The effect of community-based social support on the health-related quality of life of pediatric oncology patients

Nichole D. Sage
Pacific University
The effect of community-based social support on the health-related quality of life of pediatric oncology patients

Abstract
Recent developments in pediatric oncology have focused on minimizing hardships and improving outcomes, such as health-related quality of life (HRQOL). Research has identified multiple evidence-based techniques and other interventions aimed at minimizing distress and improving functioning. One important factor in improving HRQOL is social support as the two constructs are positively linked. A particular type of social support, community-based social support (CBSS), has been provided to pediatric cancer patients and their families in an effort to improve the treatment experience. Although the effect of individual and familial social support on the HRQOL of pediatric populations has been investigated, research on CBSS and its effect on HRQOL among pediatric cancer patients has been lacking. The purpose of the current study was to examine the effect of one specific CBSS program, the Chemo Palà program, developed by the Children's Cancer Association, and to assess the impact of this program on the HRQOL of pediatric cancer patients. The small sample size ($n = 3$) precluded conclusions. Interview data suggested positive impacts of CBSS services on HRQOL through distraction, anxiety reduction, comfort during medical procedures, and mood improvement. Additionally, positive impacts of CBSS services on social support were reported through respite, socialization/friendship, and in some cases continued contact with families post-treatment as part of CBSS services. Overall, the current study served to operationalize CBSS services and provide initial insights into these services and how they affect pediatric cancer patients and their families.

Degree Type
Dissertation

Rights
Terms of use for work posted in CommonKnowledge.

Comments
Library Use: LIH
Copyright and terms of use

If you have downloaded this document directly from the web or from CommonKnowledge, see the “Rights” section on the previous page for the terms of use.

If you have received this document through an interlibrary loan/document delivery service, the following terms of use apply:

Copyright in this work is held by the author(s). You may download or print any portion of this document for personal use only, or for any use that is allowed by fair use (Title 17, §107 U.S.C.). Except for personal or fair use, you or your borrowing library may not reproduce, remix, republish, post, transmit, or distribute this document, or any portion thereof, without the permission of the copyright owner. [Note: If this document is licensed under a Creative Commons license (see “Rights” on the previous page) which allows broader usage rights, your use is governed by the terms of that license.]

Inquiries regarding further use of these materials should be addressed to: CommonKnowledge Rights, Pacific University Library, 2043 College Way, Forest Grove, OR 97116, (503) 352-7209. Email inquiries may be directed to: copyright@pacificu.edu

This dissertation is available at CommonKnowledge: http://commons.pacificu.edu/spp/1076
THE EFFECT OF COMMUNITY-BASED SOCIAL SUPPORT ON THE HEALTH-RELATED QUALITY OF LIFE OF PEDIATRIC ONCOLOGY PATIENTS

A DISSERTATION

SUBMITTED TO THE FACULTY

OF SCHOOL OF PROFESSIONAL PSYCHOLOGY

PACIFIC UNIVERSITY

HILLSBORO, OR

BY

NICHOLE D. SAGE, M.S.

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PSYCHOLOGY

JULY 25, 2013

APPROVED BY THE COMMITTEE:

Susan T. Li, Ph.D., Director, Child and Adolescent Track

Daniel Munoz, Ph.D., Director, Solutions for Eating and Weight Problems, Children’s Program

PROFESSOR AND DEAN:

Christiane Brems, Ph.D., ABPP, Dean
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>5</td>
</tr>
<tr>
<td>List of Tables</td>
<td>6</td>
</tr>
<tr>
<td>List of Figures</td>
<td>7</td>
</tr>
<tr>
<td>Introduction</td>
<td>8</td>
</tr>
<tr>
<td>Literature Review</td>
<td>10</td>
</tr>
<tr>
<td>Hardships Faced By Pediatric Cancer Patients</td>
<td>10</td>
</tr>
<tr>
<td>Stressors and symptoms</td>
<td>10</td>
</tr>
<tr>
<td>Adjustment issues</td>
<td>12</td>
</tr>
<tr>
<td>Functioning of Pediatric Cancer Families, Survivors, and Patients</td>
<td>12</td>
</tr>
<tr>
<td>Social</td>
<td>14</td>
</tr>
<tr>
<td>Emotional/Psychological</td>
<td>17</td>
</tr>
<tr>
<td>Cognitive</td>
<td>20</td>
</tr>
<tr>
<td>Psychosocial Treatment and Support for Pediatric Cancer Patients</td>
<td>24</td>
</tr>
<tr>
<td>Individual intervention</td>
<td>24</td>
</tr>
<tr>
<td>Parent- and caregiver-targeted intervention</td>
<td>27</td>
</tr>
<tr>
<td>Community-based intervention</td>
<td>28</td>
</tr>
<tr>
<td>The Role of Social Support</td>
<td>30</td>
</tr>
<tr>
<td>Social support from family and peers</td>
<td>30</td>
</tr>
<tr>
<td>Online social support</td>
<td>31</td>
</tr>
<tr>
<td>Community-based social support</td>
<td>32</td>
</tr>
<tr>
<td>Health-Related Quality of Life</td>
<td>33</td>
</tr>
<tr>
<td>Measurement of HRQOL</td>
<td>33</td>
</tr>
</tbody>
</table>
HRQOL in children and pediatric populations ..............................................................35

Factors affecting HRQOL ...............................................................................................37

Purpose of the Current Study .........................................................................................39

Method .............................................................................................................................43

Phase 1—Caregivers of Children Undergoing Cancer Treatment............................43

Caregiver Participants .................................................................................................43

Caregiver Demographics ............................................................................................43

Children of Caregiver Participants ..............................................................................43

Setting for Phase 1 and Phase 2 ..................................................................................44

Children’s Cancer Association© ..................................................................................44

Design and Procedures .................................................................................................45

Measures .........................................................................................................................46

Demographic Questionnaire ..........................................................................................46

   Pediatric Quality of Life (PedsQL) Cancer Module ..................................................46

   Child and Adolescent Social Support Scale (CASSS) ...............................................48

   Social Support Scale Short Form (SSQ6) .................................................................50

   Parent/caregiver perceptions of Chemo Pal® program ............................................50

Phase 2—Volunteers and Staff from the Children’s Cancer Association© ...............51

   Participant Demographics .......................................................................................51

   Setting .........................................................................................................................51

Design, Procedure, and Measures .................................................................................52

Results .............................................................................................................................52

Phase 1 .............................................................................................................................52

Overview of the Caregiver Data Collection .................................................................52
Abstract

Recent developments in pediatric oncology have focused on minimizing hardships and improving outcomes, such as health-related quality of life (HRQOL). Research has identified
multiple evidence-based techniques and other interventions aimed at minimizing distress and improving functioning. One important factor in improving HRQOL is social support as the two constructs are positively linked. A particular type of social support, community-based social support (CBSS), has been provided to pediatric cancer patients and their families in an effort to improve the treatment experience. Although the effect of individual and familial social support on the HRQOL of pediatric populations has been investigated, research on CBSS and its effect on HRQOL among pediatric cancer patients has been lacking. The purpose of the current study was to examine the effect of one specific CBSS program, the Chemo Pal® program, developed by the Children’s Cancer Association©, and to assess the impact of this program on the HRQOL of pediatric cancer patients. The small sample size (n = 3) precluded conclusions. Interview data suggested positive impacts of CBSS services on HRQOL through distraction, anxiety reduction, comfort during medical procedures, and mood improvement. Additionally, positive impacts of CBSS services on social support were reported through respite, socialization/friendship, and in some cases continued contact with families post-treatment as part of CBSS services. Overall, the current study served to operationalize CBSS services and provide initial insights into these services and how they affect pediatric cancer patients and their families.

**Keywords:** Pediatric Cancer, Oncology, Health-Related Quality of Life, Social Support

**List of Tables**

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1: Comparison of Mean PedsQL Cancer Module Scores by Sample</td>
<td>55</td>
</tr>
</tbody>
</table>
Table 2: Comparison of Mean CASSS Scale Scores by Sample

List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1: Participant 1 scores at T1, T2, T3</td>
<td>60</td>
</tr>
</tbody>
</table>
The Effect of Community-Based Social Support on the Health-Related Quality of Life of Pediatric Cancer Patients

**Introduction**

Approximately 8,500 children a year under age 15 will be diagnosed with one of the many forms of pediatric cancer (Ries et al., 1999; Ross & Olshan, 2004). In the last few decades, there has been an increase in the annual incidence rate of pediatric cancer by 0.06 to 1.1%
(Linabery & Ross, 2007). More importantly, the last few decades have seen a dramatic decrease in childhood cancer-related deaths in the United States (Ries et al., 1999). For example, there has been an approximate 10% increase in survival for children in the first year since diagnosis and 15% in the first 3 years since diagnosis from 1970 to 1995 (Ries et al., 1999). Further, Dilley (2005) reported over 70% of cancer-related malignancies are now cured.

There are several types of cancer that affect children. The most common type of cancer is leukemia, which accounts for approximately 31% of pediatric cancer diagnoses. According to the American Cancer Society (2010), the two most prevalent types of leukemia are acute lymphoblastic leukemia (ALL) and acute myelogenous leukemia (AML), which cause pain, weakness, fever, weight loss and other symptoms. Approximately 21% of all cancers affecting children are bone and nervous systems cancers; symptoms caused by these cancers include headaches, nausea, blurred vision, vomiting and dizziness. The third most prevalent pediatric cancer, accounting for approximately 7% of diagnoses, is neuroblastoma, which generally develops in the nerve cells of embryos of fetuses. Symptoms associated with neuroblastoma include swelling, pain, and fever. Other, rarer types of pediatric cancers include Wilms tumor, lymphoma (Hodgkin and non-Hodgkin), Rhabdomyosarcoma, Retinoblastoma, and bone cancers (Ewing sarcoma and Osteosarcoma). Treatment protocols for pediatric cancer are usually specific to the type of cancer. However, in general, most treatment options for cancer patients include chemotherapy, surgery, or radiation therapy (American Cancer Society, 2010). For the purposes of this study, the term cancer patient will be utilized for children who are currently undergoing treatment, whereas the term cancer survivor will be utilized for children who have been successfully treated and no longer have cancer.

Although many children are now surviving cancer, they continue to struggle with the short- and long-term sequelae of pediatric cancer such as treatment-related physical changes and
cognitive late effects. While it is encouraging that fewer children are dying of cancer than in previous decades, there is still a lack of information about how to best support pediatric cancer patients and their families during and after the treatment process to improve their level of comfort, functioning and quality of life.

Thus far, social support has shown to be effective in improving functioning in children with cancer (e.g., Decker, 2007), however, little is known about the degree of improvement or the impact of social support specifically on health-related quality of life (HRQOL). Although there is no universally agreed upon definition of HRQOL, Spieth and Harris (1996) suggested HRQOL is the “subjective and objective impact of dysfunction associated with an illness or injury, medical treatment, and healthcare policy” (p. 176). In addition to limited research on the role of social support and HRQOL, there is scant research on the role of community-based social support services, despite the existence of organizations with these services in many cities across the United States. Some of these programs include local chapters of national organizations such as American Childhood Cancer Organization© (Candlelighters) and Leukemia Lymphoma Society® as well as state and local level organizations such as Oklahoma Children’s Cancer Association© or Jacob’s Heart Children’s Cancer Support Services™. For the purposes of this paper, the term community-based social support (CBSS) services is defined as providing an identified companion to a child with cancer to engage the child in ongoing, positive social interactions and recreational activities, which may occur during hospitalization and throughout the treatment process to provide support to the child. The services are provided by a local, regional, or national organization with the purpose of serving the specific needs of that population.

The purpose of this research study is to investigate caregivers’ perceptions of the effect of CBSS on the HRQOL of pediatric cancer patients. For the purposes of this paper, pediatric
cancer refers to a cancer diagnosis given to a child or adolescent and cancer patients are considered people who are currently receiving medical treatment for the disease, whereas cancer survivors have been treated and no longer have a cancer diagnosis. In the following literature review, the hardships faced by children with cancer; functioning of pediatric cancer patients, survivors, and their parents/caregivers; psychosocial supports and treatments for patients, survivors, and parents/caregivers, HRQOL, and the role of social support during and after treatment will be discussed.

**Literature Review**

**Hardships Faced By Pediatric Cancer Patients**

**Stressors and symptoms.** Pediatric cancer patients often endure months of intensive treatments, which can entail invasive and painful procedures. For example, the treatment for the most common type of pediatric cancer involves intravenous injections, lumbar punctures, and blood marrow aspirations. Lumbar punctures and blood marrow aspirations involve inserting a needle into the child’s spine and pelvis. These procedures have been rated by both self-report and by behavior observation as being very painful. As a result, many children develop intense anxiety or fear of these procedures (Kuppenheimer & Brown, 2002). In addition to painful treatments, families of pediatric cancer patients also report significant body changes such as weight change, bruising, and alopecia (i.e., hair loss) (Berrios-Rivera, Rivero-Vergne, & Romero, 2008). Pediatric cancer patients also suffer from many somatic symptoms commonly associated with the diagnosis including fever, headaches, gastrointestinal issues, vomiting, body pain, fatigue, sore throat, lethargy, and drowsiness. These types of symptoms may significantly limit a patient’s physical functionality (Baggot, Dodd, Kennedy, Marina, et al., 2009).

Physical symptoms, however, are not the only factors that affect patient functioning. Research has suggested that simply the communication of the cancer diagnosis has an impact on
children. Slavin, O’Malley, Koocher, and Foster’s (1982) work has suggested that children whose parents had not directly disclosed the child’s health status to the child had poorer long-term psychosocial adjustment relative to children whose parents did directly disclose or discuss the diagnosis.

Pediatric cancer patients also experience significant life changes when undergoing treatment. Because of the lengthy and intense treatment schedule, many patients are unable to continue regular school attendance and as a result, they experience disrupted peer relationships, changes in relationships, or even loss of friends due to cancer and its treatment (Aamodt, Grassl-Herwehe, Farrell & Hutter, 1984; Rechner, 1990; Stern, Norman, & Zevon, 1993; Woodgate, 1999). In addition to peer relationships, familial relationships may also be strained. Pai et al. (2007) reported that families, specifically mothers, of children with cancer had poorer coping and higher levels of distress than a comparison group. This distress potentially causes significant shifting in family roles leading to further distress and strained relationships. In addition, normative developmental milestones such as social skills may not be achieved at the same rate as healthy peers due to a child’s cancer and the severity of the treatments required.

**Adjustment issues.** Children and families affected by cancer must take into consideration how to manage the re-entry of the child back into school following lengthy and intensive medical treatments for cancer. Research has demonstrated that there are few school-based services in place to facilitate or support a child’s re-entry into the classroom (Moore, Kaffenberger, Goldberg, Oh, & Hudspeth, 2009); as a result, children, families, and school personnel may be unprepared for the range of issues that may arise during the transition (e.g., informing staff and students regarding the child’s health issues, classmates’ anxiety and fear of the child’s illness, how the child will make up missed coursework, etc.). The next section
addresses the functioning of pediatric cancer patients and their families given the hardships that have been noted.

