threatening illness or injury					
13. Severe human suffering					
14. Sudden, violent death (for example, homicide, suicide)	N/A				
15. Sudden, unexpected death of someone close to you	N/A				
16. Serious injury, harm, or death you caused to someone else	(Check here if you were directly involved)				
17. Any other stressful event or experience					

## Appendix D

### Impact of Events Scale – Revised (IES-R)

Instructions: The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you *during the past 7 days* with respect to the time you received your child's cancer diagnosis. How much were you distressed or bothered by these difficulties?

		<b>Not at all</b>	<b>A little bit</b>	<b>Moderately</b>	<b>Quite a bit</b>	<b>Extremely</b>
1.	Any reminder brought back feelings about the time I received my child's cancer diagnosis.	0	1	2	3	4
2.	I had trouble staying asleep.	0	1	2	3	4
3.	Other things kept making me think about the time I received my child's cancer diagnosis.	0	1	2	3	4
4.	I felt irritable and angry.	0	1	2	3	4
5.	I avoided letting myself get upset when I thought about, or was reminded of, time I received my child's cancer diagnosis.	0	1	2	3	4
6.	I thought about the time I received my child's cancer diagnosis when I didn't mean to.	0	1	2	3	4
7.	I felt as if the time I received my child's cancer diagnosis hadn't happened or wasn't real.	0	1	2	3	4
8.	I stayed away from reminders of the time I received my child's cancer diagnosis.	0	1	2	3	4
9.	Pictures about the time I received my child's cancer diagnosis popped into my mind.	0	1	2	3	4

10.	I was jumpy and easily startled.	0	1	2	3	4
11.	I tried not to think about the time I received my child's cancer diagnosis.	0	1	2	3	4
12.	I was aware that I still had a lot of feelings about the time I received my child's cancer diagnosis, but I didn't deal with them.	0	1	2	3	4
13.	My feelings about the time I received my child's cancer diagnosis were kind of numb.	0	1	2	3	4
14.	I found myself acting or feeling like I was back at the time I received my child's cancer diagnosis.	0	1	2	3	4
15.	I had trouble falling asleep.	0	1	2	3	4
16.	I had waves of strong feelings about the time I received my child's cancer diagnosis.	0	1	2	3	4
17.	I tried to remove the time I received my child's cancer diagnosis from my memory.	0	1	2	3	4
18.	I had trouble concentrating.	0	1	2	3	4
19.	Reminders of the time I received my child's cancer diagnosis caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	0	1	2	3	4
20.	I had dreams about the time I received my child's cancer diagnosis.	0	1	2	3	4
21.	I felt watchful and on guard.	0	1	2	3	4
22.	I tried not to talk about the time I received my child's cancer diagnosis.	0	1	2	3	4

## Appendix E

### Pediatric Inventory for Parents

Below is a list of difficult events which parents of children who have (or have had) a serious illness sometimes face. Please read each event carefully, and circle HOW OFTEN the event has occurred for you in the past 7 days, using the 5 point scale below. Afterwards, please rate how DIFFICULT it was/or generally is for you, also using the 5 point scale. Please complete both columns for each item.

EVENT	HOW OFTEN?					HOW DIFFICULT?				
	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often					1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely				
1. Difficulty sleeping .....	1	2	3	4	5	1	2	3	4	5
2. Arguing with family member(s) .....	1	2	3	4	5	1	2	3	4	5
3. Bringing my child to the clinic or hospital .....	1	2	3	4	5	1	2	3	4	5
4. Learning upsetting news .....	1	2	3	4	5	1	2	3	4	5
5. Being unable to go to work/job.....	1	2	3	4	5	1	2	3	4	5
6. Seeing my child's mood change quickly .....	1	2	3	4	5	1	2	3	4	5
7. Speaking with doctor .....	1	2	3	4	5	1	2	3	4	5
8. Watching my child have trouble eating .....	1	2	3	4	5	1	2	3	4	5
9. Waiting for my child's test results .....	1	2	3	4	5	1	2	3	4	5
10. Having money/financial troubles .....	1	2	3	4	5	1	2	3	4	5
11. Trying not to think about my family's difficulties .....	1	2	3	4	5	1	2	3	4	5
12. Feeling confused about medical information.....	1	2	3	4	5	1	2	3	4	5
13. Being with my child during medical procedures .....	1	2	3	4	5	1	2	3	4	5
14. Knowing my child is hurting or in pain .....	1	2	3	4	5	1	2	3	4	5
15. Trying to attend to the needs of other family	1	2	3	4	5	1	2	3	4	5

<b>EVENT</b>	<b>HOW OFTEN?</b>					<b>HOW DIFFICULT?</b>				
	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often					1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely				
members.....										
16. Seeing my child sad or scared.....	1	2	3	4	5	1	2	3	4	5
17. Talking with the nurse .....	1	2	3	4	5	1	2	3	4	5
18. Making decisions about medical care or medicines ....	1	2	3	4	5	1	2	3	4	5
19. Thinking about my child being isolated from others ...	1	2	3	4	5	1	2	3	4	5
20. Being far away from family and/or friends.....	1	2	3	4	5	1	2	3	4	5
21. Feeling numb inside.....	1	2	3	4	5	1	2	3	4	5
22. Disagreeing with a member of the health care team....	1	2	3	4	5	1	2	3	4	5
23. Helping my child with his/her hygiene needs.....	1	2	3	4	5	1	2	3	4	5
24. Worrying about the long term impact of the illness ....	1	2	3	4	5	1	2	3	4	5
25. Having little time to take care of my own needs .....	1	2	3	4	5	1	2	3	4	5
26. Feeling helpless over my child's condition .....	1	2	3	4	5	1	2	3	4	5
27. Feeling misunderstood by family/friends as to the severity of my child's illness .....	1	2	3	4	5	1	2	3	4	5
28. Handling changes in my child's daily medical routines.....	1	2	3	4	5	1	2	3	4	5
29. Feeling uncertain about the future .....	1	2	3	4	5	1	2	3	4	5
30. Being in the hospital over weekends/holidays.....	1	2	3	4	5	1	2	3	4	5
31. Thinking about other children who have been seriously ill.....	1	2	3	4	5	1	2	3	4	5
32. Speaking with my child about his/her illness .....	1	2	3	4	5	1	2	3	4	5
33. Helping my child with medical procedures (e.g. giving shots, swallowing medicine, changing dressing) .....	1	2	3	4	5	1	2	3	4	5
34. Having my heart beat fast, sweating, or feeling tingly	1	2	3	4	5	1	2	3	4	5

<b>EVENT</b>	<b>HOW OFTEN?</b>					<b>HOW DIFFICULT?</b>				
	1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often					1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely				
35. Feeling uncertain about disciplining my child.....	1	2	3	4	5	1	2	3	4	5
36. Feeling scared that my child could get very sick or die.....	1	2	3	4	5	1	2	3	4	5
37. Speaking with family members about my child's illness .....	1	2	3	4	5	1	2	3	4	5
38. Watching my child during medical visits/procedures..	1	2	3	4	5	1	2	3	4	5
39. Missing important events in the lives of other family members.....	1	2	3	4	5	1	2	3	4	5
40. Worrying about how friends and relatives interact with my child .....	1	2	3	4	5	1	2	3	4	5
41. Noticing a change in my relationship with my partner	1	2	3	4	5	1	2	3	4	5
42. Spending a great deal of time in unfamiliar settings....	1	2	3	4	5	1	2	3	4	5

## Appendix F Feedback

Please answer the following questions based on your experiences in the **Parent Empowerment** program:

1. I enjoyed participating in the **Parent Empowerment** program.

1	2	3	4	5
Strongly Disagree	Moderately Disagree	Neither Disagree nor Agree	Moderately Agree	Strongly Agree

2. I felt comfortable with my **Parent Empowerment** support provider.

1	2	3	4	5
Strongly Disagree	Moderately Disagree	Neither Disagree nor Agree	Moderately Agree	Strongly Agree

3. The content of my individual **Parent Empowerment** session was relevant to my concerns.

1	2	3	4	5
Strongly Disagree	Moderately Disagree	Neither Disagree nor Agree	Moderately Agree	Strongly Agree

4. Since your **Parent Empowerment** session, how often have you used the **Parent Empowerment** problem-solving materials (Parent Manual and Mini Strategy Card) to help you solve a difficult problem? Check the most appropriate option:

- \_\_\_\_ Never
- \_\_\_\_ 1-2 times per month
- \_\_\_\_ 3-4 times per month
- \_\_\_\_ 1-2 times per week



\_\_\_\_ 3-4 times per week

\_\_\_\_ More than 4 times per week

5. Since your **Parent Empowerment** session, how often have you used the **Parent Empowerment** problem-solving strategies (1. “How do I see the problem?”; 2. “Getting the facts”; 3. “Brainstorming Solutions”; 4. “Making a Decision”; and 5. “How did my solution work?”) in your mind, *without* looking at the **Parent Empowerment** Parent Manual or Mini Strategy Card? Check the most appropriate option:

\_\_\_\_ Never

\_\_\_\_ 1-2 times per month

\_\_\_\_ 3-4 times per month

\_\_\_\_ 1-2 times per week

\_\_\_\_ 3-4 times per week

\_\_\_\_ More than 4 times per week

**Please respond to the following questions in the space provided.**

1. What aspect of the **Parent Empowerment** program was most helpful to you? Least helpful?

2. Do you have any suggestions for improving the **Parent Empowerment** program?

**Appendix G**  
**Medical Record Review Form**

For each caregiver participant, the following information will be gathered from the pediatric patient's medical record:

Age: \_\_\_\_\_

Gender: \_\_\_\_\_

Diagnosis: \_\_\_\_\_ Stage: \_\_\_\_\_ Risk level (ALL only): \_\_\_\_\_

Treatment (check all that apply):

\_\_\_\_\_ Chemotherapy

\_\_\_\_\_ Surgery

\_\_\_\_\_ Radiation

\_\_\_\_\_ Stem Cell/Bone Marrow Transplant

## Appendix H

### Additional Utilization of Services Log

For each support session that occurs between baseline measurement and the 3-month follow-up, log the following information: (1) Date; (2) Support provider – Psychologist (P), Social worker (SW), Chaplain (Ch), Child Life specialist (CL); (3) To whom support was provided – Child, Parent or Both.