**Functioning of Pediatric Cancer Families, Survivors, and Patients**

**Familial.** Pai et al. (2007) asserted that parental psychosocial functioning is a critical element influencing their child’s physical and psychological functioning throughout the course of cancer treatment as parental distress can affect their child’s psychosocial functioning. Research has indicated that children whose parents experience high levels of distress experience significant distress themselves (Robinson et al., 2007; Trask et al., 2003). Most parents appear to have levels of distress that are below the clinical range; however, when parents do experience high levels of distress, the consequences can be significant (Trask et al., 2003). For example, poor parental coping has been shown to lead to poorer outcomes (e.g. increased anxiety, externalizing behaviors, hopelessness, etc.) for their children with cancer (Suzuki & Kato, 2003). There is also a relationship between greater use of maladaptive coping (i.e., avoidance) by parents (versus adaptive coping) and higher distress levels (Trask et al., 2003).

In contrast to findings suggested by Trask et al. (2003), Hutchinson (2009) reported that parents of pediatric cancer patients experienced significantly higher levels of stress related to the parenting role, when compared to parents of healthy children. High stress levels as related to the parental role were found to be more closely related to child-specific factors versus individual factors of the parent, suggesting that qualities in the children can create challenges for the caregiver (e.g. needs related to the child’s health status). Parents of patients with non-brain tumor cancer diagnoses were found to be at highest risk for stress. Hutchinson (2009) hypothesized that parents of children with brain tumors are informed of the possibility of physical and cognitive late effects, as well as other difficulties, whereas parents of children with non-brain tumor cancers may have higher expectations for good outcomes and functioning. Factors of the family
environment also predict a parent’s stress level (Hutchinson, 2009). Higher levels of family conflict and lower levels of family support were found to be associated with higher parental stress.

As compared to the findings of Trask et al. (2003) and Hutchinson (2009), Rabineau, Mabe, and Vega (2008) also reported higher levels of parenting stress in parents of pediatric oncology patients; however, the high level of stress appeared to be transitory and fluctuated depending on the phase of treatment. Rabineau et al. (2008) indicated that intervention may be warranted in order to decrease the parent’s high level of stress during intense periods in the treatment process.

In summary, general levels of parental stress for caregivers of pediatric cancer patients have been found to be both typical and elevated, when considering particular types of stress, compared to other caregivers. However, some differences may be due to variability in the course of cancer treatments and the resultant stress associated therewith. What has been suggested is that specific types of stress (e.g., related to the parental role and the child’s cancer diagnosis) may be higher when compared to parents of healthy children. Furthermore, when parents are stressed, their distress has been shown to have an impact on pediatric cancer patients. When parent stress levels are higher, more negative outcomes for the child can be expected.

**Social.** Given the degree of change that is associated with a cancer diagnosis and treatment, is it to be expected that a pediatric cancer patient’s functioning will be impacted. However, the aim of the research has been to learn more about the way in which functioning changes, and the effects of such changes. Social functioning is an area that may be especially difficult for young cancer patients and survivors. Because of school absences, body changes due to medical interventions, and a restriction in the amount of physical activity allowed, children who have been diagnosed with pediatric cancer can be more vulnerable to social difficulties
Among teens, limited participation in social activities and social perceptions of their illness and treatment are primary social struggles (Lam, Cohen, & Roter, 2013). When compared to another illness group (juvenile rheumatoid arthritis), survivors of brain tumors showed significant deficits in their abilities to accurately recognize adult facial expressions (Bonner et al., 2008), which can impact their ability to read social cues and interpret nonverbal behaviors. Moreover, Bonner et al. reported that pediatric brain tumor survivors exhibited significantly more impairment in social functioning across multiple self- and parent-report measures than a comparison group. These data suggested that children affected by brain tumors may experience more social difficulties than other pediatric populations.

There is also evidence of mixed results in regards to social functioning. Duchoslav (2010) suggested that some children exhibit lower levels of social functioning when compared to their pre-cancer functioning, including quantity of social interaction, whereas other children maintain their social functioning throughout treatment. When young cancer survivors’ dyadic peer interactions were examined, results suggested that the cancer survivors were less likely to be engaged (e.g., participating in fantasy play) and were more likely to become disengaged (e.g., leaving the common play area) when compared to their healthy counterparts (Katz et al., 2010). Overall, there appears to be a reduction in the frequency of social interactions. However, despite the reduced frequency of social interactions, Duchoslav’s findings suggested that some pediatric cancer patients may demonstrate an improvement in social skills. Duchoslav hypothesized that improved social skills are a result of the young cancer patients increased contact with adults, and discussing mature topics such as death, health, illness, etc. Moreover, children may gain skills for self-control, cooperation, and a sense of responsibility by complying with medical treatment and care, which could result in strengthened social skills (Duchoslav, 2010).
In terms of how pediatric cancer patients are viewed by others, research has shown that social perceptions of adolescents toward a peer who has cancer are more positive than early researchers hypothesized (Gray & Rodrigue, 2001). Adolescent participants in the study rated a hypothetical new peer with cancer more favorably than the comparable but healthy hypothetical new peer. According to Gray and Rodrigue, the findings suggest that a cancer diagnosis in a same-age peer may not be a stigmatized condition. Similarly, Noll et al. (1999) reported that peers of pediatric cancer patients perceived them as having greater social acceptance than healthy children. In terms of pediatric cancer survivors’ level of social acceptance, there were no significant differences in peers’ ratings of their cancer survivor classmates (Reiter-Purtill et al., 2003). Thus, there may be a difference in the level of social acceptance between pediatric cancer patients receiving active treatment and those who are post-treatment and/or age effects such that children who already have social skills do well but those who are still developing them may struggle. It is also possible that there may be a mismatch between the peer’s and the child’s perceptions of social difficulty. Nonetheless, social acceptance for children who have been touched by cancer appears to be equal to or greater than their healthy counterparts.

In addition to peer perceptions, teachers rated pediatric cancer patients as being more sociable (Noll et al., 1999) and pediatric cancer survivors as less aggressive (Reiter-Purtill et al., 2003) with their peers than healthy controls. Noll’s finding relating to the children’s level of sociability seems inconsistent with what would be expected given the study by Katz et al. (2010) regarding social disengagement by pediatric cancer survivors. However, it is important to note that Katz et al.’s participants were survivors of cancer who were cancer-free at the time of the study, whereas Noll et al.’s participants were children receiving active treatment for their disease. It is possible social functioning differs between treatment and post-treatment phases and affects levels of peer engagement and the child’s behavior at school and with peers.
One important variable that may be relevant for findings of social acceptance is the type and intensity of treatment. Treatment appears to play a factor in acceptance. Children who have completed intensive central nervous system (CNS) treatment were rated as being less socially accepted by their peers, and this association was stronger for boys and children who were under 10 years old at diagnosis (Vannatta, Gerhardt, Wells, & Noll, 2007). Additionally, Vanatta et al. reported that treatment type (specifically CNS-targeted treatment) and the level of treatment intensity predicted teachers’ ratings of higher levels of aggression toward peers and disruptive behaviors. Contrary to the peer reports, Vannatta et al. reported there were no significant differences on teacher ratings of social acceptance between healthy children and children who had received CNS-targeted treatment.

In summary, the research on the social functioning of pediatric cancer patients and survivors is mixed. Although no definitive conclusions can be drawn, it appears as if some children who are undergoing or who have undergone treatment have social deficits, whereas others do not. Some children appear to be less engaged and interested in social interactions with peers, despite peers having positive views toward the cancer patient. Other studies suggested that children’s social skills might actually improve during the treatment process, suggesting that the disengagement is not due to a loss in social skills. Variability in the findings of the studies in regards to social functioning is likely due to several factors. Important concerns and variables that may impact social functioning are whether cancer is in remission or not, type of diagnosis (e.g. brain tumor), intensity of treatment, age, area of the brain damaged by the cancer and subsequent treatment, and possibly the child’s level of social skills prior to diagnosis and treatment. Additional factors may be the type of rater, such as peers versus teachers, and their attitudes toward the affected child both before and after treatment.
**Emotional/Psychological.** Currently, the literature points to concerns about both the psychological functioning of pediatric cancer patients and survivors, and the psychological effects that the diagnosis and treatment process may have on the parents or caregivers. Given the differences in findings between the children and the adults, these groups will be discussed separately in this review.

*Psychological functioning of patients and survivors.* On the whole, results suggest that pediatric cancer patients and survivors experience psychopathology at a prevalence rate similar to the general population (Noll & Kupst, 2007). A review of several articles suggests that cancer patients and survivors are highly resilient in terms of psychosocial functioning and do not endorse more symptoms of anxiety, depression or low self-esteem when compared to healthy controls (Eiser, Hill, & Vance, 2000). Many studies have demonstrated that the majority of pediatric cancer survivors report levels of adjustment on psychological measures that are not significantly different from comparable control samples (Patenaude & Kupst, 2005). However, Patenaude and Kupst reported that outcomes depend on characteristics within the patient. For example, if the patient has an underlying vulnerability to distress, he or she may be more likely to experience symptoms. Moreover, functioning may also be influenced by the type of cancer the child has or the treatment that he or she receives, the age at diagnosis and the age of the youth when the study was conducted. Adolescent survivors of pediatric blood and brain cancers scored lower on measures of psychosocial functioning than non-cancer-affected controls (Schultz et al., 2007), and children diagnosed with bone cancer endorsed poorer psychological outcomes when compared to other pediatric cancer survivors (Eiser et al., 2000). According to Shultz et al. (2007), children with pediatric cancer who had undergone radiation as part of their treatment package endorsed more psychosocial problems in areas such as anxiety, mood, attention, social competence and pro-social behavior when compared to children who just received surgery to
treat the cancer. Research has suggested that psychosocial problems may be related to the late
effects of treatment, such as disfigurement. Children who experience disfigurement have poorer
psychosocial functioning, particularly in the domains of mood and anxiety, attention and
antisocial behaviors (Schultz et al., 2007). Further, adolescent survivors may have a heightened
sense of how their cancer is affecting their functioning, relative to peers, that is not yet
understood by elementary-age youth.

Although the majority of cancer survivors are psychologically well adjusted, some
studies have demonstrated that pediatric cancer survivors endorse symptoms consistent with
posttraumatic stress disorder (PTSD) at a higher rate when compared to the general population
(Noll & Kupst, 2007). In contrast, Eiser et al. (2000) argue other research has not supported the
assertion that the prevalence rate for PTSD in pediatric cancer survivors is higher than a control
group or the general population. For example, Gerhardt et al. (2007) reported that adults who had
survived pediatric cancer demonstrated a similar incident rate of PTSD as the comparison group.
These data suggested that there is inconclusive evidence as to whether pediatric cancer survivors
experience PTSD at a rate similar to the general population and at what point PTSD symptoms
should be considered post-treatment.

During the process of cancer treatment is a time when higher levels of distress and
anxiety (compared to healthy children) are endorsed by pediatric cancer patients (Kuppenheimer
& Brown, 2004). Fortunately, as children are normalized to the treatment process, anxiety levels
appear to decrease (Sawyer, Antonio, Toogood, Rice & Baghurst, 2000). These data, and the
data presented above, suggest that pediatric cancer patients experience feelings of anxiety and
distress during treatment likely as a result of painful medical procedures and significant life and
physical changes. Nonetheless, a pediatric cancer diagnosis has not been shown to cause
significant late psychological effects for all survivors and may be dependent of the type of
treatment and the type of cancer. Thus, it is likely most effective for pediatric cancer patients to receive services focused on improving their functioning during the treatment process when distress is highest and for post follow-ups to occur for those who are not adjusting well.

*Psychological functioning of parents and caregivers.* The patients are not the only ones who may be psychologically affected by the diagnosis and treatment of the cancer. As a result of costs and hardships of a cancer diagnosis (see Fletcher, 2010), there may be considerable emotional and psychological impact on a patient’s family. Mothers of pediatric cancer patients endorsed significantly higher rates of anxiety than mothers of healthy children (Gerhardt et al., 2007). In contrast, Gerhardt et al. reported fathers of pediatric cancer patients did not endorse experiencing higher levels of anxiety, although other research has suggested fathers experience significant cancer-related stress (Rodriguez et al., 2012). For mothers, it appears as if some types cancer diagnoses appear to cause more worry than other types. Mothers of children who were diagnosed with CNS cancers endorsed a greater overall level of fear about their child’s future functioning when compared to parents of children with acute lymphoblastic leukemia (ALL) (Anclair, Hoven, Lannering, & Boman, 2009).

In terms of general stress, the majority of mothers (88%) and fathers (74.3%) reported emotional strain related to the caring for a child with cancer. Consistent with reported levels of anxiety, mothers endorsed a significantly higher amount of cancer-related stress than fathers. Both fathers and mothers reported daily/role functioning (e.g., paying bills, having less time for other children in the family, etc.) as a significant stressor (Rodriguez et al., 2012).

Although distress levels appear to be particularly high during the treatment process, research has demonstrated that parental anxiety and distress diminishes over time (Sawyer, Antonio, Toogood, Rice & Baghurst, 2000). However, Wijnberg-Williams, Kamps, Klip, and Hoekstra-Weebers (2006) reported that five years after their child had been diagnosed, parents
endorsed levels of anxiety that were significantly higher than the comparison group. Moreover, parents of children who had relapsed reported higher levels of anxiety than parents of survivors or children who had died from cancer (Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006). These results indicate that although parental anxiety and distress diminishes over time, parents of pediatric cancer patients continue to experience more intense anxiety than parents of healthy children, and this is especially true for parents of children who have relapsed. Thus, psychosocial interventions that are aimed at teaching parents skills for decreasing anxiety may help improve their psychological functioning both during the treatment process and in the long term.

**Cognitive.** The cognitive effects of pediatric cancer and its treatment have been well documented in the literature. Brown and Madan-Swain (1993) reported that children with leukemia evidenced deficits in their cognitive, neuropsychological, and academic functioning. Both the cancer itself and the direct and indirect effects of radiation and chemotherapy on the central nervous system can have affects on cognitive functioning (Moore, 2005). Cranial radiation therapy (CRT) has been implicated as having a major role in the cognitive declines of children being treated, as well as high dose chemotherapy regimens (Moore, 2005). However, pediatric cancer patients who do not receive CRT may also be at risk for cognitive late effects, although these effects may be subtle (Winick, 2011). Children who suffer from CNS tumors are at greatest risk for global deficits in cognitive functioning largely due to the intensive treatment that targets sensitive CNS structures (Winick, 2011). According to Winick, factors related to the tumor (e.g., tumor location), host (e.g., child’s age), and treatment (e.g., length and intensity) impact the severity of late effects. Survivors of CNS tumors commonly have memory dysfunction, including inefficient storage and consolidation; attention and concentration deficits; slow processing; impairments in adaptive functioning; and declines in overall intellectual ability.
(i.e., full scale IQ declines; Winick, 2011). Patients and survivors of ALL, particularly when treated by cranial radiation, are also at high risk for cognitive impairments, such as lower intellectual functioning and problems with attention, concentration, processing speed, adaptive behavior, and visual-motor integration (Winick, 2011).

Recent research has suggested that the neurocognitive deficits caused by cancer and its treatments are long lasting. Harila et al. (2009) reported that impairments persisted 20 years after diagnosis and were especially present for survivors who had been treated with cranial radiation procedures. Reliable demographic predictors of poorer neurocognitive late effects have been identified. Younger patients who received treatment for CNS cancers have consistently evinced poorer cognitive functioning following treatment (Mulhern et al., 2001). Similarly, a considerable body of evidence suggested female patients are at higher risk for poorer outcomes compared to males (Lahteenmaki et al., 2008).

Given the extensive research on the cognitive impairments suffered by pediatric cancer survivors, the focus has shifted to interventions that prevent or minimize these late effects. The medical community has emphasized the development of advanced radiotherapy techniques, described by Askins and Moore (2008) as the “use of fractionated cranial radiation therapy to deliver a greater number of small doses [to] effectively [reduce] toxicity to surrounding tissue,” (p. 1166) as an important step in minimizing neurocognitive late effects. Similarly, researchers are focusing on improving advanced chemotherapy regimens in order to reduce the late effects these treatment methods often have on patients (Askins & Moore, 2008).

Given the academic problems many pediatric cancer survivors experience because of neurocognitive late effects, Askins and Moore (2008) asserted that early intervention is critical in minimizing delays. Such interventions can include school continuation programs or cognitive training. According to Askins and Moore, hospital-based school continuation programs allow
children to receive academic instruction during cancer treatment. As a result of these programs, children are able to re-enter school after treatment without having lost credit or fallen significantly behind. School continuation programs can also take place in the community or the child’s home. Although guidelines for school continuation programs currently exist (Nathan et al., 2007), comprehensive studies of their utility have not yet been conducted.

Cognitive training has also been indicated for minimizing neurocognitive late effects in pediatric cancer survivors. Training programs (e.g., Butler & Copeland, 2002) teach the students a range of cognitive strategies such as skills for paying attention and focusing, metacognitive and executive functioning skills, and cognitive-behavioral skills to reduce stress associated with academic work. Early investigations into cognitive training programs demonstrated that participants’ cognitive skills improved significantly (Butler & Copeland, 2002). Moreover, in a randomized clinical trial, participants who underwent a Cognitive Remediation Program (CRP) demonstrated significant increases in academic achievement (Butler et al., 2008). Butler et al. (2008) noted effect sizes were modest but compared to clinical trials involving pediatric brain injury survivors. Similarly, positive changes in brain activity, as measured by fMRI, have also been observed for pediatric cancer survivors who have participated in a CRP (Zou et al., 2012). The lasting clinical significance of this intervention has yet to be established. As beneficial as these interventions may be in improving cognitive functioning and preventing late effects, it is also imperative that patients and their families receive psychosocial interventions and support to promote their emotional and psychological wellbeing.

**Psychosocial Treatment and Support for Pediatric Cancer Patients**

Currently, there are no gold standard treatments that have been designed specifically for supporting children adjusting to pediatric cancer. Individual, family-based, and community-
based interventions have been identified in the literature as showing promise in promoting healthy adjustment and reducing distress among patients and their families.

**Individual interventions.** As with other types of psychosocial treatment, interventions that are practical, user-friendly, and accessible will likely be most effective for those who use them. Given the increasing use of the Internet by adolescents to access health information (Gray et al., 2005), O’Conner-Von (2009) designed an educational program for older children and adolescents with cancer in a web-based format. The online program, *Coping With Cancer*, provides information about cancer and treatments, and focuses on strategies for coping with the diagnosis and treatment process. Program users also have the ability to offer each other advice and encouragement about the cancer process. O’Conner-Von reported that initial feedback about the program from content experts was largely positive and that early users indicated that the program was useful for its intended purposes.

Another innovative cognitive-behavioral program aimed at improving the emotional functioning of pediatric cancer patients is the Cellie Coping Cancer Kit (Marsac et al., 2011). The kit includes several cards containing evidenced-based coping skills for use by the child. A parent book that parallels the coping skills presented in the child's kit is also included in the materials. According to Marsac et al., preliminary results suggested that families found the materials to be engaging and useful. Parents endorsed using the information contained in the kit to talk to their child about the cancer treatment process. Further evaluations of this coping program are currently underway.

The Surviving Cancer Competently Intervention Program (SCCIP), another evidence-based cognitive-behaviorally focused intervention developed by Kazak et al. (1999), has demonstrated effectiveness in improving patients’ adjustment to cancer. SCCIP is a manualized three-session intervention for parents, caregivers, and siblings of pediatric cancer patients.
focused on fostering healthy adjustment to the diagnosis and treatment of pediatric cancer. Although this treatment is delivered to parents, children benefit from the skills learned by their caregivers. SCCIP has demonstrated effectiveness in significantly reducing symptoms of post-traumatic stress in pediatric cancer survivors through a randomized clinical trial (Kazak et al., 1999).

Reducing procedural pain is another important area of intervention for pediatric cancer patients, and is one of the most studied areas of treatment for this population. Kazak et al. (1996) reported that an intervention wherein parents of pediatric cancer patients were trained in cognitive-behaviorally-based strategies to minimize the child’s distress during medical procedures was effective. Various other cognitive-behavioral techniques, including relaxation, imagery, preparation, desensitization, modeling, distraction, and positive reinforcement, have been demonstrated to be effective in reducing distress during procedures, or decreasing procedure-related pain when taught to the individual child (Kazak, 2005).

Attending a residential camp designed specifically for cancer patients or survivors has been demonstrated as improving the psychosocial functioning of pediatric cancer patients (Langer & Roll, 2011). Patients in this study reportedly endorsed that camp provided an opportunity to escape cancer-related stigma, receive social support from peers and counselors, foster a sense of community, cultivate relationships, improve self-efficacy in tasks common to healthy peers, and develop skills for discussing their experiences. Other research on the impact of camp on pediatric cancer patients has suggested that attending camp improves a patient’s health-related quality of life (HRQOL; Epstein et al., 2005). Given the link between HRQOL and social support among children with chronic health conditions, it is possible that the opportunity to socialize and receive social support from peers during camp strongly contributes to the increased HRQOL ratings of the campers.
Non-clinical interventions have also been identified in the literature as being helpful in supporting cancer survivors to explore methods of coping and improve adjustment. Lam et al. (2013) utilized a participatory approach wherein adolescents created cancer-survivor related t-shirts and blog entries about their illness and treatment as a platform for discussing their experiences. Participants identified difficulties with medically-related communication, social role, and physical effects as primary sources of adjustment difficulties. Through the participatory activities, themes of resilience and humor were elicited from the adolescents to “explore their own ideas of coping with cancer” (Lam et al., p. 14). However, no standardized measure of change or improvement of coping was included in the study.

Although programs and treatments exist to address various hardships faced by cancer patients and survivors, research has suggested that many needs may go unmet and children may not be appropriately identified as needing services. Unmet needs are likely given that 82% of ALL survivors reported concerns in either the behavioral, cognitive, or emotional domain (Kahalley et al., 2012). Of the children with concerns, only 38% had been referred for follow-up care (Kahalley et al., 2012). Thus, cancer survivors would likely benefit from more thorough screening of emotional, behavioral, and cognitive concerns in order to link them to effective treatment.

Of the treatments that are commonly indicated for use with pediatric cancer patients in the literature, many are cognitive-behavioral in nature and several include a family component, such as those described above. In fact, treatments that are focused on improving family functioning also have a strong presence in the literature and have been established as efficacious in improving both child and family functioning. The next section reviews interventions for families and caregivers of pediatric cancer patients.
**Parent- and caregiver-targeted interventions.** The SCCIP is also used as an intervention for improving adjustment and decreasing anxiety in the whole family, not just the individual patient. Kazak et al. (2004) reported that the randomized clinical trials revealed that fathers experienced a significant reduction in PTSD symptoms and a decline in overall anxiety following treatment. No differences in overall anxiety symptoms or PTSD symptoms were found for the mothers who participated in the program. Marsland et al. (2013), who also created a stress management program for caregivers of children recently diagnosed with cancer, reported that caregivers with lower baseline social support appeared to benefit more from the intervention at follow-up than did caregivers with high levels of social support.

Another type of intervention aimed at parents and caregivers of pediatric cancer patients are retreats or support groups. Arnaert, Gabos, Ballenas, and Rutledge (2010) reported that parents who attended a retreat for building coping skills following a pediatric cancer diagnosis endorsed numerous positive impacts. As a result of the retreat, attendees disclosed having an improved sense of emotional openness and relief about being able to share their experiences. Moreover, the participants experienced feeling mutual support with the other families and having shared experiences with others who were struggling with similar issues. Taken together, these group programs created an overall greater sense of community between the families, helping them to feel as if they were no longer alone in their experiences. These effects were sustained upon re-evaluation one month after the retreat (Arnaert et al., 2010).

In summary, there is some evidence that parent- and caregiver-targeted interventions for improving coping and adjustment are effective in some cases particularly for fathers and those with little baseline support. However, there is little evidence on specifically which therapeutic techniques, and how much treatment, are most beneficial. Moreover, some of the more widely used techniques described in the literature were not effective for mothers. Given the potential for
psychological symptoms and distress in families of pediatric cancer patients, more research in this area is necessary to further investigate effective treatment techniques, especially for mothers. It is possible that families, and especially mothers, need a more comprehensive package of services from multiple providers that support them through the difficult diagnosis and treatment process. Community-based intervention is another option to meet families’ need for support.

**Community-based interventions.** Previous research has addressed the effect of community-based interventions, or therapeutic or recreational services offered by an agency or organization, on chronically ill populations and their families. Duaz Williams et al. (2003) found significant improvements in the functioning of the families of chronically ill children in various domains, including behavior issues, self-esteem, social support, mental health, knowledge of the patient’s illness, and family cohesion with community-based intervention. However, there is scant research on the effect of community-based interventions for pediatric cancer patients in particular.

National organizations that offer services to children and families, such as the American Cancer Association, American Childhood Cancer Organization, and The Leukemia & Lymphoma Society, have existed for decades yet the effectiveness of the services offered is largely unknown within the psychological community. Given the use of these services by the families experiencing pediatric cancer, it is imperative that their effect be evaluated. The services offered by these organizations are largely to supply the family with information about cancer and the treatment process and connect them with other available services. Resources, such as children’s books, videos, and coloring books about cancer, are also provided to aid children and families with the adjustment to cancer. The exact focus and goal of the services offered varies widely by agency.
Another service offered by local chapters of these national organizations or local organizations, such as the Children’s Cancer Association® (CCA), is community-based social support (CBSS) programs, which may include support groups or linking the family with a volunteer who provides companionship to the child. CCA, the organization associated with this study, provides CBSS by identifying a volunteer companion to engage in ongoing, positive social interactions and recreational activities with the child with the purpose of creating positive enjoyment for the child, and often respite for the families through the Chemo Pal® (Children’s Cancer Association®, n.d.) program. The recreational activities occur during hospitalization and throughout the treatment process and take place in the medical, home, or community setting. CCA’s goal in offering these services is to provide support and joy to children, not with the intention of causing a therapeutic effect that changes the child’s or family’s functioning (M.K. Turina, personal communication, November 3, 2010). However, it is currently unknown what type of an effect these services have on the children’s and families’ functioning. Similar to the body of research on the services offered by national organizations, the efficacy of local organizations and programs also remains largely unexamined. Given the emphasis on social support in the services offered by many of these organizations, it is important to understand the effect of social support on the functioning of pediatric cancer patients.

The Role of Social Support

The underlying concept of the Chemo Pal® program is providing social support; thus, the relationship between social support and cancer will be reviewed. The impact of social support from family and peers, as well as CBSS, will be discussed.

**Social support from family and peers.** Research has demonstrated that social support plays an important role in decreasing distress and improving coping in adolescents who are being treated for cancer (Decker, 2007). Decker also reported that families are a major source of
support for children with cancer, as well as friends, including both peers with cancer and healthy peers. The amount of perceived family support received by children with cancer versus healthy peers is unclear. Some studies have suggested that pediatric cancer patients perceive significantly more familial support than healthy peers (Brown, Madan-Swain & Lambert, 2003; Haluska, Jessee, & Nagy, 2002 as cited in Woodgate, 2006) whereas other studies found no difference (Kazak & Meadows, 1989; Manne & Miller, 1998).

A review of perceived support from friends also yielded conflicting findings (Decker, 2007), with some authors reporting no significant differences in the amount of perceived support (Brown, Madan-Swain & Lambert, 2003; Manne & Miller, 1998) and others reporting pediatric cancer patients perceive significantly less support from friends when compared to a sample of healthy children (Kazak & Meadows, 1989). In terms of satisfaction with the support they received from their families, pediatric cancer patients reported being satisfied (Woodgate, 1999). When children with cancer did perceive high amounts of social support, the support was associated with increased adjustment by pediatric cancer patients and their families (Woodgate, 1999). Additionally, pediatric cancer patients reported that their relationship with their parents became stronger throughout the course of treatment (Kvist, Rajantie, Kvist & Siimes, 1991; Woodgate, 1999).

An indirect effect on children’s level of social support is the social support received by their parents from others. Research has suggested that the size of a parents’ social network, and that of the child are linked (Uhlendorff, 2000). Thus, the scenario that is likely most impactful for the child is having a parent who has high levels of their own social support and provides a high level of social support to their child, as higher levels of social support are associated with healthier adjustment to the cancer diagnosis and treatment process. Furthermore, research has suggested that pediatric cancer patients may benefit from sources of social support outside of
their family unit and network of friends. As such, the impact of a specific type of outside social support, CBSS, will be discussed.

**Online social support.** Families and caregivers, in particular, may choose to reach out to others who are experiencing cancer for support, especially given increased access to the Internet. Coulson and Greenwood (2011) analyzed messages shared in a childhood cancer online support group. Themes that were revealed through the analyses included five overall categories of social support including emotional, informational, esteem support, network support, and tangible assistance. Emotional support included understanding, encouragement, prayer and sympathy, whereas informational support included advice, teaching, or referrals. Examples of esteem support were compliments, validation, and relief from blame. Network support involved access to new people and companions. Lastly, tangible assistance included financial help, assistance completing tasks, and participation in activities by others. Emotional and informational support emerged as being the most useful types of social support offered by use of the online support group. Coulson and Greenwood (2011) noted despite the apparent utility of the support groups there are limitations such as lack of responses by other users and challenges to maintaining relationships outside of the online group format and context. The research findings suggested, however, that support on a community level, whether virtual or actual, may be helpful in supporting families.

**Community-based social support.** Although research has been conducted on the role of social support systems such as peers and family, little research has been conducted on the effect of community-based social support for pediatric cancer patients. Research has indicated that families, in particular single-caregiver families, may benefit from community support but continue to have unmet social/emotional, financial, and practical support needs (Rosenberg-Yunger et al., 2013). Chernoff et al. (2002) designed a study to evaluate community-based
support programs for children suffering from chronic illnesses. The results indicated that the children experienced modest positive results due to having frequent visits and contact from a representative of a community-based support program. Although none of the participants in the study suffered from pediatric cancer, the authors suggested that the results could likely be generalized to children facing other chronic health conditions, given the severity of the conditions represented in the study (e.g. sickle cell anemia, cystic fibrosis). At present, this is the only study that has investigated the effects of CBSS for children with chronic illness.