Date	Support Provider	Service for Child	Service for Parent

**Appendix I**  
**Treatment Fidelity Measure – Session 1**

While listening to the audio recorded intervention sessions, indicate whether the following topics were covered:

Topic Area Did the therapist....	Did the therapist cover this topic area?	
	YES	NO
<b>Introduction</b>		
Explain the purpose of the Parent Empowerment (PE) program		
Say that having difficult problems is typical for parents of children with cancer (normalizing problems)		
Therapist builds rapport with parent by asking what difficult experiences he or she has had since the child's diagnosis		
<b>Rationale for Problem-Solving Therapy (Basis of PE program)</b>		
Ask the parent what types of problems he or she copes well with		
Therapist reviews how PE program can help the parent and his or her family		
Therapist asks parent to identify a specific problem which he or she is facing that can be addressed in the PE session ( <i>problem identification</i> )		
<b>Step 1: Positive Problem Orientation</b>		
Therapist describes problem orientation		
Therapist reviews 4 components of positive problem orientation		

Therapist reviews with parent his or her current problem orientation		
Therapist discusses with parent how to make his or her problem orientation more optimistic		
<b>Step 2: Problem Definition and Formulation</b>		
Discusses three sources from which to get facts to solve problem: medical team, other parents, printed brochures		
Emphasizes objectivity when examining available facts		
Therapist helps parent practice gathering facts as they apply to the present problem: The WHO, WHAT, and WHY		
<b>Step 3: Generation of alternative solutions</b>		
Therapist explains ways to devise possible solutions (brainstorm and think of possible strategies)		
Therapist helps parent devise possible solutions to the present problem		
<b>Step 4: Decision Making</b>		
Therapist explains steps for making decision: (identify consequences, cost-benefits analysis, likelihood of success for each alternative)		
Therapist helps parent apply these three steps to the present problem.		
<b>Step 5: Solution Implementation and Verification</b>		
Therapist explains that solutions are not always effective		
Therapist explains how to evaluate whether or not a solution was effective		
<b>Wrap-Up</b>		
Therapist asks parent how PE skills can be helpful in the future		
Therapist asks about and addresses barriers to implementation of skills		

Therapist shows parent how to use PE manual		
Therapist encourages the parent to practice the PE skills		

**Appendix J**  
**Randomization Plan**

<b>Participant ID</b>	<b>Treatment Condition 1 = Intervention 2 = Control</b>
01	2
02	1
03	2
04	1
05	1
06	1
07	1
08	2
09	2
10	1
11	2
12	2
13	2
14	2
15	1
16	2
17	1
18	1
19	2
20	1
21	1
22	1
23	1
24	2
25	2
26	2
27	1
28	2
29	2
30	1
31	1
32	2
33	2
34	1

35	2
36	2
37	1
38	1
39	2
40	1
41	2
42	2
43	1
44	1
45	1
46	1
47	2
48	2
49	2
50	1



## **Appendix K**

### **Parent Empowerment Manual**

#### **Problem-solving training for parents of children with cancer**

#### **THERAPIST MANUAL**

*Based on "Helping Cancer Patients Cope," by Nezu, Nezu, Friedman, Faddis, and Houts*

#### **PROBLEM-SOLVING INTERVENTION**

Therapist preparation:

1. Eligible participants: Any primary caregiver of a child who has been diagnosed with cancer is eligible for participation. Caregivers include anyone who provides routine care to the child and most likely lives in the home with the child, such as a parent, step-parent, or grandparent. If 2 or more primary caregivers from the same family want to participate in the study, they must be randomized to the same treatment condition. If 2 or more primary caregivers want to participate, they should ideally receive the intervention together in order to promote family problem-solving. However, if logistical issues do not allow for joint participation, the intervention may be conducted separately for each caregiver.
2. Location: This intervention can be conducted at any location that is convenient for parents. Most likely it will take place in the Pediatric Hematology/Oncology Clinic or on the pediatrics in-patient floor of Main Hospital. However, parents must be able to devote 60 minutes of time to the intervention without being distracted, or having to stop the intervention to attend to the child. Therefore, the intervention should only be conducted when the parent can devote his/her attention to the intervention. Ideally, the intervention should be conducted in a private room. The interventionist will work with parents and nursing staff to find a suitable time when the session will be minimally interrupted by medication administration, procedures, etc. Whenever possible, the intervention will be conducted while the child is sleeping, at a time when another caregiver is available, or while a hospital volunteer is occupying the child.

### 3. Needed Materials:

Parent packet with handouts

Laminated index card with problem-solving therapy (PST) reminders

Pen

## I. Program introduction

(Please emphasize that it is a *program*, do not emphasize that it is a research study - but must inform parents that it is.)

### A. Introductions

Therapist: *Thank you for deciding to participate in The Parent Empowerment Program. Before we get started, I'd like to introduce myself, get to know you, and tell you a bit more about what we will be doing today, and how it might be helpful to you in the future.*

*My name is \_\_\_\_\_ and I am a \_\_\_\_\_ (state title, education level, experience). I am happy to have the opportunity to spend a little time with you today so that I can provide you with some skills to help you solve problems that you experience as a parent of a child with cancer. This program is also part of a research study we are conducting through the Division of Pediatric Hematology/Oncology and Department of Psychology. We want to figure out the best way to help parents solve difficult problems during their child's cancer treatment. So, by being a part of this study, you can learn some ways to better problem-solve; but will also help us to develop our program to help other parents in the future. I would like to let you know also, that I am NOT a member of the Division of Pediatric Hematology/Oncology staff, and that I am not a member of your child's care team. I am only helping with the Parent Empowerment program, so there may be some questions that I cannot answer for you.*

*What we talk about today will be very structured. For the first part of the session, I will use my notes to make sure that I am giving you all the information that you need for our session. Also, out of respect for your time, I will work to keep our meeting time to around 60 minutes. So, just in case we get a bit off-track, I will re-direct our discussion back to the Parent Empowerment skills. Do you have any questions so far? (Emphasize your role here as a teacher/provider of information, rather than psychotherapist.)*

## B. Overview/purpose of the program

*This intervention is part of a new program for parents and caregivers of children diagnosed with cancer at VCU Children's Medical Center. We've developed this program because we know that diagnosis and treatment are very stressful and frightening for parents. It's likely that you have been faced with many problems and challenges, and have had to make difficult decisions.*

*The purpose of the Parent Empowerment Program is to talk about problem-solving skills that will hopefully help you solve problems that come up during your child's treatment. Solving problems may be difficult for you now because you probably feel stressed and overwhelmed. By using the Parent Empowerment skills, you will be able to better solve problems. You may even feel less stressed, and as a result, be better able to care for your child!*

## C. Tell parents what today's session will entail

*There are 5 Parent Empowerment problem-solving steps. We will go through the 5 steps together today, and apply the Parent Empowerment steps to a problem that you are having now. I will also give you a workbook and a laminated index card with reminders of how to use the Parent Empowerment steps. Again, out of respect for your time, I want to keep our session brief, no more than about 60 minutes. So we'll stick to the information that is in the workbook.*

*Let's now look at the first page of the workbook with ways that the Parent Empowerment program can help you and your family.*

Review the "How can Parent Empowerment help me and my family?" worksheet. This sheet provides a rationale to parents for participation in the program and can help answer questions.

*I want to make sure that we use the Parent Empowerment steps to apply directly to you and your family. So I'd like to talk to you a bit about your child and your experiences with his/ her treatment, before we get started on the Parent Empowerment steps.*

*Would you please tell me a bit about your child?*

(In the interest of time, try to encourage just a brief overview of the diagnosis, treatment trajectory, psychosocial issues, etc. This information will be important in order to focus the intervention on the parent's specific needs.)

*What has been most difficult for you in having a child with cancer?*

(Because this intervention is parent-focused, try to get a sense of how the parent is handling the diagnosis/treatment. Again, try to encourage brevity.)

*What have you dealt with best?*

(Ask this question to get a better sense of the parents coping ability/style.)

(Get a sense of how the participant copes with stress. This will give you some idea as to what steps of the problem-solving intervention you need to focus on, and which ones you may be able to move through quickly.)

## II. Overview of Parent Empowerment - (Problem-Solving Therapy - PST)

### A. Rationale for PST

*As I mentioned earlier, the main focus of the Parent Empowerment program is on problem-solving skills. Today, we will talk about ways to improve your problem-solving skills. We will use the skills to come up with a solution to a problem you have now. The goal is for you to use these Parent Empowerment skills with other problems that come up in the future.*

#### 1. Child's disease is a new, major stressor

*Also as I mentioned before, we have developed the Parent Empowerment program because we know that a child's diagnosis and treatment are big sources of stress for parents. We want to give parents more tools for solving problems that cause this stress. It is likely that you are dealing with many different problems such as taking care of your child with cancer, taking care of other children, relationship or family issues, work difficulties or financial difficulties.*

#### 2. PST as a method of reducing parent stress

*Different people have different ways of solving problems that come up, and you probably have your own method for solving problems. What is different for you now, however, is that your child has been diagnosed with a serious disease, and you are now faced with many tough problems all at once. In the Parent Empowerment program, we focus on reminding parents how they can use problem-solving skills to solve problems that are related to their child's medical care, or the other problems that come up during treatment. It is likely that you already have some of these skills, but may need to practice others.*

*Do you have any questions before we get started?* (Answer questions or review parts of the PST process that the participant does not understand.)

### III. Parent Empowerment Five-Step Process

#### **A. Problem identification**

*Ok, now that we've talked about the purpose of the Parent Empowerment Program, let's go through the five steps. It will be easiest to understand the Parent Empowerment steps if we do it while talking about a problem you are having now. This problem must be one that you are involved in. It could be related to your child's medical treatment, but might also be related to other problems you have had as a result of your child's diagnosis. It might be family-related, work-related; anything that is currently a problem for you.*

*Can you think of a problem that you are having now, one that you play a role in, that you would like to use the Parent Empowerment steps to work through?*

Allow the participant to come up with one problem with which he/she is currently dealing. It must be a problem that he/she has a role in, and therefore cannot be exclusively medically-related (e.g., "My child's white blood count isn't staying at a normal level."), but try not to "give" them a problem to talk about, be sure that he or she comes up with in on his/her own. Some examples of applicable problems might be: ("I can't stand to see my child go through medical procedures."; "My husband and I never see each other."; "Family members keep telling me what to do.")