In summary, social support has been demonstrated to be an important facet in positively affecting a patient’s level of functioning. Many of the factors affected by social support are constructs that are related to health-related quality of life (HRQOL). Although the field of psycho-oncology has experienced an influx of HRQOL research, little is known about the direct effect of social support on HRQOL in pediatric cancer patients, specifically. Nonetheless, it is important to understand the effect of HRQOL on other facets of a patient’s functioning. Thus, an overview of HRQOL in pediatric populations and pediatric cancer patients will be discussed.

Health-Related Quality of Life

Due to invasive and painful procedures, and life changes associated with the diagnosis and treatment of pediatric cancer, such as those described above, some children experience poor adjustment and functioning in core areas during and after treatment, which affects their HRQOL. As stated previously, a suggested definition for HRQOL by Spieth and Harris (1996) is the “subjective and objective impact of dysfunction associated with an illness or injury, medical treatment, and healthcare policy” (p. 176). This definition is suggested to apply to both adults and children; however, there is currently no universal definition of this construct. The core domains generally indicated as being associated with HRQOL include cognitive, physical, emotional, and social functioning (Eiser, 2007). The perceived level of HRQOL can vary across
these four domains, between healthy and sick children, across pediatric populations, and even among individual pediatric cancer patients, depending on multiple factors. As such, the accurate measurement of HRQOL can be complicated.

**Measurement of HRQOL.** In general, HRQOL is measured by standardized measures that were normed on samples representative of the target population. Both general and disease-specific HRQOL exist for children and adults. General HRQOL measures are used to assess a person’s HRQOL in all areas; whereas, disease-specific measures examine functioning related to the specific health condition of the patient. The majority of HRQOL measures are divided into domains of functioning, for example, social, cognitive, emotional, etc. Patients provide responses about their level of HRQOL in each area.

Only in the last several years has the construct of HRQOL received more attention and effort within research and clinical communities (Spieth & Harris, 1996). Currently, there is a larger body of research on adult HRQOL measures relative to children and adolescents. As such, the construct of HRQOL in children is far less understood compared to that of adults. Not until recently has adequate and psychometrically sound assessment of HRQOL, particularly for pediatric cancer patients, become available (Varni, Seid, & Rode, 1999).

Parsons and Brown (1998) suggested that the investigation of HRQOL is complicated due to the developmental differences between children and adults, as most of the HRQOL research has been focused on people above age 18. Furthermore, research has been complicated by the discrepancies between parental perception and patient perception of pediatric quality of life. Parent proxy report of a child’s HRQOL is used when child self-report is not feasible or practical to obtain. Research has demonstrated pediatric cancer patients and their parents have lower concordance rates on HRQOL ratings than do healthy children and their parents (Sawyer et al., 1999), with parents rating their child’s HRQOL lower than the child self-report (Ingerski et
al., 2010). However, parent proxy and self-report ratings on the Pediatric Quality of Life Inventory (PedsQL; Varni et al., 1999), a prominent pediatric HRQOL measure containing general and disease-specific modules, were found to be consistent across children with cancer and their caregivers (Russell, Hudson, Long, & Phipps, 2005).

HRQOL is considered to be a dynamic construct. Bernhard et al. (2004) suggested a potential challenge in the measurement of HRQOL is the changing nature of a patient’s perceived HRQOL over time or setting; that is, the meaning of HRQOL to the patient shifts across distinct clinical phases depending on the nature of treatment and other factors. Despite the challenges of HRQOL measurement, there is an emerging body of literature on the HRQOL of children and pediatric populations, including pediatric oncology survivors and patients. The status of the literature in each of these areas will be reviewed.

**HRQOL in children and pediatric populations.** In terms of the level of HRQOL in general child populations, research has suggested that HRQOL is lower for youth of low socioeconomic status, those with barriers to accessing medical care, adolescents (versus younger children), and, as expected, youth with medical problems (Simon, Chan, & Forrest, 2008). Among pediatric populations, HRQOL also differs (Ingerski et al., 2010), likely due to the unique diagnostic and treatment variables that accompany different medical problems. Thus, research suggests that there are differences in HRQOL both between healthy and ill populations, and among chronically ill populations.

**HRQOL in pediatric cancer survivors.** HRQOL has been demonstrated to be comparable between pediatric cancer survivors and people who have never experienced cancer. Harila et al. (2010) reported that among long-term survivors of ALL, HRQOL levels are comparable or higher when compared to healthy controls. Stam et al. (2006) reported that HRQOL for survivors who were one to two months post-treatment was lower in many domains when compared to their
healthy counterparts. Survivor HRQOL also appears to improve over time, following successful treatment of non-CNS tumors, especially in younger children (Maurice-Stam et al., 2008). Thus, following successful treatment of pediatric cancer, it is expected that HRQOL will improve over time and will ultimately be commensurate with or better than that of the general population, and will presumably return to what the level of the survivor’s HRQOL was prior to diagnosis and treatment. Some studies have reported a significant increase in HRQOL between three (i.e., when it is significantly lower than a comparison group) and eight years (when it is commensurate with comparison group) following treatment (Koopman, 2005), whereas other researchers have found levels of HRQOL were comparable to healthy controls in as few as three years post-treatment (Maurice-Stam et al., 2008). However, little definitive information is known about the course of improvement of HRQOL and at what points HRQOL should be increasing, leveling off, or matching that of healthy populations. Taken together, these findings suggested that it is imperative that monitoring and support of survivor psychosocial functioning continue post-treatment and not cease upon the end of medical treatment.

**HRQOL in pediatric cancer patients.** Few studies on the HRQOL of pediatric patients receiving active treatment are available. However, data suggests that adult cancer patients who are newly diagnosed have significantly lower HRQOL compared to post-treatment survivors, as well as relative to healthy controls (Baker, Denniston, Haffer, & Liberatos, 2009; Johansson et al., 2008). Of the few studies on pediatric patients that have been conducted, results suggested a similar pattern to adults in that patients who were undergoing treatments consistently endorsed significantly poorer HRQOL when compared to pediatric cancer survivors and their healthy counterparts (Landolt et al., 2006; Shankar et al., 2005). Given the relatively few studies on this topic that are available, further investigation in this area is warranted. In addition to the importance of understanding patients’ HRQOL, another pivotal question is what factors
moderate the maintenance, improvement, or decline of the level of HRQOL in pediatric cancer patients.

Factors Affecting HRQOL. Although many children adjust to their cancer diagnosis over time, certain qualities and characteristics place some children at higher risk for experiencing poor quality of life (Sung et al., 2009a). These factors include treatment characteristics, demographic variables, family factors, and social support.

Treatment factors. Sung et al. (2009b) reported that more intensive chemotherapy treatment was related to poorer quality of life, specifically poorer emotional functioning. Survivors who received cranial radiation for CNS tumors are at the greatest risk for having poorer HRQOL, when compared to survivors who received other types of treatment (Cantrell, 2011). Research conducted by Reimers, Mortensen, Nysom, and Schmiegelow (2009) also cited radiation therapy as an important predictor of HRQOL. Long-term survivors of pediatric cancer who received radiation therapy for malignant brain tumors had significantly poorer quality of life when compared to survivors who had not been treated with radiation therapy. Maurice-Stam et al. (2008) suggested that longer duration of treatment and poor prognosis also negatively impact HRQOL.

Demographic factors. Some demographic variables also impact HRQOL. In a review of the state of the literature, Cantrell (2011) reported that gender is an important factor in HRQOL, with female patients experiencing poorer HRQOL compared to males. Moreover, children who are diagnosed at an older age are at a higher risk for poorer HRQOL than younger children (Cantrell, 2011). According to Cantrell, socioeconomic status and whether or not a child is insured also affects HRQOL. In that study, low socioeconomic status and no access to health insurance were found to be related to poorer HRQOL in pediatric cancer patients.
**Family factors.** Family and parental factors affect HRQOL. Hullman et al. (2010) reported that pediatric cancer patients of parents who were overprotective and viewed their child as vulnerable had significantly lower HRQOL when compared to patients whose parents did not have these qualities. The researchers observed the relationship between over-protectiveness and lower HRQOL after control for child and parent factors such as child age, gender, age of diagnosis, illness duration, disease group, parent age and parent education. These findings suggested that parental over-involvement can impact a child’s functioning, especially in terms of his or her HRQOL.

**Social support.** In terms of the documented effect of social support on HRQOL, available research suggests that higher levels of social support significantly improve HRQOL in adult cancer patients (Michael et al., 2002). However, this has not yet been thoroughly researched for pediatric cancer patients, specifically. Level of social support has been identified as a predictor of HRQOL in children with other chronic health conditions (Dobson, Zelikovsky, Miller, & Skira, 2011; Zeller & Modi, 2006). Given the positive impact that social support has on the functioning of pediatric cancer patients in other domains including adjustment to cancer (Woodgate, 1999), and the link between social support and HRQOL in other pediatric patients, it is expected that higher levels of social support would also significantly improve HRQOL in pediatric patients.

**Summary**

Recent developments in medical oncology treatments have shifted the focus to minimizing hardships faced by pediatric cancer patients and improving outcomes in other areas, such as psychosocial functioning and HRQOL. Research efforts have documented that survivors of pediatric cancer generally function adequately with outcomes dependent on several factors. Nevertheless, functioning immediately following diagnosis and during the treatment process can
be affected in patients and their families. Fortunately, several evidence-based interventions and
techniques have been developed with the intent to minimize distress and improve functioning
during the active phase of pediatric cancer. One important factor in improving functioning and
buffering against distress is social support. Level of social support can increase positive
functioning and coping of pediatric cancer patients and their families across various domains.
Although the effect of individual and familial social support on the HRQOL of pediatric
populations has been investigated, research on community-based social support and its effect on
HRQOL among pediatric cancer patients, in particular, is seriously lacking.

**Purpose of the Current Study**

The purpose of this research was to examine the effect of community-based social
support on pediatric cancer patients by determining whether or not there is a statistically
significant change in HRQOL (as measured by caregiver report on the Cancer Module of the
PedsQL) of pediatric cancer patients who receive community-based social support, after
considering a patient’s pre-program level of social support. Because familial support has been
shown to improve functioning and adjustment to pediatric cancer diagnosis and treatment
(constructs associated with health-related quality of life; Woodgate, 1999; Decker, 2007),
perceived social support, as measured by an adaptation of the Child and Adolescent Social
Support Scale (CASSS; Malecki & Demaray, 2002), was evaluated in order to control for any
effect non-community-based social support may have. As mentioned previously, the size of the
parental social network has been found to be similar to the size of the social network in their
children (Uhlendorff, 2000). Thus, these constructs appear to be related among parents and their
children. As such, the level of the parent participants’ social support was also assessed. The
hypotheses for this study are as follows:
A1). Parent perception of the level of HRQOL of their children with cancer (obtained at baseline) should be lower than the sample on which the measure was normed. Research findings on the HRQOL of pediatric patients undergoing treatment suggest pediatric cancer patients have significantly poorer HRQOL than healthy children (Landolt et al., 2006; Shankar et al., 2005). Thus, it was hypothesized that the pediatric cancer patients would be rated as having lower HRQOL compared to the population on which the measure was normed.

A2). Parent perception of the level of overall social support of the pediatric cancer patients (obtained at baseline) should be lower relative to the normative sample. The level of social support of pediatric cancer patients has not been consistently documented in the literature. Some research has reported patients as having comparable social support to healthy children (Brown, Madan-Swain & Lambert, 2003; Manne & Miller, 1998), whereas other researchers have indicated that pediatric cancer patients have significantly lower levels of social support (Kazak & Meadow, 1989). Because the families are seeking out social support services at CCA, it may be that parents perceive their child as needing more support in this area. Thus, it was hypothesized that parents’ perceptions of their children’s level of social support would be lower than the population on which the measure was normed.

A3). It was hypothesized that the parent or caregiver’s level social support would be lower than that of the population on which the measure was normed. Because research has suggested that parents’ social networks mirror that of their children (Uhlendorff, 2000), it was hypothesized that parent’s level of social support would be lower than that of the normative population (thus matching the hypothesis for the child’s level of social support).

B1). Parental perception of the child’s HRQOL will increase from baseline (T1) to 1 month (T2), and from 1 month to 2 months (T3).
Given the link between social support and a patient’s level of functioning, and because community-based social support in general has been demonstrated to improve functioning in pediatric patients (Chernoff et al., 2002), it was hypothesized that parent perception of the child’s level of HRQOL will reflect significantly improved scores over time (i.e., from T1 to T2). It was expected that the children and Chemo Pals will be further developing their relationship with each month. Thus, it was hypothesized that there would also be improvement in HRQOL scores from T2 to T3.

B2). It was hypothesized that CBSS should have a positive effect on HRQOL after controlling for pre-program levels of social support.

It was hypothesized that a child’s pre-program level of overall social support would have a positive impact on the effects of the community-based social support services on HRQOL. As described above, research indicates that children with higher levels of social support function better and are more well-adjusted than patients with lower levels of social support. More well-adjusted participants are expected to have higher HRQOL. Thus, pediatric cancer patients with higher levels of pre-program social support were expected to demonstrate fewer gains in HRQOL, due to the probability that they will already have high HRQOL, creating less opportunity for improvement.

C1). It was hypothesized that perceived social support would be positively related to HRQOL scores.

Due to the link between HRQOL and social support in adult cancer patients as well as other pediatric populations, it was hypothesized that scores on these measures would be associated. Specifically, it was expected that these scores would be positively correlated, as research has demonstrated a connection between high levels of social support and endorsement of good HRQOL.
It was hypothesized that parent perception of their child’s level of overall social support would increase over time (i.e., from T1 to T2, and from T2 to T3).

Because the services offered by CCA are providing the children with companionship and opportunities to engage in recreational activities (elements of social support), an exploratory hypothesis was considered. It was thought that the parents or caregivers’ perceptions of the child’s overall level of social support would increase as a result of engaging in the program was created. There was no literature supporting the notion that receiving CBSS improves overall level of parent or caregiver perception of their child’s level of overall social support. Thus, this hypothesis was exploratory.

Method

Phase 1—Caregivers of Children Undergoing Cancer Treatment

Caregiver Participants. Participants included three adult caregivers of children actively undergoing cancer treatment and who had applied for services from the Children’s Cancer Association’s® (CCA) Chemo Pal® program.

Caregiver demographics. A total of three individuals participated in part or all of the study. One caregiver completed the entire study (initial, 1-month, and 2-month follow-up surveys) and two dropped out and did not complete the entire study. Of the two caregivers who dropped out of the study, one did not respond to prompts to begin the 1-month follow-up and one only completed half of the 1-month follow-up and then did not respond to prompts to finish the 1-month follow-up or other attempts at contact. Both of the participants who dropped out were female as was the participant who completed the entire study. Participants ranged in age from 35

40
to 36. The caregiver who completed the entire study was Caucasian, whereas the other two participants were Caucasian and Latino. Two caregivers were divorced/remarried and one was partnered/in a committed relationship (not legally married). Two of the participants had attended some college and one had a college degree. One participant had a family income of less than $25,000, another $25,000 - $40,000 per year, and the third had an annual income of $65,000 - $80,000. None of the caregivers had a family history of cancer with the exception of their child. All participants in the study spoke fluent English and had Internet access as this was a requirement of the study.

**Children of caregiver participants.** Caregivers had children ranging in age from 11 to 15. The minimum age requirement was 5 and the maximum age requirement was 18. One child whose parent participated in the study was Latino and two of the children were Caucasian. All caregivers who completed the survey had a child who had been diagnosed with cancer and no other major medical illnesses. Two were diagnosed with acute lymphoblastic leukemia and one was diagnosed with medulloblastoma. Age of initial diagnosis ranged from 5 to 14 years old and two of the children had relapsed at least once. All children were receiving chemotherapy at the time their parents participated in the study and two of the three were also receiving radiation in addition to chemotherapy. None of the children were attending school due to their health status and needs.

**Setting for Phase 1 and Phase 2.**

**Children’s Cancer Association**®. CCA is an Oregon-based non-profit agency that provides a variety of services to infants, children, teens, and families facing pediatric cancer and similar medical disorders. The Chemo Pal program, one of the services offered by CCA, matches a volunteer companion (called “Chemo Pals”) with a child undergoing chemotherapy or other cancer treatment. Chemo Pals offer social support by engaging the children in
conversation, games, and recreational activities focused on creating a more fun and positive environment for the child. Chemo Pals spend approximately 8-10 hours per month with the child, and make visits to the hospital, clinics, or home environment, based on the needs of the patient. Number of hours spent with the child and family is related to the availability of patients. Volunteers also keep in contact with the family through phone calls or text messages, emails, cards, and letters to the children/family.

**Design and Procedures.**

This study was approved by Pacific University Institutional Review Board (study # 060-12). Following IRB approval, recruitment emails were sent by CCA staff to families who met the study inclusion criteria. Families were encouraged to contact the principal investigator by email and were then sent a link to an online survey. Recruitment began in September 2012 and was terminated in April 2013 after 6 months had elapsed. As noted above, three caregivers participated in this timeframe. Measures and demographic questionnaires were administered to caregivers via Survey Gizmo, a web-based survey tool. The investigator sent a link to the survey to each caregiver’s email address at 3 time points (i.e., T1, T2, and T3). Families were compensated with a $5 gift card for each completed survey and were entered into a raffle for an opportunity to win a $40 gift card.

Using the online survey, caregivers rated their child’s HRQOL using the Cancer Module of the Pediatric Quality of Life Inventory (Varni et al., 2002) on three occasions: at baseline (T1), after 1 month (T2), and at 2 to 3 months (T3). Parent and caregiver perception of the child’s level of social support was also assessed by a modified version of the Child and Adolescent Social Support Scale (CASSS) (Malecki & Demaray, 2002) at T1, T2, and T3.
Parental perception of child social support was examined to control for the impact of existing social support systems the participants may have that are improving their HRQOL. Caregivers completed the Social Support Questionnaire Short Form (SSQ6) (Sarason, Levine, Baskman, & Sarason, 1983) at T1, T2, and T3. Participants were administered the survey at different points throughout the data collection period as families engaged CCA services at differing times. CCA offered participation to all families who engaged CCA services during the data collection period.

**Measures.**

**Demographic questionnaire.** A demographic questionnaire was administered to collect information about the adult participants and the child undergoing cancer treatment.

*Adult demographics (demographics of caregiver participants).* Separate demographic questionnaires for the parent and the parents’ report of the child were administered. Information gathered about the caregiver included age, gender, ethnicity, level of education, number and ages of immediate family members, and family income level.

*Adult report of child demographics.* Information gathered about the child included age, gender, and ethnicity.

*Adult report of child cancer.* Items relating to the child’s health and treatment status were included. These questions were created to gather information about the child’s specific diagnosis, age at diagnosis, relapse history, treatment type, and course of treatment. Moreover, information about the child’s health and treatment status was gathered at each reporting period (T1, T2, and T3). For example, questions included information about how much the child was hospitalized during the current reporting period; if the cancer symptoms remained the same, worsened, or improved; and how the parent would rate the child’s health status. See Appendix A for a complete list of demographic questions.
Pediatric Quality of Life Inventory (PedsQL) Cancer Module. As stated previously, the child’s HRQOL was assessed by the Cancer Module of the PedsQL (Varni et al., 2002), a 27-item quality of life inventory designed for pediatric cancer patients. The Cancer Module contains questions designed for children with a cancer diagnosis who are undergoing treatment. Eight domains are represented on the PedsQL including pain and hurt, nausea, procedural anxiety, treatment anxiety, worry, cognitive problems, perceived physical appearance, and communication. The inventory is intended to measure the patient or parent’s perception of the impact of a disease or treatment (i.e. health-related quality of life) in different areas including physical, psychological, and social functioning (Varni, Seid, & Rode, 1999). The inventory allows for both a self-report of quality of life (children ages 5-18) and a parent proxy-report (children ages 2-18). In this study, only the parent proxy was used.

Varni et al. (2002) assessed the PedsQL and concluded that overall the Cancer Module has acceptable psychometric properties. In terms of internal consistency reliability, all of the parent proxy-report scales met or exceeded the minimum criteria used by Varni et al. (2002), which was a coefficient of .70. Construct validity was also shown to be adequate, as the measure was able to discriminate healthy versus sick children, across comparisons of all scales. Furthermore, some scales were shown to discriminate between pediatric cancer patients currently in treatment and those not currently receiving treatment (Varni et al., 2002).

Parent proxy report was utilized in this study due to the superior psychometric properties when compared to the self-report version of the measure and because the measures were administered online. Responses were rated on a 5-point Likert-type scale, with higher scores indicating higher quality of life. The scale allowed for a range of responses from 0 (never) to 4 (almost always) for each item. The parent-report version included items such as “getting anxious to go to the doctor” and “worrying about side effects from medical treatments.” Scores were
calculated for each subscale, including Pain and Hurt, Nausea, Procedural Anxiety, Treatment Anxiety, Worry, Cognitive Problems, and Communication, with higher scores indicating better HRQOL.

Ewing, King, and Smith (2009) reported the results of a confirmatory factor analysis of the PedsQL Cancer Module as confirming the factor solution proposed by Varni et al. (2002). According to the analysis of proportions of variance accounted for by proxy-report for the Cancer Module, 84% of the variance was explained by a six-factor solution. From these results the authors concluded that construct validity was confirmed. In addition, Ewing et al. (2009) also reported strong internal consistency reliability, as all Cronbach’s alpha coefficients met or exceeded the acceptable level.

Child and Adolescent Social Support Scale (CASSS). Because social support has been shown to improve functioning in domains associated with the HRQOL of pediatric cancer patients (Decker, 2007; Woodgate, 1999), social support of the patients was assessed using parent report. Currently, no published parent proxy measures of a child’s level of social support were found. Thus, items from the Child and Adolescent Social Support Scale (CASSS) (Malecki & Demaray, 2002) were adapted to allow for parent proxy-report and only relevant domain sections were utilized. The modified version adjusted wording to allow for parent report (e.g., changing “I” to “my child”) and deleted scales that were not relevant for parent report. Remaining scales included Parent (I), Teacher, Classmates, Close Friend, and People in My Child’s School. The original CASSS is a multidimensional, 40-item scale that measures perceived social support from the following sources: parents, friends, classmates and teachers. It is a self-report measure designed for children and adolescents from third to twelfth grade. Two levels divide the age groups; Level 1 for grades three to six and Level 2 for children from sixth through twelfth grade. Each of the sources of support represents a subscale of the measure.
(parents, friends, classmates, and teachers), for a total of four subscales. The scale includes items such as “My parents tell me how well I do on tasks,” and “My close friend understands my feelings.” Each subscale produces two scores, a frequency score and an importance score. The frequency score allows the child (in this case the caregiver) to report on the frequency of contact they perceive from the four sources, whereas the importance score reflects the child/caregiver’s perceived importance of that support. The importance scale was created primarily for clinical interpretation and use and significantly lengthens the questionnaire. As a result, the importance scale was modified in this study and information about the importance of the social support in the global category (versus each individual item) was collected. Frequency ratings include a 6-point Likert scale, ranging from 1 (never) to 6 (always). The importance ratings include a 3-point scale ranging from 1 (not important) to 3 (very important).

The psychometric properties of the CASSS were found to be acceptable for child self-report of perceived social support in children third through twelfth grade (Malecki & Demaray, 2002). There is no available psychometric data for parent proxy report of child social support, which was the mode of administration in this study. Thus, the psychometric information presented is for the child self-report version of the questionnaire. Based on reliability findings, Malecki and Demaray (2002) concluded that the CASSS is a reliable indicator of perceived social support in children. The internal consistency reliability coefficient for the Level 1 and Level 2 Total scales were .94 and .95 respectively. The coefficients for the four subscales at each level ranged from .87 to .93 for Level 1, and .89 to .94 for Level 2. In terms of test-retest reliability, the coefficients for the Total scale ranged from .60 to .76 on the subscales, after an 8-week time lapse between administrations. Validity was also found to be adequate for the CASSS. Construct validity findings indicate that the scales on the CASSS had subtest intercorrelations ranging from .20 to .54 for Level 1 and from .32 to .54 for Level 2. The correlations between the
subscales and the Total scale score ranged from .65 to .86 and from .71 to .78 for Levels 1 and 2, respectively. When the CASSS was compared to another scale measuring a similar construct (i.e., social support) in order to evaluate convergent validity, the correlation between the Total scales was .70, and the subscale correlations ranged from .55 to .66. Furthermore, a confirmatory factor analysis was conducted to assess the proposed structure of the CASSS. Results on both Level 1 and Level 2 indicated that the four-factor solution (i.e., parent, teacher, friend, classmates) was supported (Malecki & Demaray, 2002).

**Social Support Scale Short Form (SSQ6).** The parent’s level of social support was measured by a brief version of the Social Support Questionnaire (Sarason, Levine, Baskman, & Sarason, 1983), the Social Support Questionnaire Short Form (SSQ6) (Sarason, Sarason, Shearin, & Pierce, 1987). The SSQ6 is a 6-item scale for measuring adults’ perceived level of social support and is an abbreviated version of the long 27-item form.

The short form was found to be psychometrically similar to the long form and to have acceptable psychometric properties. Specifically, the internal reliability ranged from .90 to .93 across three separate samples for the number of socially supportive relationships (Number). The internal reliability for the satisfaction with social support also ranged from .90 to .93 across three separate samples (Satisfaction; Sarason et al., 1987). Thus, the SSQ6 is acceptable from a psychometric standpoint. The internal reliability for the long form SSQ ranged from .97 to .98 for Number and .96 to .97 for Satisfaction, which is considered acceptable (Sarason et al., 1987). Given the available psychometric information, it can be concluded the SSQ and SSQ6 are psychometrically similar and sound and appropriate for use in research.

**Parent/caregiver perceptions of Chemo Pal® program.** Finally, general questions regarding caregiver and caregiver perception of the child’s satisfaction with the CBSS and how supportive or helpful they found the program were included. Two open-ended items were
developed to assess the parent or caregiver’s perceptions of the Chemo Pal® program and their satisfaction with the Chemo Pal® program and CCA. The questions included, “What does your child think about their Chemo Pal®?” and “How has the Chemo Pal® program services affected your family?”

Phase 2—Volunteers and Staff from the Children’s Cancer Association© (CCA).

As the number of participants in the caregiver-focused portion of the study was below the anticipated sample size, a second phase of the study was conducted to provide additional perspectives on the services that CCA provides, specifically the Chemo Pal® program including volunteers and staff from CCA as the participants. In this second portion of the study (i.e., Phase 2), additional data were collected through interviews to provide further information and insight into the impact of the Chemo Pal® program on the health-related quality of life of the children and general effects the services have on families.

Participant demographics. A recruitment email was sent out by CCA staff to a total of 29 active Chemo Pals. Two staff and three volunteers agreed to participate in the study and completed the interviews. Staff/volunteer participants ranged in age from 27 to 78. Four were female and one was male. All participants in Phase 2 identified as Caucasian. The average tenure in years as a Chemo Pal was 4.5 (range of 3 to 7 years) and the mean number of families served by volunteers was 3.67, with a range of 3 to 7. For staff, the mean years employed at CCA was 5.25.

Setting. The setting for Phase 2 was the same as for Phase 1.

Design, Procedures, and Measures. Participants were recruited through an email sent to eligible volunteers and selected staff members by a Chemo Pal® program staff member. Participation was voluntary and no incentive was provided. Interested participants responded to
the contact information provided in the email and a date for the interview was arranged. CCA staff emailed a recruitment email to all active Chemo Pals (a total of 29) and three responded to the solicitation. Interviews were conducted by telephone and the average length of interview was 39.2 minutes. The interviews proceeded in a semi-structured format and included six questions (see Appendix C) that had been designed to assess the staff/volunteer’s perception of the effect of the program services on the child and family. No standardized measures were used with the staff/volunteer participants. The six interview questions were designed to elicit information specific to the effectiveness of the Chemo Pal® program as well as information about staff/volunteer participants’ background and experiences. For example, items such as, “How are the child and caregiver benefitting from the program?” were utilized. The questions were modeled after the open-ended items administered to caregivers about their and their child’s fit with their Chemo Pal® and the effect the services have had on their family.

Results

Phase 1

Overview of the Caregiver Data Collection. There were many challenges that arose during the 6-month caregiver data collection phase of the study. Despite thorough and systematic recruitment by investigators and the partner agency, the expected number of participants was not reached. Initially, the goal was to have 5-10 caregivers complete the entire study, which included surveys at all three time points. However, only one caregiver completed all three data collection time points of the study, with two other caregivers dropping out after the first survey. Further, the caregiver who completed the study indicated in the interview questions that the family was on a break and not actively engaged in the Chemo Pal® program.

Based on the low response to the study and the fact that participants were not completing all data collection time points, the investigator submitted a modification to the IRB protocol
approximately 4 months into data collection phase, to attempt to address the problems with data collection. The investigators revised the survey content to shorten and streamline the measures and added the option of telephone administration. Unfortunately, no additional caregivers initiated participation in the study following these changes. Through conversations with CCA, the partner agency, it became apparent that there had been some months of lower referral rates and the current goal of number of participants was not viable. Thus, a decision was made to terminate data collection. No significant data was provided by parents on the Chemo Pal® program-related questions (see Appendix B) as participants had either not yet met the Chemo Pal (e.g., T1), dropped out of the current study, or were not actively participating in CCA services.

Data Screening. Pre-analysis data screening was performed with available data. The data was examined for completeness and no items were found to be blank or skipped, with the exception of sections that were discontinued due to participant dropout. Moreover, the accuracy of responses was appraised to eliminate the possibility of respondent error in entering the information into the online survey. All responses were found to be accurate and within expected limits.

Hypothesized Analyses. As a result of the small number of participants and the lack of any participants whose children were actively engaged in the program finishing the entire study, most of the hypotheses were not appropriate for analysis and could not be tested. The following section presents any results that could be reported from the available data.