#### **B. Parent Empowerment Five step process**

##### **1. "How do I see the problem?" (Problem orientation)**

###### **a. Background information:**

*The first thing to do is to think about how you see the problem. How parents look at problems that come up during treatment sets the stage for how well they can solve the problem. You have a better chance of solving a problem if you look at the problem in a hopeful or optimistic way, rather than in a negative or pessimistic way. Let's use Handout #1 for this step. (Direct participant's attention to Handout #1. Go through each point in detail and further explain if necessary.).*

*It is normal and ok to be stressed and to have negative emotions. Having negative emotions may make being optimistic difficult. With cancer treatment in children, there are going to be problems that may seem to not have a positive possible outcome. We want you to look at problems in a realistic way. But, no matter how serious the problem is, you can still look at your role as caregiver in a hopeful and optimistic way. If you are hopeful and optimistic, your child will also be hopeful and optimistic. Even young children can pick up on their parents' optimism.*

*Here are some things that you can tell yourself to look at your role as a caregiver in solving problems in a hopeful and optimistic way: (On Handout #1)*

- 1. Remind yourself that it is normal for problems to come up.*
- 2. Remind yourself that you can pinpoint the source of a problem.*
- 3. Remind yourself that you have the ability to affect your child's well-being.*
- 4. Remind yourself that you can deal with problems without letting your emotions get in the way or avoiding the problem all together.*

**b. Application to parent:**

*Let's now talk about how you can apply the first Parent Empowerment step, "How do I see the problem?"*

*Since your child's diagnosis, how have you looked at problems that have come up?*  
(Discuss with the participant his/her typical problem orientation style.)

*Let's now talk about \_\_\_\_\_* (insert type of problem he/she brought up at the beginning of the session).

*How do you think you could change the way you see problems to think more optimistically?* (Use the positive problem orientation components to address the parent's problem orientation. Use worksheet #1 to help parent outline his/her problem-orientation.)

*So it's important to remember that the best way to approach a problem is with hopeful optimism.*

**2. "Do I have all the facts I need to solve this problem?" (Problem definition and formulation):**

*The next step is to gather all the information you need to solve the problem. When solving problems related to your child's cancer treatment, it's important to be well-informed of the facts related to the problem. It's important to take the time to get the facts, rather than trying to solve the problem too quickly. Let's talk about some ways to find the facts that you need. We'll also talk about how to make sure that you have all the necessary facts for solving your problem. We'll use handout #2 in your workbook. (Use handout #2)*

*How to get the facts:*

- 1. You aren't expected to know everything about your child's disease. The best source of information is your child's medical team. If you have a question or don't understand something, ask them! They want to help keep you informed as much as possible. Remember that providing care to your child is their number one priority, and they want to hear from you if there is a problem. Your child has (or will be) assigned a nurse in the clinic who will follow him or her during outpatient visits. During working hours, the nurse is a good person to call for questions when your child is not at the hospital. On nights and weekends, there is always a doctor on-call who is available. Seeking out information as soon as a problem arises may help prevent a bigger problem from developing.*
- 2. Other parents who have had a child with cancer are great resources for information. After all, they've been in your shoes! If you would like to be introduced to a parent who has had a child with cancer, let a member of your child's care team know. They would be happy to help you find another parent to talk to and ask questions of.*
- 3. Parent information guides printed by national cancer resource organizations are also good sources of information. Be careful of information you find on the internet, however. Anyone can post information, which may or may not be accurate, and which may or may not actually apply to your child.*

*The next part is to take the information you have and develop a possible solution:*

- 1. Look at all the facts that you have. When you're frustrated, it's easy to ignore some of the facts of the situation. Be specific about what you know about the problem.*
- 2. Be objective - separate facts from assumptions. Be sure that you are considering only actual facts, not your own assumptions. Your efforts to solve the problem may not work out in the end if you use your assumptions.*



*An easy way to get facts is to think like a detective. Detectives must get all the facts, the WHO, WHAT, WHY, WHEN, and WHERE. Let's work together to use this method to define the problem of \_\_\_\_\_ (insert problem of interest).*

(Complete worksheet #2 with the participant, again based on the problem he/she identified. Be sure to help him/her define the problem in objective, specific terms!)

### **3. Develop possible solutions to the problem (Generation of alternative solutions):**

*Next we want to think of solutions, or ways to solve the problem. Often, there is more than one way to solve a problem. Before we can decide the best way to solve a problem, we need to figure out all the possible, but realistic, ways to solve the problem. This is like a brainstorming activity that helps you find the best way to solve the problem.*

*Let's talk about some ways to come up with possible solutions:*

(Present handout #3 to explain this step; and have the participant follow along.)

*1. First, brainstorm all the possible ways to solve the problem.*

*2. Second, focus on solutions that are realistic, but don't worry just yet about whether or not each way will work. If you worry now about what will work and what won't work, you might accidentally miss finding a solution that might work.*

*3. Finally, think about the strategies you'll need to carry out each possible solution.*

*Now, let's think of all the possible solutions for the \_\_\_\_\_ problem (insert problem of interest), and all of the strategies that could be used for each. Remember, don't judge how well each solution will work just yet, write down all realistic solutions that come to mind!*

(Use worksheet #3 to help parent identify possible solutions.)

### **4. Decision making:**

*Now it's time to decide which possible solution to use to solve your problem. Remember to go through the first three steps, and don't be tempted to jump straight to this step.*



*Going through all of the steps helps you to make the best choice. Taking your time and going through the first three steps will lead to better solutions for you and for your child.*

*Now let's talk about what steps to take to solve the problem of \_\_\_\_\_.*

*We'll use Handout #4:*

(Present Handout #4 so that the participant can understand each step)

*1. First, think about the consequences of each potential solution. How will each possible solution affect you, your child, and other important people involved in the care of the child, such as family members? Also think about both the short-term and long-term consequences of each potential solution.*

*2. Second, weigh the pros and cons of each of the consequences you listed. What kind of result does each consequence have, positive, negative, or neutral?*

*3. Finally, think about how likely each solution is to work, and how likely you are to actually use each solution.*

Now assist the parent in using these steps to come up with a solution to the present problem.

*Which solution would you like to use to solve your problem?*

The chosen solution should have the most possible positive effects, be likely to succeed, and be realistic to implement.

## **5. Evaluating your solution (Solution Implementation and Verification):**

*The last step is to see how well your solution worked to solve your problem. We'll use Handout #5. (Review handout #5)*

*As a parent of a child with cancer, you face many tough problems. After you have made a decision and carried it out, it is important to see if your solution worked or not. If your solution worked, remind yourself that you have what it takes to solve problems. Remember, that during your child's cancer treatment, unexpected problems do come up, and there may be times when your solutions don't work out the way you expected. When your solutions don't work out the way you expected, it's important to figure out what could have been done differently, and try another solution. Remember that it is not always your fault if a solution does not work out. Child cancer treatment can have*

*unexpected or unplanned roadblocks and there will be situations that you cannot control. These situations tend to be directly related to your child's illness. When this happens, getting expert advice from your child's medical team is the best option. Remember, you are not expected to solve every problem on your own. Your child's medical team is the best source of information when you feel stuck. (Review with parent how to use worksheet #5.)*

#### IV. Wrap-Up

*We've now finished the Parent Empowerment problem-solving method and applied it to a problem you are currently encountering. How do you think the Parent Empowerment steps can help you in the future? Is there anything that might stop you from using these steps?*

*Remember that the Parent Empowerment steps will work best for you in the future if you practice them. We've provided you with extra copies of the worksheets so that you can use the Parent Empowerment steps with new problems that come up. It may seem bothersome to fill out the worksheets, but they can help you practice the Parent Empowerment steps. That way, when you are faced with a tough problem, you'll have practiced the skills to solve the problem. We are confident that if you use the Parent Empowerment steps, it will become easier to deal with the many problems that you, as a parent of a child with cancer, face. If you practice these steps, it will also be easier to solve problems when you are feeling stressed.*

STRONGLY emphasize to parents that they should practice these steps and apply them to problems that arise. Encourage them to use the steps with a small problem first, so that when a larger problem arises, they have the skills to utilize the steps as applied to a larger problem. Remind parents that you will have a booster session in 2 weeks, and encourage them to apply these steps to a problem that you can review with them during the booster session.

*In about two weeks, we'll do a follow-up session where we'll talk about the Parent Empowerment steps again. If possible, in the next 2 weeks, try out the solution of \_\_\_\_\_ to solve the problem of \_\_\_\_\_.*

Encourage parent to try out the solution he/she developed.

*If a new problem comes up, and you think you can use the Parent Empowerment steps to solve it, use the extra worksheets to try to solve the problem. We can also talk about how you used the Parent Empowerment steps to solve any new problems that come up.*

*Remember, the problem might be related to your child's medical care, or it might be related to your jobs as a caretaker, but it should be one that you play a role in. When we meet next time, we'll talk about what works for you and what doesn't work, and talk about ways to make these strategies work for you and your family. GOOD LUCK!!!*

**Appendix L**  
**Parent Empowerment Worksheets and Handouts**

# Parent Empowerment

*Helping parents of children with cancer cope*

**VCU** Children's Medical Center  
Virginia Commonwealth University  
Every Day, A New Discovery.®



## How can the Parent Empowerment Program help me and my family?

- Provide specific tools for solving problems related to your child's treatment
- Help make overwhelming problems seem more manageable
- Help you focus when feeling overwhelmed with difficult problems
- Help relieve some of the stress that you experience



# Step 1: How do I see the problem?

## Handout #1

- Parents who look at problems in a hopeful or optimistic way have a better chance of solving problems successfully.
- It is important for the well-being of your child to let him or her know that you are looking at the problem in an optimistic or hopeful way.
- Here are some things you can tell yourself to see problems more optimistically:
  - In the early stages of cancer treatment, it is normal and expected for problems to come up.
  - Reassure yourself that you can notice problems when they occur and pinpoint the source of the problem.
  - The way that you look at a problem can affect the well-being of your child, yourself, and your family.
  - You can deal with problems without letting your emotions get in the way or avoiding the problem all together.



## Worksheet #1: Changing how you see a problem

This worksheet can help you see the problem in a more optimistic way:

What is the problem? \_\_\_\_\_

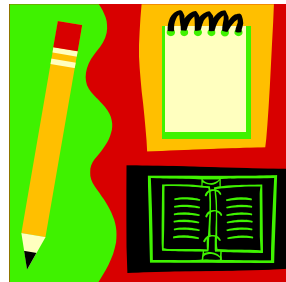
How do I see the problem now?	How can I see the problem more optimistically?
1.	1.
2.	2.
3.	3.
4.	4.




## Step 2: Getting the facts

### Handout #2

- Ask yourself:
  - *Do I have all the facts I need to solve the problem?*
- You need the right facts to solve a problem.
- Good ways to get facts about your problem:
  - Your child's medical team.
  - Other parents of a child with cancer
  - Parent education brochures
- Remember: Work with only facts, not assumptions!





## Worksheet #2: Getting the facts about the problem

This worksheet can be used to help you be sure you have all the necessary facts to solve the problem. Remember to be specific!

- Who is involved in this problem?
- What is the exact cause of the problem?
- Why is this situation a problem?





## Step 3: Brainstorming solutions

### Handout #3

- Now think of all the possible solutions to the problem.
  - Quantity leads to quality - make a list of all realistic solutions!
- Don't judge any ideas until later
- Think of strategies for solving the problem





## Worksheet #3: Brainstorming Solutions

Use this worksheet to come up with all possible solutions

*Remember, don't judge the value of the possible solutions yet!*

Possible solution	Strategies



## Step 4: Making a Decision

### Handout #4

- The next step is to pick a solution from the list of possible solutions
- The BEST solution is one that:
  - ☐ Solves the problem
  - ☐ Has the most positive consequences
  - ☐ Has the fewest negative consequences
- Think about how each solution will work for:
  - ☐ You
  - ☐ Your child
  - ☐ Those involved in the child's care
- The consequences of each solution:
  - ☐ Short-term consequences
  - ☐ Long-term consequences
- How likely it is that the solution will solve the problem
- How likely it is that you will be able to carry out the solution
- Choose the solution with more pluses (+) than minuses (-)



## Worksheet #4: Making a Decision

### Instructions:

#### On the next page...

- (1) Write the problem-solving goal
- (2) Write an abbreviated form of each possible solution
- (3) Guess the consequences of each possible solution
- (4) Evaluate each possible solution using the following scale

### Rating Scale:

+ = Generally positive consequences (1-5); OR  
Very likely (6-7)

- = generally negative consequences (1-5) ; OR  
Not very likely (6-7)

0 = neutral

Goal: How can I...

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Possible solution	1. Effect on you	2. Effect on your child	3. Effect on others involved in child's care	4. Short-term effects	5. Long-term effects	6. Likelihood of success	7. Is it realistic? Can I do it?



## Step 5: How did your solution work?

### Handout #5

Now it's time to evaluate how well your solution worked.

1. Carry out the solution you chose
2. Monitor the outcome of your solution
3. Evaluate the outcome: Did it work?
  - If yes: Reward yourself for your success
  - If no: Troubleshoot other options
    - ☐ Gather additional facts
    - ☐ Try another solution
    - ☐ Talk with healthcare providers (especially with illness-related problems)





## Deciding how well your solution worked

### Worksheet #5

- What were the results of your solution?

How well did your solution meet your goals?

1	2	3	4	5
Not at all		Somewhat		Very well

- 
- What were the effects on your child?

How well did your solution meet your goals?

1	2	3	4	5
Not at all		Somewhat		Very well

- 
- What were the effects on you?

How well did your solution meet your goals?

1	2	3	4	5
Not at all		Somewhat		Very well

**Appendix M**  
**Parent Empowerment Pocket Reminder Card**



## Remember the 5 Parent Empowerment Steps to Solving a Difficult Problem:

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1. Think positively about your ability to solve the problem.
2. Get all the facts you need to solve the problem.
3. Brainstorm all possible solutions
4. Make a decision
5. See if your decision worked

**Appendix N**  
**Session Note**

**To be filled out by interventionist prior to phone follow-up. This information will be used as the basis for the follow-up:**

Problem discussed in intervention session:

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Areas of major concern for the parent:

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Potential areas of weakness in the problem solving process:

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## Appendix O

### Follow-up session script

(To be scheduled at a time convenient for the parent.)

#### 1. Brief check-in (5 minutes)

*How have you and your family been doing since we last spoke?*

(Process any new concerns or problems that may have arisen for the family.)

#### 2. Review of the problem-solving steps and inquiry about progress in each (20 minutes)

Use the problem that the parent addressed in session 1.

*When we met last, we talked about the Parent Empowerment steps for solving problems. We used your problem of \_\_\_\_\_ to learn these steps. Let's review those steps now, and we'll talk again about how each step was used for the problem of \_\_\_\_\_. If you used these steps for a different problem, we can talk about that too.*

*The first step is to think about how you see the problem. Remember, that how you see the problem matters a great deal in how you will go about trying to solve the problem. There are many problems that you, as a parent of a child with cancer, are faced with, and they may seem overwhelming. However, it is important to approach a problem in a realistic and hopeful way.*

*Here are some things that you can tell yourself to look at your role as a caregiver in solving problems in a hopeful and optimistic way: (On Handout #1)*

- 1. Remind yourself that it is normal for problems to come up.*
- 2. Remind yourself that you can pinpoint the source of a problem.*
- 3. Remind yourself that you have the ability to affect your child's well-being.*
- 4. Remind yourself that you can deal with problems without letting your emotions get in the way or avoiding the problem all together.*

*Since we last spoke, how have you looked at the problem of \_\_\_\_\_. How have you looked at problems that have come up?*

Speak with parents about their current problem-orientation. If it has improved, discuss ways in which to maintain these improvements. If it has not improved, review the above 4 statements and help the parent apply them to the problems that they experience.

*The second step is to be sure that you have all the facts that you need to solve the problem. Sometimes when parents feel overwhelmed, they try to solve problems in a hurry without getting all the information that they need. It is very difficult to solve a problem without all the necessary information. Remember, that the best source of facts is your child's medical team. You're not expected to solve every problem on your own or to know all of the answers. If you have a question or need information, ask your child's doctor or nurse.*

*Before making a decision, it is important to look at all the facts. Since we last spoke, how has it been for you to get information that you need before making a decision?*

Speak with the parent about gathering facts before making a decision. Emphasize talking with the child's medical team.

*Once you have gathered all the facts, the third step is to think of all the possible solutions to a problem. It is best to brainstorm everything that might solve a problem, because this increases your chances of coming to a solution. Remember though, at this step, you don't need to worry whether or not each solution will work. Last, think about the strategies you'll need to carry out each solution. Have you found it helpful to think of several possible solutions before trying to solve a problem?*

Talk with the parent about devising several possible solutions to a problem. Emphasize that being flexible and creative with possible solutions is important to solving problems effectively.

*After you have thought of all the possible solutions, the fourth step is to decide which solution is the best. In order to decide which solution is the best, it is important to do two things:*

- 1. First, think about the consequences of each potential solution. Think about how each possible solution will affect you, your child, and other important people involved in the care of the child, such as family*

*members. Also think about both the short-term and long-term consequences of each potential solution.*

*2. Second, weigh the pros and cons of each of the consequences you listed. What kind of result does each consequence have, positive, negative, or neutral?*

*3. Finally, think about how likely each solution is to succeed, and how likely you are to actually use each solution.*

*How has it been for you to decide what solutions to use to solve a problem?*

Discuss with him or her how he or she decides what solutions to use in problem solving.

*The final step is to see how well your solution worked to actually solve the problem. Since we didn't get to talk about this step during the last session, let's talk about it now. Did you get the chance to use your strategy of \_\_\_\_\_ to solve the problem of \_\_\_\_\_?*

If the parent did use the strategy: *What was the result of your strategy?* (If the parent perceives the outcome as positive, praise his/her efforts and encourage continued problem-solving in the manner discussed.)

If the parent did not use the strategy: *Is this still a strategy you think could work? Is this something you can still try?* (If the parent is willing, encourage him/her to use the strategy. If not, help him/her brainstorm new ideas.)

For all parents: *What was the effect on you? What was the effect on your child? Were there any other positive outcomes?*

Talk with parents about their perceptions of how their problem solving efforts have worked. Emphasize to parents that the child's medical team is the best source of information if plans do not work. Remind them that, just because a solution didn't work, they are not failures. Encourage them to identify what went wrong, and develop another course of action.

3. Wrap-up (5 minutes)

*Thank you again for being a part of the Parent Empowerment program. We hope that these skills have been helpful. For these skills to be helpful to you in the future, it is important to keep practicing them.*

*Do you have any questions before we wrap-up?* (Answer any questions the parent has.)

*In order for us to see how well Parent Empowerment helps parents, we are having parents fill out questionnaires two more times. In about 4 weeks, one of our research team members will meet with you when you and your child are in the outpatient clinic or on the inpatient unit and ask you to fill out those questionnaires. For filling out these questionnaires, you will receive a \$15 store gift card. Then, about 2 months after that, we will also meet with you to fill out the questionnaires one more time. After filling out the last set of questionnaires,, as a thank you for your time and participation, we will give you an additional \$10 gift certificate.*

Answer any final questions and thank the parent for his or her time.



**Appendix P**  
**Control Condition Session Handouts**

## At the Hospital: Helping My Child Cope With Illness

### What Parents and Caregivers Can Do

Feeling distressed or having strong emotional reactions is common when children are hospitalized. Even though it is your child who is ill, your whole family can feel overwhelmed or unprepared to cope. With time, understanding, and support, most children and families learn to adjust to the illness and cope with the hospital experience.

#### Things in the hospital that can be distressing or traumatic:

- Not knowing what is going to happen
- Changes in appearance – hair loss, weight gain/loss, surgical scars, etc.
- Being afraid of dying
- Being left alone or separated from siblings and pets
- Seeing other sick kids
- Being in pain or going through painful procedures
- Being exposed to equipment that looks or sounds scary
- Thinking that being in the hospital is a punishment



#### Common changes in children when distressed or hospitalized:

- Being cranky, having tantrums, talking back
- Bed-wetting or thumb-sucking in younger children
- Being easily upset or feeling worried or confused
- Problems with eating, sleeping, or having nightmares
- Wanting to be alone or clinging to parents or other adults
- Feeling left out, missing friends or family
- Worrying about looking or feeling different from others

#### Parents and caregivers can get distressed too:

- They often get upset at seeing their child in pain and can feel helpless or frustrated as a result
- They may not want to be away from their child and always feel “on guard”
- They may have a shorter fuse, trouble eating and sleeping, or feel overwhelmed by their child’s medical needs
- They may worry in private about their child dying, but not want to share their worries with anyone

In addition, many parents and caregivers are unsure about how to talk with their sick child (or with their other children at home) about their feelings, fears, and questions.