Hypotheses A1, A2, and A3: PedsQL, CASSS, SSQ-6 Scores at T1 Compared to Normative Samples. It was initially hypothesized that the pediatric cancer patients would be rated at baseline as having lower HRQOL, as measured by the PedsQL, compared to the population on which the measure was normed. Due to quantitative data limitations, including the small sample size, statistical analyses could not be utilized. At T1, which coincided with the
initiation of the program services and the child’s treatment, the average total score for the three participants on the PedsQL Cancer Module Parent Proxy Report was 73.67 ($SD = 18.77$). The average score on the Pain and Hurt subscale was 70.83 ($SD = 25.67$) and 45 ($SD = 25.50$) on the Nausea subscale. On the Procedural Anxiety and Treatment Anxiety subscales, the average scores were 75 ($SD = 18.00$) and 63.89 ($SD = 25.76$), respectively. On the Worry subscale, there was a mean score of 52.77 ($SD = 34.92$), whereas the average score was 75 on the Cognitive Problems subscale ($SD = 21.21$). The mean score for the Perceived Physical Appearance subscale was 83.33 ($SD = 23.57$). Lastly, the average score for the Communication subscale was 52.78 ($SD = 37.48$).

There was variability across subscales when scores were compared to the normative population (Varni et al., 2002). The Pain and Hurt mean subscale score appeared to be commensurate between the current study ($M = 70.83$) and normative sample ($M = 70.34$), although statistical analyses were not performed to test for significant differences. The Treatment Anxiety mean subscale scores also appeared to be approximately commensurate between the Chemo Pal® ($M = 63.89$) and normative sample ($M = 67.37$), as did the Cognitive Problems mean subscale scores (Chemo Pal® sample $M = 75$; normative sample $M = 74.96$). The Worry mean subscale score also appeared commensurate between the Chemo Pal® sample ($M = 52.77$) and the normative sample ($M = 70.74$) as did the Communication subscale (Chemo Pal® sample $M = 52.78$; normative sample $M = 77.99$). Additionally, the Perceived Physical Appearance mean subscale score for the Chemo Pal® sample ($M = 83.33$) also appeared commensurate with the normative sample ($M = 75.73$). The Nausea mean subscale score for the Chemo Pal® ($M = 45$) sample appeared to be lower than the normative sample ($M = 70.58$). The Procedural Anxiety mean subscale score was higher for the Chemo Pal® sample ($M = 75$) than the
normative sample \( (M = 54.49) \), indicating better HRQOL for the Chemo Pal® sample. Table 1 displays mean T1 PedsQL Cancer Module mean subscale scores as compared to a normative sample (Varni et al., 2002).

Table 1

\textit{Comparison of Mean PedsQL Cancer Module Scores by Sample}

<table>
<thead>
<tr>
<th>Scale</th>
<th>( n )</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain and Hurt</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemo Pal® Participants</td>
<td>3</td>
<td>70.83</td>
<td>25.67</td>
</tr>
<tr>
<td>Normative Sample</td>
<td>177</td>
<td>70.34</td>
<td>26.30</td>
</tr>
<tr>
<td>Nausea</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemo Pal® Participants</td>
<td>3</td>
<td>45.00</td>
<td>25.50</td>
</tr>
<tr>
<td>Normative Sample</td>
<td>179</td>
<td>70.58</td>
<td>24.60</td>
</tr>
<tr>
<td>Procedural Anxiety</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemo Pal® Participants</td>
<td>3</td>
<td>75.00</td>
<td>18.00</td>
</tr>
<tr>
<td>Normative Sample</td>
<td>178</td>
<td>54.49</td>
<td>31.74</td>
</tr>
<tr>
<td>Treatment Anxiety</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemo Pal® Participants</td>
<td>3</td>
<td>63.89</td>
<td>25.76</td>
</tr>
<tr>
<td>Normative Sample</td>
<td>179</td>
<td>67.37</td>
<td>29.71</td>
</tr>
<tr>
<td>Worry</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemo Pal® Participants</td>
<td>3</td>
<td>52.77</td>
<td>34.92</td>
</tr>
<tr>
<td>Normative Sample</td>
<td>175</td>
<td>70.74</td>
<td>31.67</td>
</tr>
<tr>
<td>Cognitive Problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemo Pal® Participants</td>
<td>3</td>
<td>75.00</td>
<td>21.21</td>
</tr>
<tr>
<td>Normative Sample</td>
<td>176</td>
<td>74.96</td>
<td>22.24</td>
</tr>
<tr>
<td>Perceived Physical Appearance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemo Pal® Participants</td>
<td>3</td>
<td>83.33</td>
<td>23.57</td>
</tr>
<tr>
<td>Normative Sample</td>
<td>178</td>
<td>75.73</td>
<td>25.95</td>
</tr>
<tr>
<td>Communication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemo Pal® Participants</td>
<td>3</td>
<td>52.78</td>
<td>37.48</td>
</tr>
<tr>
<td>Normative Sample</td>
<td>173</td>
<td>77.99</td>
<td>22.28</td>
</tr>
</tbody>
</table>

Initially, it was hypothesized that parents’ perceptions of their children’s level of social support, as measured by domain scores on the CASSS, would be lower than the scores from the sample population. Although statistical analyses were not performed as a result of data limitations, average domain scores were calculated for the following subscales: Parent, Teacher, Classmates, Close Friend, and People in My School. A global Importance Scale was
administered for each subscale (Likert scale of 1-3, which corresponded to the descriptive labels of Not Important, Important, Very Important) to assess for the level of importance of each type of social support. The overall average Importance Scale score across subscales was 2 or “Important.” At T1, the average score for the Parent scale was 71.33 (\(SD = 6.35\); Importance scale \(M = 3\) or “Very Important”); and, 71.33 for the Teacher scale (\(SD = 1.15\); Importance scale \(M = 2\) or “Important”). The mean Classmates scale score was 58.67 (\(SD = 22.48\); Importance Scale \(M = 3\) or “Very Important”), and the Close Friend scale score was 53.33 (\(SD = 21.94\); Importance Scale \(M = 2.67\) or between “Important” and “Very Important”). Lastly, the average score for the People in My Child’s School scale was 67.67 (\(SD = 4.93\); Importance Scale \(M = 3\) or “Very Important”).

The descriptive data provided by the test authors in the manual (Malecki & Demaray, 2002) was noted to be from a non-representative sample and cautious interpretation of the data was advised. For example, only normative data for middle school (grades 6-8) and high school students (grades 9-12; separate samples) were available from the authors, although the authors were currently working on building a database to bolster normative data. For this study, comparisons were made between scores of children with cancer (current sample) relative to healthy high school students from the normative sample, as two of the three participants in the current sample were adolescents. When compared to scores from the normative sample, scores across scales were higher for the current study sample (see table 2). Although statistical analyses could not be performed to test hypotheses about the degree and nature of differences between the two samples due to data imitations, a trend of higher caregiver perceived child social support was observed.

Table 2
Comparison of Mean CASSS Scale Scores by Sample

<table>
<thead>
<tr>
<th>Scale</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>People in My Child’s School</td>
<td></td>
<td>67.67</td>
<td>4.93</td>
</tr>
</tbody>
</table>
Because research has suggested that parents’ social networks mirror that of their children (Uhlendorff, 2000), a third initial hypothesis was that the parent or caregiver’s level of social support would be lower than that of the population on which the measure was normed. This hypothesis could not be tested due to data limitations and due to the unavailability of the normative data for this abbreviated measure. At T1, the mean score for the SSQ6 Number scale (e.g., number of socially supportive people in the participants’ lives) was 2.67 (SD = 1.70). A higher value on the Number scale indicates more social support. The SSQ6 Satisfaction scale score was 5.67 (SD = 0.47). No normative comparison sample data is available for this hypothesis.

**Hypotheses B1 and B2: Change in HRQOL Over Time and Effect of CBSS on HRQOL.** Given the link between social support and a patient’s level of functioning, and because community-based social support in general has been demonstrated to improve functioning in pediatric patients (Chernoff et al., 2002), it was initially hypothesized that parent perception of the child’s level of HRQOL would reflect significantly improved scores over time (from T1 to T2). It was also expected that the children and Chemo Pals would further develop their relationship with each month, leading to improvement in HRQOL scores from T2 to T3. The
mean HRQOL total score at T1 \((n = 3)\) was 74, compared to 61 at T2 \((n = 2)\) and 18 at T3 \((n = 1)\), indicating poorer HRQOL at T2 and T3 than at T1. However, given the data limitations (i.e., very small sample size and one participant who was not actively participating in the Chemo Pal® program), statistical analyses were not performed and conclusions were not made regarding the change in HRQOL over time.

It was initially hypothesized that a child’s pre-program level of overall social support would have a positive impact on the effects of the community-based social support services on HRQOL. As described above, research indicated that children with higher levels of social support function better and are more well-adjusted than patients with lower levels of social support. More well-adjusted participants are expected to have higher HRQOL. Thus, pediatric cancer patients with higher levels of pre-program social support are expected to demonstrate fewer gains in HRQOL, due to the probability that they will already have high HRQOL, creating less opportunity for improvement. Due to data limitations, this hypothesis was not addressed as scores for both HRQOL and social support were only available for one participant (who was not actively participating in the Chemo Pal® program services) at T2 and T3.

**Hypotheses C1 and C2: Change in Social Support Over Time and Relationship Between HRQOL and Child Social Support.** Due to the link between HRQOL and social support in adult cancer patients as well as other pediatric populations, it was hypothesized that scores on the PedsQL and CASSS would be associated. Specifically, it was expected that these scores would be positively correlated, as research has demonstrated a connection between high levels of social support and endorsement of good HRQOL. Unfortunately, this hypothesis was not fully addressed statistically due to data limitations. However, observation of the available data did not suggest a strong relationship between scores on the modified CASSS and HRQOL. For example, at T1 participant 1 scored a total CASSS score of 258 and PedsQL score of 70,
participant 2 scored 361 on the CASSS and 57 on the PedsQL, and participant 3 scored 348 and 94, respectively. Thus, the participant with the lowest HRQOL score had the highest child social support score and the participant with the highest HRQOL score only had the second highest child social support score.

Because the services offered by CCA are aimed to provide children with companionship and opportunities to engage in recreational activities (elements of social support), an exploratory hypothesis that parents or caregivers’ perceptions of the child’s overall level of social support would increase as a result of engaging in the program was created. There was no literature supporting the notion that receiving CBSS improves overall level of caregiver perception of their child’s level of overall social support, which was the justification for the exploratory nature of the hypothesis. Given the limitations of the available data, only modified CASSS scores for one participant can be reported for T1, T2, and T3, to address the hypothesis of change over time. At T1 ($n = 3$) the mean CASSS total score was 322. At T2 ($n = 1$) the score increased to 346 and to 366 at T3. Although data would suggest child social support increased over time with engagement in the Chemo Pal® program, no strong conclusions were drawn from this trend because the participant who completed all time points reported that her child was not actively engaged in the program during her participation in the study.
Figure 1. Participant 1 scores at T1, T2, T3.

Note. Participant 1 dropped out of the study after T1.

Figure 2. Participant 2 scores at T1, T2, T3.
Phase 2
Overview of Volunteer and Staff Data Collection and Procedures. Interviews with staff and volunteers associated with the Chemo Pal® program were conducted by the investigator to further assess the impact of the program on the children and families it serves. General themes were identified from the interview question responses and category labels (e.g., distraction, anxiety-reduction, etc.) were applied by the investigator to reflect these interview themes. Participant responses to the interview questions were collapsed in some instances to protect the confidentiality of the participants. Across the responses, it was noted that staff responses tended to be directed more at the program level whereas volunteers mostly spoke about their personal experiences with their current and former Chemo Pals. Overall, all staff members and volunteers perceived the CBSS services as impactful to families. Specific benefits were discussed relating to impact on HRQOL, social support, and other areas of functioning.
Impact of CBSS Services on HRQOL. Four main themes emerged during interviews regarding the impact of CBSS services on HRQOL that were categorized by the investigator as follows: distraction, anxiety reduction, comfort during medical procedures, and mood improvement.

Distraction. Participants indicated that one function of having a Chemo Pal and/or the Chemo Pal® program was distraction. Spending time engaging the child in activities tailored to his or her interests and allowing him or her to direct the play, meant that the child was distracted from the medical environment and related stressors. According to both staff and volunteer interviewees, being distracted by enjoyable activities helped the child focus on positive tasks versus experiencing worry or other feelings they might have about being in the medical setting, receiving treatment, or having cancer. One volunteer participant noted playing with the Chemo Pal helped “get their mind off of cancer.” Examples of distraction provided by interviewees included games, imaginary play, conversation, arts and crafts, reading stories, or any leisure activity in which the child expressed interest. Volunteer interviewees indicated that some parents chose to remain with the Chemo Pal and child during visits. As a result, parents who were involved in the activities also often benefitted from distraction from the medical environment. To that end, one participant stated “it ended up being fun for [the parents] to see [their child] play.”

In summary, Chemo Pal activities gave the child something to look forward to amidst the multiple medical procedures he or she endured during hospitalization and clinic visits. Caregivers also benefitted from the service as observing the Chemo Pal playing with their child was a distraction for family members as well.

Anxiety Reduction. A second function served by the Chemo Pal and the Chemo Pal® program was anxiety reduction. Participants reported that children in the program had reduced anxiety as a result of the services. One way in which they believed anxiety was decreased was through listening to the children express their feelings and talking about distress related to
procedures. Having the Chemo Pal present was also reported by both volunteers and staff to be helpful in anxiety reduction because the Chemo Pal might be “the only person outside of the family to talk to” or to interact with the child without administering a medical procedure. One participant, a volunteer, noted some children “lose trust in strangers [due to receiving repeated painful medical procedures] but can regain trust in someone consistent and there for fun,” such as a Chemo Pal. Simply being in the same room with the child was reported as having a calming presence for some children. Additionally, it was indicated that in some instances the Chemo Pal may display more comfort with the medical situation and less anxiety about the diagnosis or treatment than family members, which may model and promote adaptive coping and put the child more at ease.

In terms of effects on the family as a whole, participants indicated parents often talked to the interviewees about their worries and stress about diagnosis and treatment to help decrease their anxiety. It was indicated that an additional benefit of having Chemo Pal visits was reducing the burden on caregivers of having to always observe and provide emotional support to the child during procedures.

In summary, Chemo Pals served to listen and help validate patients’ feelings and thereby eased their anxiety and distracted them from the medical environment as they are available specifically to listen and play with the child. Parents may also experience anxiety regarding their child’s procedures as witnessing the child in pain or distress can be difficult. Thus, having the Chemo Pal present to assist in comforting the child and the parent can be beneficial.

**Comfort and Assistance During Medical Procedures.** According to participant reports, Chemo Pals were often in the role of coaching or comforting the child during medical procedures. One participant noted the child with whom she was matched “wanted me to hold her while they gave her the sedation for the radiation.” Other participants indicated they assisted
children by holding their hand, talking them through the procedure, or reminding them to breathe.

Participants matched with older children found that they helped re-frame the child’s attitude about diagnosis, treatment, and medical staff. For example, a participant matched with an adolescent female who was angry and “felt that all the doctors and hospital staff were against her” helped the youth by “connecting with her,” “listening and letting her vent,” and helping her think differently about the situation. The outcome of the Chemo Pal’s support was improved adherence and a “change in her attitude” toward staff and treatment. One staff interviewee credited a Chemo Pal’s focus of being there solely “for the child without an agenda” as being an important factor in improving the adolescent’s experience and why the situation ended positively.