**Special information for parents and caregivers of children:** It is common for children and parents to feel overwhelmed or frustrated by the illness or the hospital experience at first. It may even take a few weeks for these reactions to settle down. If your child continues to be upset, if you have questions about how to help your child, or if *you* need to talk, there are staff members at the hospital whose job it is to help. In addition to the doctors and nurses, mental health professionals (including social workers, counselors, psychologists, and chaplains) are skilled at helping children and families cope. Also, read the other side of this handout for tips on helping your child cope while at the hospital.

## Nine Ways You Can Help Your Child Cope While At The Hospital

1

**You are the best person to comfort your child.** Although it may be difficult at times, try to be calm and reassuring. Give frequent praise and hugs if your child wants them. During tests and procedures, hold your child's hand and distract your child with books, toys, or games.

2

**Be patient with your child.** Children's early reactions - including crying, whining, clinging, or acting out - are common and expected in small amounts. If they happen too often, it's okay to set rules and limits like you would at home. Work with the medical team to plan a daily routine so that things are more predictable and familiar.

3

**Help your child understand what is happening.** Use simple words and examples he or she can understand. If your child needs a scary procedure, be honest about the fact that it may hurt, but also explain its purpose is to help fight the illness.



4

**Encourage your child to share his or her feelings.** Help your child name his or her feelings such as being scared, angry, or sad. Sharing your feelings lets your child know that it's okay to share too. Remind your child that other children in the hospital have these feelings. Remember that younger children are often better at *"talking about"* their feelings through play, drawing, or storytelling.

5

**Remember that children have active imaginations.** Children can tell when others are upset or not telling them things. Without the facts, they can easily misunderstand and *"fill in the blanks"* with their imagination. Sometimes, children mistakenly believe that they did something wrong to cause their illness. Ask questions to figure out what they know and what they imagine (ex: *"What do you think is going to happen?"*) As realistically as possible, share the facts about the illness and let your child know that he or she has done nothing wrong to cause it.

6

**Help your child think of the hospital staff as helpers.** Remind your child that the staff has a lot of practice helping other sick children. Encourage your child to ask questions to the doctors or nurses. When possible, allow your child to make choices to give him or her a feeling of control.

7

**Young children are often more upset at being left alone.** While taking a break from the hospital can be helpful, have a family member or familiar adult stay with your child. *Always* tell your child when you are leaving, why, and when you will be back.

8

**Take care of yourself.** If you are worried, upset, or not sleeping, it will be harder to help your child. Don't be afraid to ask friends or family for help. Talk about your worries with other adults, such as family, friends, a counselor, a member of the clergy, or one of the medical staff.

9

**Remember that siblings and other children may also feel afraid, worried or jealous.** Siblings' needs are sometimes forgotten when a child is seriously ill. Set aside time to talk with your other children about what is happening, what to expect, and what they are feeling. Let them ask a lot of questions. Lean on close friends or family to provide *"special time"* and to help maintain daily routines.

# At the Hospital: Helping My Teen Cope With Illness

## What Parents and Caregivers Can Do

Feeling distressed or having strong emotional reactions is common when teens are hospitalized. Even though it is your teen who is ill, your whole family can feel overwhelmed or unprepared to cope. With time, understanding, and support, most teens and families learn to adjust to the illness and cope with the hospital experience.

### Things in the hospital that can be distressing or traumatic:

- Not knowing what will happen next
- Being in pain or going through painful procedures
- Fear of dying
- Side-effects or complications of treatment
- Concerns about relapse
- Changes in appearance - hair loss, weight loss or gain, or surgical scars, etc.
- Being separated from siblings, friends, and pets
- Seeing other sick teens or knowing others in the hospital who have died



### Common changes in teens when distressed or hospitalized:

- Being irritable, more sensitive, or talking back
- Feeling empty or numb
- Problems with eating, sleeping or having nightmares
- Wanting to be alone or with you all the time
- Feeling left out, missing friends or family
- Worrying about looking different or what others will think

### Parents and caregivers can get distressed too:

- They often get upset at seeing their teen in pain and can feel helpless or frustrated as a result
- They may not want to be away from their teen and always feel “on guard”
- They may have a shorter fuse, trouble eating and sleeping, or feel overwhelmed by their teen’s medical needs
- They may worry in private about their teen dying, but not want to share their worries with anyone

In addition, many parents and caregivers are unsure about how to talk with their sick teens (or with their other children at home) about their feelings, fears, and questions.

**Special information for parents and caregivers of teens:** It is common for teens and parents to feel overwhelmed and frustrated by the illness or hospital experience at first. It may even take a few weeks for these reactions to settle down. If your teen continues to be upset, if you have questions about how to help your teen, or if *you* need to talk, there are staff members at the hospital whose job it is to help. In addition to the doctors and nurses, mental health professionals (including social workers, counselors, psychologists, and chaplains) are skilled at helping teens and families cope. Also, read the other side of this handout for tips on helping your teen cope while at the hospital.

Developed by the Center for Pediatric Traumatic Stress (CPTS) at The Children’s Hospital of Philadelphia for the Health Care Toolbox: [www.healthcare toolbox.org](http://www.healthcaretoolbox.org)



## Nine Ways You Can Help Your Teen Cope While At The Hospital

- 1 You are the best person to comfort your teen.** Although it may be difficult at times, try to be calm and reassuring. Give frequent praise and hugs if your teen wants them. Understand that, at times, your teen may want to appear “grown up,” but also might be in need of your comfort and support.
- 2 Be patient with your teen.** Strong feelings are common but temporary reactions to the hospital experience. Remind your teen that it’s okay to be confused, angry, or scared. If your teen’s behavior gets to be too much, it’s okay to set rules and limits like you would at home.
- 3 Be honest with your teen.** Teens may want information, even if they don’t ask. Share the all facts about the illness and treatment –be realistic but hopeful. If your teen needs to go through a painful procedure, explain that it may hurt, but that its purpose is to fight the illness. The more your teen knows what to expect, the more prepared he or she will be.
- 4 Include your teen in medical discussions when appropriate.** Address any questions or concerns that your teen may have about the illness - from the biggest worries to the smallest hassles. Encourage your teen to ask questions of the doctors and nurses. Help your teen participate in decisions by planning how to cope with pain and stressful procedures in advance.
- 5 Talk about your feelings together.** Teens can sometimes jump to conclusions or misjudge what others are thinking. Gently ask questions to learn what your teen thinks and believes, and be a good listener. Be open to their feelings and what they have to say, even if it is upsetting or hard to hear. Sharing your feeling lets you teen know that it is okay to share theirs.
- 6 Teens are self-conscious and like to feel in control of their lives.** They will especially worry about how they will look and fit in with others. Reassure your teen, but don’t dismiss his or her concerns – even the small ones. Because many aspects of the illness are unpredictable, allow your teen to make choices and do some things on his or her own, which can provide a sense of accomplishment and control.
- 7 Help your teen stay connected with old friends and make new friends.** Being in the hospital can increase feelings of loneliness. Encourage your teen to keep in touch with friends by phone or email on a regular basis. Talk ahead of time about how to explain the illness and answer questions. Also, ask the medical staff to introduce your teen to others on the floor with similar experiences.
- 8 Take care of yourself.** Your teen can tell if you are worried, upset, or not sleeping, which makes it harder on everyone. Don’t be afraid to ask family or friends for help. Talk about your worries with other adults, such as family, friends, a counselor, a member of the clergy, or one of the medical staff.
- 9 Create a familiar environment.** Hospitalized teens feel more comfortable when surrounded by things that are familiar. Decorate the hospital room with stuff that helps your teen stay connected to his or her world back home. Also, work with the medical staff to plan a daily routine that is predictable and allows time for privacy and keeping in touch with friends and family.



# After the Diagnosis: Helping My Family Cope

## What Families Can Do

Feeling distressed or having strong emotional reactions is common with the diagnosis of a serious illness. Even though it is your child who is ill, your whole family – parents, brothers, sisters, or other relatives – can feel overwhelmed or unprepared to cope with the new demands and uncertainty that illness brings.

**What should I expect in the days and weeks after being diagnosed with a serious illness?** It is common for children (and other family members) to feel confused, upset, frustrated, or worried. Most need extra time to adjust to the illness and to treatment. After the diagnosis, some children and parents may act differently – they may keep thinking about the illness and get upset when they do. Sometimes, they try to avoid places (such as the clinic or hospital) and things that remind or upset them. These reactions usually get better with time, understanding, and support.

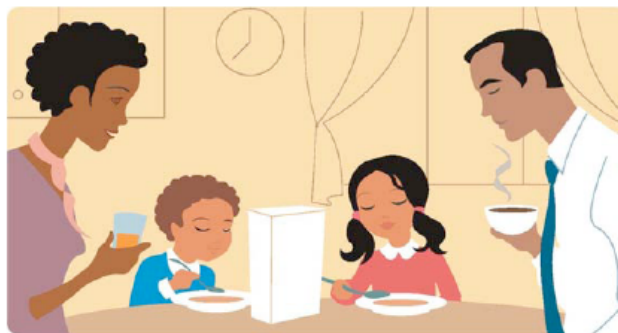
**Other common (but usually temporary) changes after being diagnosed with a serious illness:**

### In younger children:

- Clinging to parents or other adults
- Bed-wetting or thumb-sucking
- Being afraid of the dark
- Trouble sleeping or having nightmares
- Being cranky or having tantrums

### In older children and teens:

- Changes in sleeping and eating
- Wanting to be alone or with you all the time
- Being irritable, more sensitive, or talking back
- Feeling empty or numb
- Being overly self-conscious or worrying about what others will think
- Feeling left out; not able to do usual activities with friends or family



### In parents and caregivers:

- Being overprotective or “on guard”
- Getting upset at seeing their child in pain or discomfort
- Feeling overwhelmed about caring for their child’s medical needs
- Having a short fuse, having trouble sleeping or eating
- Worrying in private that their child might die, but not wanting to share their worries with anyone

### Signs that your child may need extra help:

- Watching out for danger all the time
- Having new fears not related to the illness
- Not wanting to go to school, or doing a lot worse in school
- Not wanting to be with friends or go back to usual activities
- Arguing more than usual with friends or family

**When and where should I get extra help for my child or family?** Even though the illness and treatment can be overwhelming at first, most children and families learn to adjust. If your child’s reactions get worse or get in the way of regular activities, or if other family members continue to be upset or worried, talk with your doctor or a mental health counselor about getting additional help. Some illnesses have associated behavior changes, so keep your child’s doctor up-to-date. Also, read the tips on the other side of this handout.

## Nine Ways You Can Help Your Family Cope With Serious Illness

**1 Be patient and give everyone time to adjust.** Members of the same family can react in different ways. Siblings and other children can feel upset or worried and may have questions. Most family members need time to adjust to and cope with the changes. It can be helpful to talk as a family about how the illness affects *everyone*.

**2 Help your family understand what is happening.** The diagnosis of a serious illness can be new, confusing, and scary for children and adults. Children have active imaginations; without all of the facts, they may get the wrong idea. Ask questions to figure out what your children know and what they are imagining. Share the facts honestly, using simple words and examples they can understand. Allow your children to ask questions and to share their worries – big and small.

**3 Encourage your family to share their feelings.** This can happen in different ways (talking, drawing, story-telling, hugging) at different times (dinnertime, bedtime) and in different places (in the car, at home). Help your children name their feelings, such as being sad, scared, or angry. Sometimes sharing your own feelings can show your children that it's okay to do the same. When your children or other family members do share, accept their feelings and be a good listener, even if what they say is hard to hear.

**4 Keep as many everyday routines as possible.** Because so many aspects of illness are unpredictable, normal routines help children feel safe. Having regular routines (meal and bed times, household chores) and activities give children and adults things to expect and look forward to.

**5 Set normal limits.** You may want to relax the rules in order to help your child or other children feel special. However, it is better if you set normal limits on behavior and keep most of your family rules and expectations the same. Plan fun activities as family rewards.

**6 Help your child do some things on his or her own.** It is often tempting to do things for your child when he or she is ill. Doing things on his /her own, as much as the illness allows, gives a child a sense of accomplishment and control, including: getting dressed, cleaning up room, and getting things for him/herself whenever possible.



**7 Encourage your child to spend time with friends.** With a serious illness, some children feel a little “different” or alone. They may also wonder how their friends will react. Talk ahead of time about how to explain the illness and answer questions (*Is it contagious? How long will you be sick?*) If possible, invite your child's friends to visit, and plan a few fun activities.

**8 Take time to deal with your own feelings.** Feeling worried or upset are common reactions in parents and caregivers. However, it will be harder to help your child if you feel overwhelmed or unable to cope. Talk about your feelings with another adult, such as a friend, a counselor, or a member of the clergy.

**9 Follow up with the doctor.** Even if your child is getting better, the doctor needs to know how he or she is coping, especially since some illnesses have behavior changes associated with them. For children and families who need extra help (*see front side*), don't hesitate to contact your doctor or a counselor.

# After the Hospital: Helping My Child Cope

## WHAT PARENTS CAN DO

When children are seriously ill or injured, and have to stay in the hospital, they and their families may feel upset or worried. These feelings are common and can continue after they return home. In addition, children and parents may wonder how they will cope without the support of hospital staff. Some families may also have difficulty readjusting to daily routines.

**What should I expect in the days and weeks after the hospital?** After being in the hospital, it is also common for some children to have minor changes in behavior. A few children and parents keep thinking about the experience and get upset frequently. Sometimes they also try to avoid places (such as the hospital) and things that remind them of it. These reactions usually get better with time, understanding, and support.

### Other common (temporary) reactions after coming home from the hospital:

#### In younger children:

- Clinging to parents or other adults
- Bed wetting or thumb sucking
- Being afraid of the dark

#### In older children and teens:

- Changes in sleeping and eating
- Being easily startled or jumpy
- Complaints of headaches or bellyaches, or other minor illnesses

#### In parents:

- Worrying a lot more about their child being safe
- Being overprotective or “on guard,” even when there’s no need
- Getting upset at reminders of what happened, especially if their children are in pain or discomfort
- Feeling anxious about caring for their child’s medical needs on their own



### Signs that your child may need extra help:

- Watching out for danger all the time
- Having new fears
- Not wanting to go to school, or doing a lot worse in school
- Not wanting to be with friends or go back to usual activities
- Arguing a lot with friends or family

**When and where should I get extra help for my child?** Most children and families feel better within a few days or weeks. (See tips for parents on other side.) Some injuries and illnesses have behavior changes associated with them, so it’s important to talk to your doctor as well. If your child’s reactions last longer, seem to get worse, or get in the way of day-to-day activities, see your doctor or a school counselor.



## Eight Ways You Can Help Your Child Cope After Being in The Hospital



- 1 Go back to everyday routines.** Normal routines help children feel safe. Help your child go back to doing his/her usual activities—as much as the injury or illness allows.
- 2 Be patient and give everyone time to readjust.** Keep in mind that people in the same family can react in different ways. Brothers and sisters can feel upset too. Most family members just need time and reassurance that things are returning to normal.
- 3 Set normal limits.** You may be tempted to relax the rules in order to help your child feel special, or to make up for the hard times that he or she is experiencing. However it is often better for your child if you set normal limits on behavior and keep most of your family rules and expectations the same.

**4 Allow your children to talk about feelings and worries, if they want to.** For younger children, encourage play, drawing, and story-telling. Ask your child (and brothers and sisters) what they are thinking, feeling, and imagining. Be a good listener—and share the facts, as well as your feelings and reactions.

**5 Encourage your child to spend time with friends.** After a serious illness or injury, some children feel a little “different.” They may also wonder how their friends will react. Invite a few of your child’s friends to visit, and help your child plan a few fun activities. It may be helpful to assist your child in answering questions his or her friends may have about the illness or injury (Is it contagious? How long will the bandages be on? etc.)

**6 Help your child do some things on his or her own.** It is often tempting to do things for your child after he or she is injured or ill. But it is more helpful for children to do things again on their own. As much as the injury or illness allows, encourage your child to do the things (including chores) he or she used to do.

**7 Take time to deal with your own feelings.** It will be harder to help your child if you are feeling really worried, upset, or overwhelmed. Talk about your feelings with another adult, such as a friend, your doctor, a counselor, or a member of the clergy.



**8 Follow up with the doctor.** Even if your child is getting better, the doctor needs to know how your child is coping, especially since some injuries and illnesses have behavior changes associated with them. For children and families who need extra help dealing with their reactions, helpful treatments are available. Your doctor will be able to help you figure out what’s best for you and your family.

*Developed by the Medical Traumatic Stress Working Group of the National Child Traumatic Stress Network.*

## Appendix Q

### Parent Recruitment Letter

Dear \_\_\_\_\_,

We are writing to invite you to participate in a new program for parents being conducted at Virginia Commonwealth University's Division of Pediatric Hematology/Oncology and Department of Psychology. This program is called the *Parent Empowerment Program* and is designed to help parents cope with having a child with cancer. This program is also part of a research study.

As a part of the *Parent Empowerment Program*, parents will meet with a counselor for two meetings during an outpatient clinic visit or inpatient hospitalization. Each meeting will last 30-90 minutes. Parents will also be asked to fill out a brief set of questionnaires before meeting with the Counselor, 1 month after the second meeting with the counselor, and again 3 months after the second meeting with the counselor. There are two different formats of the *Parent Empowerment Program*. If you decide to be in this research study, you will be randomly assigned to one of the formats. In one format, parents and caregivers will talk with the counselor about ways to solve problems that come up during a child's cancer treatment. Parents in this format will also have a 30 minute booster session around 2 weeks after the first session. In the other format, parents will meet with a counselor for a 30-60 minute session, and then a second 30-60 minute session two weeks later. The counselor will talk with caregivers about ways to help their child cope with having cancer and being in the hospital. These sessions will also be audio recorded so that we can be sure we understand parents' and caregivers' concerns.

In addition, your child's medical record will be reviewed to get information about his or her diagnosis and treatment. We will also count the number of times you or your child meet with any of the Division of Pediatric Hematology/Oncology support providers (e.g., psychologist, social worker, chaplain, child life specialist).

As a thank you for participating in this study, we will give you a \$25.00 gift card for completing both sessions and the three sets of questionnaires. Please remember that your participation is *voluntary*. We would like you to be a part of the *Parent Empowerment Program*, but you do not have to. Even if you decide to be in this study, you may choose not to answer some questions or quit the study at any time.

If you are interested in participating in this study, please fill out the enclosed return form and send it back to us. You will then be contacted by a member of the research staff who will provide you with more information.

Feel free to use the contact information below if you have any questions about what we are asking you to do:

Matt Bitsko, PhD  
Division of Pediatric Hematology/Oncology Psychologist  
mbitsko@mcvh-vcu.edu  
(804) 828-9048

Jennifer Lamanna, MA  
Project Coordinator  
lamannajd@vcu.edu  
804-828-5923 ext. 3

Thank you,

Matt Bitsko, PhD  
Licensed Clinical Psychologist  
Division of Pediatric Hematology/Oncology  
Virginia Commonwealth University Health Systems

**Appendix R**  
**Return Form**

**RETURN FORM:**

Thank you for taking the time to read through the information we sent and considering participation in the *Parent Empowerment Program*.

PLEASE RETURN THIS FORM in the postage-paid envelope stating whether you would like to participate in the study by attending the parent focus groups and filling out questionnaires.

**Please check one box to indicate your choice:**

- ☐ I would like to participate in the *Parent Empowerment Program*.  
☐ I do not want to participate.