In sum, a function of a Chemo Pal is validating the child’s feelings, re-framing the situation, and assisting the children in how to communicate with the medical team. The ability of Chemo Pals to listen and validate a child’s feelings as well as help to re-frame maladaptive thoughts, although not necessarily a goal of the services, may help comfort a child during procedures or improve treatment adherence.

**Mood Improvement.** Another theme that emerged from the interviews was the idea that being matched with a Chemo Pal who consistently visited and engaged a child in activities ultimately improved the child’s mood. This occurred for several reasons. First, the presence of the Chemo Pal including the activities they directed provided a sense of normalcy for the youth while they were hospitalized. According to participants, children who are receiving treatment are often isolated from their peers, which may lead to boredom, loneliness, and changes in mood. The participants conveyed that having a Chemo Pal available to engage the child in enjoyable activities helped lift a child’s spirits during the treatment process. One participant described how
the child with whom she was matched would “perk up when I came in the room” and another participant reported observing “a shift in personality” during treatment after being matched with the Chemo Pal. The interviewees also noted that this effect seemed to be reflected in comments from parents and caregivers as well. One participant recalled a parent remarking that the family “used to have to drag kids to the hospital but now they look forward to it [because the Chemo Pal would be there].”

Staff interviewees commented on the additional benefits of the Chemo Pal® program such as special community activities for Chemo Pals sponsored by CCA including basketball games, soccer matches, theater performances, etc. Staff noted that children who participated in these activities had the opportunity to get out into the community and be involved in special events. As a result, staff members and volunteers noted that these activities appeared to improve the child’s mood as they engaged the child in positive activities with their peers and community.

In summary, Chemo Pal services positively affect a child’s mood by giving the child something to look forward to while hospitalized and helping them engage in activities, thereby leading to improved mood. Additionally, participation in special events sponsored by the Chemo Pal® program connected the child with other children and provided enjoyable activities to improve their mood.

**Impact of CBSS Services on Social Support.** This section reviews interviewee responses regarding the impact of CBSS services on both child and caregiver social support. Participants described having parents express sincere gratitude for the Chemo Pal’s role in the child’s life and how much it helped the child. Several participants noted that the support looked different for each family and depended on the needs of the child and caregiver. For example, the interviewees noted that some of the families they served had excellent existing social support and needed less
intensive services from the Chemo Pal. Therefore, some Chemo Pal relationships were viewed as shorter term and less intensive, whereas others were described as long-lasting and intimate. Main themes of benefits of the social support provided by CBSS services included: respite, socialization and friendship, and continued support.

**Respite.** All participants spoke about the benefit of the services for providing respite for caregivers. Having a trusted person available to entertain the child allowed caregivers to get out of the hospital room for a break. Often, caregivers were reported to be with the child (especially young children) all day for several days or weeks in a row at the hospital, especially if there were no other family members who were available to assist.

Participants noted caregivers would often take time during Chemo Pal visits to get a cup of coffee, make phone calls to family, talk privately with medical staff, shower, or complete other errands or tasks. In some cases this time was also used as an opportunity to give undivided attention and time with the patient’s sibling. One interviewee, a volunteer, stated that although not all caregivers initially felt comfortable leaving the child alone with the Chemo Pal, most families took advantage of this opportunity for respite.

Taken together, staff and volunteer responses suggested that the respite support from Chemo Pals was valuable to families because it provided the parents an opportunity to complete activities they otherwise may not have had time to finish because of the need to stay with their child in the hospital room. This service was especially helpful once the family felt comfortable leaving the child alone with the Chemo Pal and trusted the volunteer. Additionally, the services were helpful for allowing families respite to have a break and reenergize.

**Socialization and Friendship.** Both staff and volunteers described the CBSS services provided by the Chemo Pal® program as offering the opportunity for the children and parents to socialize with someone outside of the family. Participants indicated that often children were
isolated without the ability to regularly interact with their family, friends, or classmates. One participant noted “the Chemo Pal may be the only person outside of the caregiver and medical team [the child] has had a conversation with for days or weeks.” For example, children who are school-age are removed from school and often not in contact with friends or peers because of medical fragility, participation in treatment, or other reasons such as a peer’s fear, anxiety, or misconception about cancer as indicated by a staff interviewee.

Participants commented that people in the family or community who had previously been a source of social support might have reacted to the child’s cancer diagnosis by withdrawing out of fear or anxiety about not knowing how to manage the situation. As told by a volunteer interviewee about one family’s experience, the family had “lost connections and their social support got scared.” Both staff and volunteers noted that Chemo Pals can step into a supportive role to listen and talk to the caregiver and child. Staff interviewees added that Chemo Pals are especially helpful sources of support as they are specially trained to navigate the delicate issues that might arise as part of the treatment process (such as children discussing death or dying). Further, staff interviewees indicated Chemo Pals are trained to “reach out” or initiate contact with families; whereas, other sources of social support may wait for the family to approach them and ask for help. Both volunteer and staff participants also responded that families often experienced a surge in support from extended family and social network but that this support faded over the course of treatment, whereas the contact with the Chemo Pal remained consistent. Moreover, participants stated that support from the Chemo Pal was particularly helpful for families “who are from out of town” and do not have their social network nearby. One staff interviewee added that for younger children, the socialization was beneficial in providing them an opportunity for play and interaction during a developmentally-sensitive period.

Staff interviewees stated that Chemo Pal® program special events, such as sports games,
theater performances, etc., afforded the child the opportunity to socialize with peers and make connections and forge relationships with other children who have cancer. Participants also noted that the events could also be a time for Chemo Pals to strengthen their bond and friendship. Several participants, both staff and volunteers, spoke about the intensity of the friendship and the “deep bonds” that were formed between Chemo Pals and the children they serve. One staff interviewee characterized the experience between a Chemo Pal and child as “intimate” and having a “significant impact” on both the child and volunteer. As told by one participant, there have been instances when Chemo Pals have been called to a child’s bedside when the child was dying or have been asked by the family to attend the funeral.

In summary, Chemo Pals provided opportunities for socialization and friendship for the child as well as the parents. Having contact initiated by Chemo Pals was especially beneficial for caregivers who were already stressed and busy and did not have the time or energy to seek the support themselves. The consistency of the Chemo Pal services provided support to the family when familial and community supports may have decreased over time. Moreover, because of the nature of the treatment and relationship, Chemo Pals were perceived to have had a significant impact on the child’s life and strong bonds developed as children often grew to trust their Chemo Pals and wanted them present at every critical moment of the treatment.

**Continued Contact.** Another theme that emerged about the impact of support from CBSS services was continued contact. According to staff interviewees, official Chemo Pal® services last from the time a child is referred to after they have finished treatment. However, staff and volunteer participants indicated some families stayed in contact unofficially with the Chemo Pal after treatment and the enrollment in CCA services had formally ended. Participants reported continued contact with families as beneficial for providing longer-term social support (including letters, phone contact, and visits) to help children process recovery from the treatment process as
well provide support at annual check up appointments. One volunteer participant stated, “the relationship did not end once the child graduated from the program” and the child and Chemo Pal “sent letters back and forth occasionally” to stay in touch. Another volunteer stated that she and the family “forged a long-term relationship where I became a part of their circle and they asked me to come to [follow-up] appointments after the match ended.”

Thus, the support and benefits of the services provided by the Chemo Pal® program sometimes continued unofficially after treatment had ended for families and volunteers who were interested. This continued support appeared to be beneficial in assisting the child and family in adjusting to and integrating back into their normal lives during recovery.

**Other Benefits of CBSS Services.** Participants reported that aside from the impact of the services on HRQOL and social support, the Chemo Pal® program had other benefits to families. The two main areas of other benefits included having a link to additional support systems and providers, and a liaison to other CCA services.

**Link to Other Support Systems and Providers.** According to both volunteer and staff participants, there was active communication between the Chemo Pal® program and providers at the hospitals. Staff interviewees noted communication with the hospital social work team regarding family needs was particularly impactful as caregivers sometimes disclosed financial or other struggles and needs to the Chemo Pal. Participants stated that the Chemo Pal was able to relay the issues to CCA, who then communicated directly with the social work team at monthly meetings to help connect the family with resources. Participants indicated that helping the family communicate with the medical team was another benefit of the program services. Interviewees noted that at times the caregivers did not understand the information shared by the medical team. The Chemo Pal helped advocate for families and assisted in requesting further explanation from the medical staff in a way the families may have not been comfortable doing.
Liaison to Other CCA Services. Staff interviewees emphasized that although it was not a requirement that families who accessed other CCA resources (such as donations, events, etc.) be engaged in the Chemo Pal® program, it was helpful to have a Chemo Pal to act as a liaison to inform families of the other services. Furthermore, volunteer and staff participants noted that Chemo Pals were able to address any financial or other difficulties the family was experiencing by communicating the concerns to CCA staff who linked the family to CCA resources, when available.

In summary, additional benefits to the children and families participating in the Chemo Pal® program included linking families to other CCA resources as well as other sources of support and additional resources. The close relationship between the Chemo Pal and the family can put the caregiver (or child) at ease and decrease any embarrassment or reservation the parent may have when discussing family struggles, allowing the caregiver to open up about the family’s needs. Then, the Chemo Pal can contact CCA staff to help connect the family with resources.

Strengths and Areas for Growth of the Chemo Pal® Program. Interview participants were asked to identify strengths and areas of growth of the Chemo Pal® program. The main strengths indicated were the impact of the services on families, ability of the program to reach families who were especially isolated, excellent volunteer support and training, ability of the program to form good matches between families and volunteers and the reputation of the program within the hospitals. Areas for growth included expanding the program to other areas in and outside of the state, adding variety to the training topics at monthly volunteer support meetings, increased support for Chemo Pals who are matched with a child who is dying or has died, and streamlining the process for connecting families with other CCA resources.

Strengths. Participants discussed the strengths of the Chemo Pal® program and a significant theme that emerged was the benefit to families. Volunteer interviewees emphasized
the availability and support provided to the child, caregiver, and family in the form of listening, talking, distracting, and advocating, which helped form relationships that served to improve the child’s treatment experience. Additionally, the ability of the Chemo Pal to support a variety of families, including Spanish-speaking families, was viewed as a great strength by staff. One staff participant stated that due to the language barrier, Spanish-speaking families were often even more isolated, and thus, greatly benefitting from the program services. Volunteer and staff participants indicated that the significant benefit to children and caregivers was a strength of the program and that this benefit was identified by families who have expressed gratitude and surprise at how helpful the services were to them. A related strength discussed was the ability of the program to find “good matches” between volunteers and families, which was considered important in ensuring that good social support and services were provided.

A second strength was excellent training and volunteer support, which was identified by both staff and volunteer interviewees. Volunteer participants reported feeling very supported by program staff when navigating problems that arose as well as general emotional support in working with children affected by cancer. Support occurred through individual contact with program staff as well as monthly support and education meetings for volunteers. Volunteers also underwent thorough training to help them be effective at setting good boundaries and learning how to establish an effective relationship for the context. One staff participant noted the training involved learning how to be “an appropriate source of support that is beneficial to families in general and to maintain good relationships that will help long-term.”

Lastly, the Chemo Pal program was reported by both volunteers and staff to be known and trusted within the hospitals. Staff noted the prominence of the program helped generate referrals to CCA and having good relationship with hospital staff helped maintain consistent support within a team that opened the door to regular communication to best serve a family.
In summary, several strengths of the Chemo Pal® program were noted by participants including the benefit of the services to children and families, especially those who were isolated and otherwise did not have consistent social support. The excellent volunteer support described by participants, along with the ability of program staff to make good matches between volunteers and families, and solid working relationships with hospital staff, are likely reasons the program was effective in maintaining supportive relationships with families.

**Areas for Growth.** In terms of areas of growth, participants suggested adding more variety to the topics of the support and education meetings, especially for seasoned volunteers who have heard many of the topics presented in the past. Increasing the number of support meetings (or offering multiple meetings to accommodate schedules) was also suggested to improve the volunteer experience. In terms of volunteer support, interviewees noted increasing the amount and availability of support for Chemo Pals who were matched with a child who is dying or has died to provide a space for the Chemo Pal to process their emotions.

Interviewees also suggested expanding special events and program services to other areas both in and outside of Oregon. They noted that families who live in the Portland area are most available for special events, whereas families living in other areas of the state are not able to attend events as frequently and holding special activities in other cities may increase access for numerous families. Participants described available special activities and events sponsored by CCA as frequently including sporting events or performances for older children. Expanding activities to be more inclusive for younger children was also discussed by interviewees as a recommendation for strengthening the program.

Finally, it was suggested by participants that CCA improve their protocol for increasing connections to other CCA services as this process was not always well-structured. Interviewees stated that donations, events, or other special offers are often advertised by email, which can be
missed by families without good access to Internet or smart phones as the offers typically are on a first come first serve basis and in many cases, families and the agency rely on Chemo Pals to alert the families of the special offers. Thus, interviewees noted that streamlining and improving this process would allow all families to have the same opportunities to access services.

In sum, according to the study participants, the Chemo Pal® program could benefit from programmatic changes that would allow the agency to serve families and support staff even more effectively. Although volunteer support was a program strength that was identified by participants, increasing opportunities for more volunteers to attend support meetings, varying meeting activities, and improving bereavement resources for volunteers would help the Chemo Pal® program be even more effective in preparing Chemo Pals to support families. Additionally, improving means of connecting other children to the program by expanding services to other geographical areas and ensuring all families have the same opportunities for accessing services or special activities would help the Chemo Pal® program better serve its target population of children with cancer.

Discussion

Children with pediatric cancer are a growing subset of youth within the United States with a serious medical condition that affects the child undergoing treatment as well as their families. Approximately 8,500 children under age 15 will be diagnosed with one of the many forms of pediatric cancer (Ries et al., 1999; Ross & Olshan, 2004) and although survival rates have increased over the years, there continues to be a need for supporting a patient’s health-related quality of life (HRQOL) and coping during treatment. Community-based social support (CBSS) services are one resource for families struggling to manage their child’s medical condition that may help improve positive functioning in light of the hardships cancer and its treatment cause.
The purpose of this study was to explore factors that contribute to pediatric oncology patients’ HRQOL by measuring the effect of CBSS services, and specifically the Chemo Pal® program on the HRQOL of children currently in treatment, as perceived by their caregivers. Additionally, a purpose of the current study was to contribute to the small amount of existing literature on the effectiveness CBSS by examining the strengths and weaknesses of the Chemo Pal® program and how this service impacts children and families coping with medical issues. The current study was also developed to explore the social support of the child and caregiver.

Due to the data collection difficulties and limitations, the original proposed hypotheses could not be tested by this study and thus, conclusions could not be drawn concerning the impact of CSBB on HRQOL from the caregivers’ perspectives. A second phase of the study was therefore generated to gain more information about the program from the perspective of Chemo Pal® program staff and volunteers. Interviews with program staff and volunteers provided some insight into the impact of CBSS services and the influence of CBSS services on HRQOL, in particular.