**Contact Information**

Name: \_\_\_\_\_

Address: \_\_\_\_\_ City, State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Alternate Phone Number (if available): \_\_\_\_\_

Email Address: \_\_\_\_\_

Alternate Email Address (if available): \_\_\_\_\_

**Appendix S**  
**Treatment Fidelity Measure – Session 2**

While listening to the audio recorded intervention sessions, indicate whether the following topics were covered:

<u>Topic Area</u> <u>Did the therapist....</u>	<u>Did the therapist cover this topic area?</u>	
	<u>YES</u>	<u>NO</u>
<u>Introduction</u>		
<u>Do informal check-in with parent; ask him or her how family has been since Session 1</u>		
<u>Tell parent that the purpose of Session 2 is to review the Parent Empowerment steps</u>		
<u>Step 1: Positive Problem Orientation</u>		
<u>Therapist reviews problem orientation</u>		
<u>Therapist reviews 4 components of positive problem orientation</u>		
<u>Therapist talks with parent about his or her current problem orientation</u>		
<u>Step 2: Problem Definition and Formulation</u>		
<u>Therapist reviews three sources from which to get facts to solve problem: medical team, other parents, printed brochures</u>		
<u>Therapist talks with parent about how they have worked to get the facts related to a problem</u>		
<u>Step 3: Generation of alternative solutions</u>		

<b><u>Therapist reviews ways to devise possible solutions (brainstorm and think of possible strategies)</u></b>		
<b><u>Therapist discusses with parent his or her efforts to devise possible solutions to problems</u></b>		
<b><u>Step 4: Decision Making</u></b>		
<b><u>Therapist reviews steps for making decision:</u></b> (identify consequences, cost-benefits analysis, likelihood of success for each alternative)		
<b><u>Therapist reviews with parent their use of these strategies in deciding on a solution to a problem</u></b>		
<b><u>Step 5: Solution Implementation and Verification</u></b>		
<b><u>Therapist asks parent if he or she was able to implement strategy developed in Session 1</u></b> (also give credit if parent mentions whether or not he or she tried the solution)		
<b><u>Therapist discusses the results of the strategy with the parent</u></b> (some parents bring this up earlier in the session, give credit if that happens)		
<b><u>Therapist talks with parents about the outcome of the solution on the parent and child</u></b> (give credit if discussed at all during the session)		
<b><u>Wrap-Up</u></b>		
<b><u>Therapist encourages the parent to practice the PE skills</u></b>		

**Appendix T**  
**Control Session Treatment Fidelity**

Please use this form for the control group sessions (non-problem solving).

PART A: Please indicate whether or not the therapist demonstrated interest and empathy during the session:

1) Did the therapist demonstrate interest in discussing concerns with the parent?

YES                      NO

2) Did the therapist demonstrate empathy to the parent?

YES                      NO

PART B: Did the therapist address any of the following topics (see instruction sheet for examples)?

1) Problem Orientation	YES	NO
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2) Problem Definition and Formulation.	YES	NO
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3) Generation of alternative solutions.	YES	NO
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4) Decision making	YES	NO
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5) Solution implementation and verification:	YES	NO
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PART C: FOR SESSION 2 ONLY:

Did the therapist follow-up with concerns expressed by the parent in session 1?

YES                      NO                      NA (parent did not express concerns in session 1)

**CURRICULUM VITA**  
**JENNIFER D. LAMANNA**  
**(Former Name: Jennifer D. Jonda)**

Date of birth: July 2, 1983  
Place of birth: Youngstown, Ohio

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**I.) EDUCATION**

**August 2007- Present**      **Virginia Commonwealth University**  
*Ph.D., Counseling Psychology in progress (expected completion: August 2012)*  
Doctoral Dissertation Title: "A brief problem-solving intervention for parents of children with cancer"

**May 2007**      **Western Kentucky University**  
*M.A., Clinical Psychology*  
Master's Thesis Title: "Similarities between etiological models of eating disorder symptomatology and muscle dysmorphia symptomatology"

**May 2005**      **Kent State University**  
*B.A., Psychology, Summa Cum Laude, with University Honors*  
Undergraduate Honors Thesis Title: "Relationships among perfectionism, body image, family environment and disordered eating"

**II.) CLINICAL EXPERIENCE**

**July 2011- Present**      **Eastern Virginia Medical School**  
*APA Approved Clinical Psychology Internship Program*

Major Rotation (January-June 2012): *Inpatient Physical Medicine and Rehabilitation*  
Provide psychological services to an inpatient rehabilitation program at Sentara Norfolk General Hospital. Services include brief assessment (e.g., cognitive/neuropsychological) and intervention (e.g., adjustment to disability).  
*Supervisor: Michael Stutts, PhD, LCP*

Minor Rotation (January-June 2012): *Outpatient Pain Management*  
Provide psychological services to an outpatient pain management clinic at Eastern Virginia Medical School. Also conduct pre-surgical evaluations and psychotherapy for chronic pain patients.

*Supervisor: Brittany Canady, PhD, LCP*

Major Rotation (July-December 2011): Psychiatry Consultation Liaison Services.

Worked as a psychological services provider on a Psychiatry Consultation Liaison team at a major tertiary medical center (Sentara Norfolk General Hospital). Provided brief psychological interventions to hospitalized medical patients for anxiety, depression, adjustment to medical illness/injury, and pain management. Also conducted brief psychological assessments to provide diagnostic clarification and treatment planning.

*Supervisor: Barbara Cubic, PhD, LCP*

Minor Rotation (July-December 2011): Inpatient Family Medicine Service

Worked as a psychology provider to family medicine patients hospitalized at Sentara Norfolk General Hospital. Duties included: 1) provided psychological consultation to family medicine team; 2) evaluated patients for adjustment to chronic illness, health behavior modification, screen for psychological disorders (primarily depression and cognitive impairment); 3) advocated for the further development of integrated care. Also supervised a psychology practicum student.

*Supervisor: Barbara Cubic, PhD, LCP*

**May 2010-May 2011                      Virginia Commonwealth University Health Systems,  
Evans-Haynes Burn Center**

Psychology Practicum Position: Worked as the primary provider of psychological services in the specialized Burn Center at a Level I trauma center. Conducted psychological evaluations, primarily for acute stress symptoms and factors that may impede recovery. Worked with large multidisciplinary treatment team to provide recommendations for inpatient and outpatient care. Provided inpatient and outpatient individual psychotherapy, as well as brief interventions for anxiety, pain management, and adjustment to injury/hospitalization. Completed hypnosis training program and implemented it as a relaxation and pain management intervention. Also conducted monthly burn survivor support group. Worked with families and caregivers to enhance support and family adjustment (especially with pediatric patients). Consulted with outside entities such as mental health providers for patients with pre-existing mental health needs and schools to facilitate reintegration for pediatric patients.

*Supervisor: James Culbert, PhD, LCP*

**July 2009 – May 2011                      Children's Hospital of Richmond, Division of Pediatric  
Hematology/Oncology**

Psychology Practicum Position: Worked as part of a psychosocial treatment team of psychologists, social workers, chaplains, and hospital teachers within a large network of multidisciplinary providers on a pediatric hematology/oncology medical service. Provided individual and family therapy on issues including adjustment to chronic illness/hospitalization, family issues in the context of chronic illness, stress management, transition to survivorship, depression, and anxiety. Also developed and conducted weekly support group for parents of inpatients. Worked with supervisor to develop dissertation project (Parent Empowerment Program) as a brief problem-solving intervention for parents of children with cancer. This project also provided an additional clinical service with the intention of developing it as a routine intervention for parents of children with cancer. Conducted psychological testing to inform educational/career planning (2 neuropsychological assessments; 6 career assessments). Also conducted outreach programming and school consultation.



*Supervisor: Matthew Bitsko, PhD, LCP*

**September 2007 – July 2010**

**Children's Hospital of Richmond, Department of  
Pediatrics TEENS (Teaching, Exercise, Education,  
Nutrition, and Support) Healthy Weight Management  
Program**

Behavior specialist position: Provided behavioral intervention for child and adolescent participants in a weight-management program. Worked with multidisciplinary team of physicians, dieticians, and exercise specialists. Created behavioral treatment plans and facilitated goal-setting for healthy lifestyle behaviors. Worked with participants and at least one parent to facilitate family-based change with regard to eating and exercise. Also co-lead parent psychoeducational groups on their role in guiding family eating and exercise habits.

*Supervisors: Marilyn Stern, PhD, LCP; Suzanne Mazzeo, PhD, LCP*

**May 2009-May 2010**

**Virginia Commonwealth University Psychology  
Department Assessment Clinic**

Psychology Practicum Position: Completed comprehensive psychological evaluations (neuropsychological, learning disability, differential diagnosis/treatment planning and career assessment). Completed intellectual disability evaluations as part of a contractual agreement with the Chesterfield County Virginia Community Services Board. Also completed intellectual evaluations on 3<sup>rd</sup> graders as part of a contract with a local preparatory school.

*Supervisors: Rebecca Stredny, PsyD, LCP; Jennifer Lumpkin, PsyD, LCP*

**May 2008 – May 2010**

**Virginia Commonwealth Center for Psychological Services  
and Development**

Psychology Practicum Position: Worked as a practicum student in the departmental training clinic which provides low-cost mental health services to a predominantly low SES, urban community. The CPSD also provides some services to college students. Provided individual psychotherapy for issues related to depression, anxiety, personal adjustment, family dynamics, relationship difficulty, legal problems, finances/employment, and education. Also supervised two student therapists in a psychotherapy training course.

*Supervisors: Micah McCreary, PhD, LCP; Jean Corcoran, PhD, LCP; Melanie Bean, PhD, LCP*

**September 2008 – May 2009**

**Virginia Commonwealth University Counseling Services**

Group therapy process observer: Held a leadership position as a process observer for group psychotherapy. Monitored interpersonal process during the session, commented on process in the group at the end of the sessions, and wrote process notes.

*Supervisor: Lyndon Aguiar, MS*

**May 2006 – July 2007**

**Western Kentucky University Counseling and Testing Center**

Psychology Intern Position: Worked as a student intern at a university counseling center at a mid-sized suburban university. Provided individual psychotherapy on issues related to depression, anxiety, relationships, family dynamics, sexual orientation, and adjustment to college life. Also conducted personality assessment to aid in treatment planning (MMPI-2). Co-lead group psychotherapy with a senior staff member. Conducted outreach programming on sexual assault awareness, diversity awareness, healthy eating/body image, healthy relationships, time management, stress management, and study skills.

*Supervisors: Karl Laves, PhD, LCP; Richard Greer, PhD, LCP*

**May 2006 – July 2007**

**Western Kentucky University Psychology Training Clinic**

Psychology Practicum Position: Conducted comprehensive psychological assessments (Attention Deficit/Hyperactivity; Learning disability; Differential diagnosis/treatment planning). Also conducted individual psychotherapy with college students for issues related to relationships, bereavement, sexual orientation, family dynamics, and body image.

*Supervisor: Rick Grieve, PhD, LCP*

### **III.) PUBLICATIONS**

#### Articles

Cubic, B., Mance, J., Turgesen, M., & **Lamanna, J.** (2012). Interprofessional education as the bridge to preparing psychologists for operating successfully in integrated care. *Journal of Clinical Psychology in Medical Settings*

Gow, R., Lydecker, J., **Lamanna, J.**, & Mazzeo, S. (2012). Media's representation of celebrities' body image and weight during pregnancy and postpartum: A content analysis. *Body Image*, 9, 172-175.

**Lamanna, J.**, Grieve, F., Derryberry, W.P., & Hakman, M. (2010). Examining the similarities between causal pathways for eating disorders and muscle dysmorphia in a non-clinical sample. *Eating and Weight Disorders*, 15, 23-33.

#### Book Chapters

Trapp, S.K., Slosky, L., Lamanna, J., Leibach, G., Durette, M., & Stern, M. (2012). Posttraumatic growth in the cancer experience. In *The Psychology of Cancer*. NOVA Science Publishers, Hauppauge, NY.

**Lamanna, J.**, Kelly, N., Stern, M., & Mazzeo, S.E. (2010). Implementing interventions to enhance quality of life in overweight children and adolescents. In V.A. Preedy (Ed.), *Handbook of Disease Burdens and Quality of Life Measures*. Heidelberg, Germany: Springer-Verlag GmbH.

Manuscripts in preparation:

**Lamanna, J.,** Bitsko, M., Godder, K., & Stern, M. A brief problem-solving intervention for parents of children with cancer.

Spiegel, D., Rajamajhi, U., & **Lamanna, J.** Recommendations for Psychiatry Consultation/Liaison use of the MMPI-2 in assessing Somatization hospitalized medical patients.

Stern, M., **Lamanna, J.,** Russell, C., Trapp, S., & Godder, K. A qualitative analysis of healthcare provider and adolescent cancer patient communication at the end of active cancer treatment.

**IV.) RESEARCH EXPERIENCE**

**January 2010 - present                      Doctoral dissertation**

This project examines the effectiveness of a brief problem-solving intervention for caregivers of children with cancer on problem-solving ability, caregiving stress, and posttraumatic stress symptoms. Developed and implemented the intervention and collected original data. Data has been collected and analyzed. Final manuscript in preparation.

*Supervisor: Marilyn Stern, PhD*

**September 2009 – March 2011              Obesity prevention in pediatric cancer survivors**

Coordinator of pilot study to develop a parent education program to prevent obesity in pediatric cancer survivors.

*Supervisor: Marilyn Stern, PhD*

**June 2009 – December 2010              Health care provider and adolescent cancer patient communication**

Coordinator for project on the range and types of communication between health care providers and adolescent cancer patients at the end of treatment.

*Supervisor: Marilyn Stern, PhD*

**January 2008 – June 2009                      Psychoeducational intervention for pediatric cancer and sickle cell patients**

Assisted with an intervention to promote academic, career, and health self-efficacy.

*Supervisor: Marilyn Stern, PhD*

**September 2007 – May 2009                      Maternal adaptation to newborn intensive care (NICU) hospitalization**

Conducted interviews with mothers of infants hospitalized in the NICU. Conducted 1-month and 3-month post-discharge follow-ups.

*Supervisor: Marilyn Stern, PhD*

**September – December 2009                      NOURISH (Nourishing our Understanding of Role Modeling to Improve Support and Health)**

Received training to deliver healthy eating and weight management program to parents recruited parents for R03 grant; entered and managed data entry.

*Supervisor: Suzanne Mazzeo, PhD*

**September 2005 – April 2007      Master's Thesis**

Compared etiological models of the development of eating disorders and muscle dysmorphia using sociocultural and intrapersonal variables (original data collection).

*Advisor: Frederick Grieve, PhD*

**February 2004 – April 2005      Undergraduate Honors Thesis**

Examined how individual and family pathology contributes to disordered eating in undergraduate females (original data collection).

*Advisor: Janis Crowther, PhD*

**January 2004 – May 2005      Eating Disorders research**

Worked as an undergraduate assistant on eating disorders projects examining the thin-ideal body internalization and the effects of social comparison on body image and disordered eating.

Responsibilities included teaching participants how to complete weekly logs and managed data.

*Advisor: Janis Crowther, PhD*

**September – December 2004      Speech pattern distortion in schizophrenia**

Worked as an undergraduate assistant on a project examining speech pattern distortion in patients with schizophrenia. Transcribed and checked taped interviews.

*Advisor: Nancy Docherty, PhD*

**September 2002 – December 2003      Attachment as predictor of social relationships in childhood**

Worked as an undergraduate assistant on a project that developed interactive interviews to study attachment in middle childhood. Transcribed taped interviews and managed data.

*Advisor: Kathryn Kerns, PhD*

**V.) INVITED TALKS**

Spiegel, D.R., Rayamajhi, U., & **Lamanna, J.** (2011, September). *Medically Unexplained Physical Symptoms: An Integrative Approach*. Grand Rounds Presentation at Eastern Virginia Medical School, Department of Psychiatry and Behavioral Sciences.

**V.) POSTER PRESENTATIONS**

**Lamanna, J.**, Bitsko, M., Godder, K., & Stern, M. (2010, September). *Evaluation of the Parent Empowerment Program: A Brief Problem-Solving Intervention for Parents of Children with Cancer*. Poster presented at the 10<sup>th</sup> annual meeting of the Children's Oncology Group (COG). Dallas, TX.

**Lamanna, J.**, Russell, C., Trapp, S., Godder, K., & Stern, M. (2010, February). *Academic-Career Communication of Adolescents with Cancer and their Health Care Providers During an End of*

*Active Treatment Visit*. Poster presented at the 7<sup>th</sup> Annual Conference of the American Psychosocial Oncology Society. New Orleans, LA.

Gow, R.W., Trace, S.E., Serdar, K., Heiman, N., **Jonda, J.**, & Mazzeo, S.E. (2008, May). *Development and Pilot Testing of Parent Intervention to Reduce Pediatric Overweight*. Paper presented at AED Annual Conference, Seattle, WA .

Foster, R., Kim, H., Durette, M., Kanotra, S., Slosky, L., **Jonda, J.**, Stern, M. (2008, April). *Building academic, career, and health-behavior self-efficacy: A psychoeducational intervention for adolescents diagnosed with cancer or sickle cell disease*. Poster session presented at the 11<sup>th</sup> Annual Graduate Student Research Symposium, Richmond, VA.

Durette, M., Foster, R., Stern, M., Slosky, L., **Jonda, J.**, Kanotra, S., & Grote, C. (2008, April). *Prematurity stereotyping and NICU hospitalization: An analysis of maternal expectations*. Poster session presented at the 11th Annual Graduate Student Research Symposium, Richmond, VA.

**Jonda, J.**, & Crowther, J. (2006, November 18). *Relationships among Perfectionism, Body Image, Family Environment and Disordered Eating*. Poster presented at the annual convention of the Association of Behavioral and Cognitive Therapies, Chicago, IL.

## **VI.) TEACHING EXPERIENCE**

<b>Summer 2009, Summer 2010</b>	<b>PSYC 407 Psychology of the Abnormal</b> <i>Instructor, Virginia Commonwealth University</i>
<b>Spring 2010; Spring 2011</b>	<b>PSYC 317 Research Methods in Psychology</b> <i>Lab Instructor, Virginia Commonwealth University</i>
<b>Fall 2010</b>	<b>PSYC 101 Introduction to Psychology</b> <i>Teaching Assistant, Virginia Commonwealth University</i>
<b>Spring 2009</b>	<b>PSYC 645 Personality Assessment</b> <i>Teaching Assistant, Virginia Commonwealth University</i>
<b>Fall 2008</b>	<b>PSYC 491 Careers in Psychology</b> <i>Teaching Assistant, Virginia Commonwealth University</i>
<b>Fall 2002, Fall 2003, Fall 2004</b>	<b>UNIV 111 University Orientation</b> <i>Student Instructor, Kent State University</i>

## **VII.) RELATED WORK EXPERIENCE**

<b>August 2008 – August 2009</b>	<b>Academic Advisor</b> <i>Psychology Department, Virginia Commonwealth University</i>
<b>August 2005 – May 2007</b>	<b>Graduate Assistant</b>

*Counseling and Testing Center, Western Kentucky University*

**September 2002 – May 2005          Peer Mentor**

*Academic Success Center, Kent State University*

**September 2002 – May 2005          Student Clerical Assistant**

*Department of Psychology, Kent State University*

## **VII.) HONORS AND AWARDS**

### **Virginia Commonwealth University (Doctoral)**

April 2011          Elizabeth Fries Memorial Scholarship (for research in cancer control)  
2007-2008 AY      College of Humanities and Sciences University Fellowship

### **Western Kentucky University (Master's Degree)**

2007                  Outstanding Clinical Psychology Graduate Student

### **Kent State University (Undergraduate)**

2005                  Phi Beta Kappa, Horace Page Memorial Award  
2005                  College of Arts & Sciences Outstanding Student Leader Award  
2005                  Wesley Zaynor Award for Research in Psychology  
2005                  Who's Who Among Outstanding College Students  
2004                  Lillian Kroenke Scholarship  
2003-2004          Michael Halpin Scholarship  
2003-2004          University Academic Scholarship  
2002-2004          Trustee Scholarship  
2003, 2004          Outstanding Student Instructor Award, University Orientation  
2002                  Outstanding Team Teaching Award, University Orientation

## **IX.) COMMITTEE MEMBERSHIPS**

### **Western Kentucky University (Master's Degree)**

2006                  Search Committee Member: Counseling and Testing Center staff position

### **Kent State University (Undergraduate)**

2004-2005          Undergraduate Council on Academic Policy  
2004-2005          Summer Reading Program selection Committee  
2004-2005          College of Arts & Sciences Student Advisory Council  
2004                  Outstanding Teaching Awards Selection Committee

## **X.) PROFESSIONAL MEMBERSHIPS**

American Psychological Association, Graduate Student Affiliate  
American Psychological Association, Division 54, Society of Pediatric Psychology

## **XI.) REFERENCES**

### **1. Brittany Canady, PhD, LCP**

Assistant Professor

Department of Physical Medicine & Rehabilitation

Eastern Virginia Medical School

Andrews Hall

721 Fairfax Avenue

Norfolk, Virginia 23507

Phone: 757-446-5915

e-mail: canadybe@evms.edu

### **2. Barbara Cubic, PhD, LCP**

Associate Professor

Department of Psychiatry and Behavioral Sciences

Eastern Virginia Medical School

Hofheimer Hall

825 Fairfax Avenue

Norfolk, VA 23507

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### **3. Marilyn Stern, PhD, LCP**

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