Summary of Results and Implications

Taken together, results suggested there is some benefit to CBSS services for pediatric cancer patients. Although the caregiver results are reported herein, these results should be viewed with extreme caution given the number of participants and other data limitations. There were variable findings of comparisons of HRQOL between the current sample and the normative sample (a sample of active-treatment pediatric cancer patients). The area in which the current sample exhibited better HRQOL included Procedural Anxiety. The current sample included a child who was newly diagnosed and two who had recently relapsed and all were on an initial round of treatment. No information about the length of time the normative sample had been on active-treatment was available but it is likely that the current sample had fewer weeks of
treatment than the normative on-treatment sample. This discrepancy in time on active-treatment could explain the higher HRQOL scores on Procedural Anxiety for the current sample as the children may not yet have received numerous painful procedures that cause an anxious response.

The current sample scores on the Nausea subscale was observed to the lower (suggesting poorer HRQOL) for the current sample. It is possible that the treatment side effects were a newer experience for the current sample than for the normative sample, leading the current sample to perceive more intense nausea as treatment had not yet become routine. This trend is consistent with research by Landolt et al. (2006) who found that children with newly diagnosed cancer had compromises in areas of HRQOL and that effects on HRQOL occurred from 6 weeks to as long as 1 year after diagnosis. The findings also suggested that HRQOL improved over the course of the year following treatment likely due at least in part to the child adjusting to the treatment routine, a phenomenon that has been reported in the literature (Sawyer, et al., 2000).

For level of child social support, scores across scales were higher for the current study sample. It is likely that the general higher level of social support of the current sample was due to the increase in social support families experience when there is a crisis, such as an illness, and when a child is newly diagnosed with cancer, in particular. This trend is consistent with data presented by Hoekstra-Weebers, Jaspers, Kamps, and Klip (2001) who found that caregivers experience significant social support at diagnosis.

No conclusions could be made about the change over time in HRQOL and child and parent social support, or relationships between these constructs, measured by the PedsQL, SSQ6, and CASSS, due to significant data limitations. Thus, Phase I results should be interpreted with extreme caution.

Interview data from staff and volunteers from Phase II suggested benefits of CBSS on both HRQOL and social support. Factors that were reported to affect HRQOL as a result of
CBSS included anxiety reduction, distraction, mood improvement, and comfort during medical procedures. Both anxiety and distress have been demonstrated to occur in pediatric oncology patients (Kuppenheimer & Brown, 2004) and impact HRQOL (Varni, et al., 1999). Furthermore, treatments available for cancer patients and families aimed at improving their treatment experience focus on reducing these symptoms (e.g., Kazak et al., 1999; Kazak, 2005; Marsac et al., 2011). Some of the approaches reported by staff and volunteer interviewees mirror those utilized in psychological treatments to reduce psychological symptoms (e.g., distraction). Thus, the services provided by the Chemo Pal® program may reflect techniques utilized in evidence-based treatments. To the extent that this is true, it may further suggest the effectiveness of the CBSS services provided by the Chemo Pal® program. Thus, further research is warranted to determine if, in fact, CBSS services are impacting the anxiety and distress symptoms of pediatric cancer patients.

The literature has suggested the importance of the role of social support in improving HRQOL (Dobson, Zelikovsky, Miller, & Skira, 2011; Zeller & Modi, 2006), and the contribution of social support, in general, for improving familial experiences during diagnosis and treatment (Decker, 2007). Interview data suggested CBSS services provided by the Chemo Pal® program helped families by primarily providing respite and socialization/companionship in the short-term (i.e., during treatment) and in some cases after the treatment was completed. Although CCA is not a clinical agency and the goal of the services is not clinical in nature (M.K. Turina, personal communication, November 3, 2010), staff and volunteer perceptions suggested program participants were experiencing meaningful therapeutic benefits. Research has suggested pediatric cancer patients and their families perceived significantly more support than healthy peers (Brown, Madan-Swain & Lambert, 2003; Haluska, Jessee, & Nagy, 2002 as cited in Woodgate, 2006); thus, some may argue that families do not need additional social support from
Chemo Pals. However, other studies have demonstrated that social support appears to decrease over time following diagnosis (Hoekstra-Weebers et al., 2001); and the need for inpatient support has not been thoroughly studied. Furthermore, not all families appear to experience the same level of baseline social support from family and peers. Thus, the consistency and length of the services provided by the Chemo Pal in the inpatient setting may be especially beneficial to the family to know they can rely on that support throughout the course of treatment. It is also likely that having the Chemo Pals initiate contact is helpful to families who are already burdened by the many hardships of cancer and their own stress levels. Another possibility is that caregivers may feel it is less of a burden to rely on a Chemo Pal who is part of a program designed specifically to provide support than on their own friends or families who did not “sign up” for such an experience or who may also have ongoing life stressors.

Although the available data provided some insight into how CBSS services may affect HRQOL and social support from caregivers and staff/volunteer perspectives, study limitations prevented stronger conclusions and further analyses from being conducted. These limitations are addressed below.

Limitations

There were several limitations to the current study. A significant methodological limitation was the very small sample size. As a result of the poor response to the study recruitment as well as the attrition rate in Phase 1, the initial sample size goal was not met and statistical analyses were not performed. Furthermore, the one participant who did complete all sections of the study indicated her child was not actively participating in the Chemo Pal® services at that time. Thus, little quantitative data from the caregivers about the change in HRQOL over time was available for children receiving the CBSS services and as a result serious caution should be exercised when making inferences based on the data. A larger sample size of
participants who finished T1, T2, and T3 would have allowed for the ability to compare change in HRQOL, child social support, and parent social support over time as well as differences between participants. It is possible attrition could have been due to the relatively long length of the study, which was approximately 25-minutes, and the online format. Although research has indicated caregivers utilize online resources (e.g., online support groups; Coulson & Greenwood, 2011), the current study was question-based and may have taken longer than was estimated by the researchers or expected by the caregivers and longer than the time they had available to commit to the study. Caregivers of children with cancer already experience several role demands (Rodriguez et al., 2012) and participating in a study could have been an additional strain. One possible explanation for the recruitment challenges is caregivers may have been experiencing emotional difficulties that prevented them from participating in a study about the child’s cancer experience while their child was in active treatment. Research has suggested that caregivers can also experience psychological symptoms and emotional distress in response to a child’s cancer treatment (e.g., Gerhardt et al., 2007; Rodriguez et al., 2012). Thus, caregivers may have been too overburdened or struggling emotionally.

An additional limitation was possible selection bias. Because participants were self-selected, it is possible there are differences between the families who chose to participate versus those who declined. For example, families who opted to participate in Phase 1 may have valued social support or community services more highly than those who declined. However, given that very few caregivers elected to participate, this weakness was not a key consideration. Possible selection bias was a greater concern for the program volunteers and staff who participated for the interviews in Phase 2. Staff and volunteers who were willing to participate may have had more positive experiences and been more committed to the mission of the organization than those who did not respond to the recruitment email.
Another limitation of the current study is a lack of information regarding what specifically about CBSS is impactful. Although data suggested there are benefits to the CBSS services and interview participants described several advantages to the Chemo Pal® program, further information is needed about which services in particular are most helpful to children undergoing chemotherapy and their families and the mechanisms by which Chemo Pal® program services are having a positive effect.

**Future Directions**

Future research on this topic would likely benefit from replication of the original methodology of the current study in a face-to-face format with hard copies of the measures due to the apparent difficulty with recruiting and conducting the study in the current format. Having investigators present at the hospital or available to meet families during hospitalization would likely decrease the burden on families and improve recruitment and retention.

An alternative to recruiting families currently undergoing treatment would be to access families who have recently completed treatment to assess their perceptions and experiences with the CBSS services. This methodology would be helpful in overcoming challenges of recruiting and collecting data from families at a high-stress time when the participants are experiencing significant levels of distress and in some cases psychological symptoms.

Including child self report on measures of HRQOL and social support would provide a richer picture of the effect of CBSS services as it is possible that the children have a different perception on the impact of the CBSS services than their caregivers. If children were able to complete the measures in the hospital in a fun and game-like format, or through a rewarding interaction/conversation, it is likely that the role the Chemo Pals play in the children’s lives would become apparent.
It is also possible fathers, or other caregivers, may have had alternative perceptions of the impact of the CBSS services. Additionally, mothers could have a different view of their child’s HRQOL than their child or another family member or caregiver. Research has indicated that parent proxy ratings and patient self-report on the PedsQL measures deviate in many circumstances. As a result, future studies could benefit from having multiple raters of HRQOL. Studies that include only parent proxy-reports should be interpreted with caution as it is possible that these ratings may not reflect the actual experiences of the pediatric cancer patients. However, research has not demonstrated a significant discrepancy for this particular measure (PedsQL Cancer Module) between parent report and the reports of their children with cancer (Russell et al., 2005).

Interviews with families, similar to those conducted with volunteers and staff, would provide further insight into the experience families have with CBSS services as well as provide a set of responses with which to compare the perceptions of the volunteers and staff. By interviewing caregivers, information about which services are most helpful could also be gathered to provide further insight into how specifically the services are impacting the child and family and which services would be best to emphasize. It is possible that qualitative methodology may be a more appropriate data gathering technique for this population given the stresses and strains of pediatric cancer noted throughout this dissertation.

Finally, continued exploration of the structure and nature of other programs that provide CBSS services or agencies similar to CCA would be beneficial in identifying alternative techniques for supporting families. Investigation into services for children with other health conditions could also be useful in refining services to best assist children with medical conditions. Further research in this area would also provide additional information about the
effectiveness of CBSS services and may elucidate the components or aspects of the services that are particularly helpful for children and families.

**Conclusion**

The current study is the only known research that provides insight into how CBSS services may help children and families affected by cancer. One benefit of the current study was in helping to define the nature of community-based social support while exploring the attention given to the role of these services as potentially being beneficial to families of children undergoing treatment for medical conditions. There is very little literature on this topic and, despite the current study’s weaknesses, the insights provided herein may be very useful for the initiation of a program of research on CBSS. Findings, especially from the interview data, suggested that there is benefit to CBSS services for families affected by cancer. In particular, results from the interviews suggested positive impacts on HRQOL and social support. However, more research on this topic is needed to further establish the effectiveness of CBSS services on the HRQOL and social support of children undergoing cancer treatment and to explore how specifically these services best help children and families.

Given the growing number of children affected by cancer, the increased survival rates, and the lengthy treatment protocols that children must endure, it is important to consider the types of services that may be beneficial to pediatric cancer patients and their families as they begin a course of treatment and throughout the intensive time in which the child is undergoing medical interventions. CBSS services, along with other adjunctive services, may promote improvement in the illness and treatment experience of pediatric cancer patients. Specifically, gains in health-related quality of life, perceived social support, and access to other resources and support may be observed as a result of being involved in CBSS services during treatment. These
services may not only serve to improve the immediate treatment experience of the child and family but may also have an enduring positive impact.

References


Ewing, J.E., King, M.T., & Smith, N.F. (2009). Validation of modified forms of the PedsQL generic core scales and cancer module scales for adolescents and young adults with cancer or a blood disorder. *Quality of Life Research, 18*, 231-244. doi: 10.1007/s11136-008-9424-4


Appendix A

Demographic Questionnaire

**Parent**

2. What is your gender? ⊗ Female ⊗ Male
3. What is your race/ethnicity? ⊗ African-American ⊗ Asian ⊗ Caucasian ⊗ Latino ⊗ Native American ⊗ Biracial ⊗ Multiracial ⊗ Other (please specify ________)
4. What is your marital status? ⊗ Single (never married) ⊗ Married to my child’s biological parent ⊗ Divorced/Re-married ⊗ Partnered/committed relationship (not legally married)
5. What is your combined family income? ⊗ Under 25,000 ⊗ 25,000-40,000 ⊗ 40,000-65,000 ⊗ 65,000-80,000 ⊗ Above 80,000
6. What is your level of education? ⊗ Did not finish high school ⊗ High school diploma/GED ⊗ Some college ⊗ College degree (AA./B.A./B.S) ⊗ Master’s degree ⊗ Doctoral or professional degree (J.D., Ph.D., M.D.)

**My Child**

1. What is your child’s gender? ⊗ Male ⊗ Female
2. What is your child’s age? ⊗ 5 ⊗ 6 ⊗ 7 ⊗ 8 ⊗ 9 ⊗ 10 ⊗ 11 ⊗ 12 ⊗ 13 ⊗ 14 ⊗ 15 ⊗ 16 ⊗ 17 ⊗ 18
3. What is your child’s race/ethnicity? ⊗ African-American ⊗ Asian ⊗ Caucasian ⊗ Latino ⊗ Native American ⊗ Biracial ⊗ Multiracial ⊗ Other (please specify ________)
4. How many siblings does your child have? ⊗ 1 ⊗ 2 ⊗ 3 ⊗ 4 ⊗ 5 ⊗ 6 ⊗ 7 ⊗ More than 7
5. In what grade is your child? ⊗ Kindergarten ⊗ 1st ⊗ 2nd ⊗ 3rd ⊗ 4th ⊗ 5th ⊗ 6th ⊗ 7th ⊗ 8th ⊗ 9th ⊗ 10th ⊗ 11th ⊗ 12th ⊗ Graduated high school
6. Is your child currently attending classes at his/her regular school ⊗ Yes ⊗ No, he/she is not able to attend due to cancer treatment

**Health/Treatment-Related Information**

1. What cancer diagnosis has your child been given? _________________
2. What age was your child when he/she was first diagnosed? ⊗ Infant ⊗ 1 ⊗ 2 ⊗ 3 ⊗ 4 ⊗ 5 ⊗ 6 ⊗ 7 ⊗ 8 ⊗ 9 ⊗ 10 ⊗ 11 ⊗ 12 ⊗ 13 ⊗ 14 ⊗ 15 ⊗ 16 ⊗ 17 ⊗ 18
3. Has your child’s cancer relapsed? ⊗ No ⊗ Yes, one time ⊗ Yes, more than one time
4. Approximately how many weeks has your child been receiving treatment during the current round of treatment? ⊗ 1 ⊗ 2-3 ⊗ 4-5 ⊗ 6-7 ⊗ 8 or more ⊗ My child is not currently receiving treatment
5. What type of treatment is your child receiving? ⊗ Chemotherapy ⊗ Radiation ⊗ Other (please specify ________)
6. How would you rate your child’s health status at this time? ⊗ Excellent ⊗ Good ⊗ Fair ⊗ Poor ⊗ Very poor
7. Do you, your spouse, or your children have a history of cancer? ⊗ No, no one in the immediate family ⊗ Yes, me ⊗ Yes, my other child ⊗ Yes, my spouse
Appendix B

Chemo Pal® Program-Related Questions

1. What does your child think of his/her Chemo Pal?
2. How have the Chemo Pal® program services affected your family?
Appendix C

Volunteer and Staff Interview Questions

1. Tell me about yourself. What is your age, gender, and ethnicity? What is the nature of your involvement with the Chemo Pal program and how long have you been involved? If you are a volunteer, how many Chemo Pals have you had?

2. What impact do the Chemo Pal® services have on the health-related quality of life of the child and caregiver?

3. What impact does the Chemo Pal® program have on social support of the child and caregiver?

4. How are the child and caregiver benefitting from the program?

5. What are the strengths of the Chemo Pal® program?

6. What could be changed in the Chemo Pal® program to make the services more effective?

7. What has/have your Chemo Pal(s) thought about you and the services they have received?