Canines and Childhood Cancer

Examining the Effects of Therapy Dogs With Childhood Cancer Patients and their Families

Literature Review

zoetis

American Humane Association
The nation's voice for the protection of children & animals

Foreword

Advances in medical knowledge, treatment and technology have all but obviated the fear of numerous childhood medical diagnoses that not so long ago could have meant a potential death sentence. Yet still today few words strike as much fear into the hearts of parents and children alike as a doctor's pronouncement, "Your child has cancer." As is rightly the case, billions of dollars are spent each year to prevent and more efficaciously treat pediatric cancer. While this work – some promising, some heartbreaking – wends its way through the proper scientific channels, a question of by no means equal but nonetheless immense import has received far less attention: "What can we do to improve the day-to-day health, healing, and quality of life of children suffering from cancer, and the families who suffer along with them?"

Common sense and anecdotal evidence point to numerous potential answers. We know one of the worst side effects of a pediatric cancer diagnosis is fear and the stress this fear produces, and that these factors alone can hinder treatment in a variety of ways. Therefore reducing fear and stress should have a positive impact. Similarly, if there were effective means to ameliorate related conditions such as loneliness, depression, isolation and the unforgiving pain associated with both the illness itself and the course of treatment, quality of life for patients and families could potentially be significantly enhanced. For many medical practitioners and lay people both within and outside the pediatric oncology community, there has existed a strong belief that – with the right patients and under the right circumstances – many of these benefits could be derived through the pairing of cancer patients and their families with loving, nurturing animals. Myriad stories of the significant healing power of animal-assisted therapy (AAT) and the human-animal bond abound. Yet little hard evidence exists as to whether these claims can be substantiated, under what conditions AAT is most effective, and how AAT, if proven useful, can best be incorporated into treatment.

In 2010, with the support of the Pfizer Foundation, two of the leading names in AAT science and practice teamed up to definitively answer these questions through a one-of-a-kind, peer-reviewed, controlled study. American Humane Association, the nation's leading advocate on behalf of children and animals as well as an AAT pioneer, and Zoetis (formerly the animal health business of Pfizer, Inc.), an international leader in animal-related medical research and development, have launched Canines and Childhood Cancer: Examining the Effects of Therapy Dogs with Childhood Cancer Patients and their Families. This three-year study taking place in hospital settings across the U.S. will examine the specific medical, behavioral, and mental health benefits animal-assisted therapy may have for children with cancer and their families, and how the benefits that may exist can be extended to an ever greater number of patients.

No child…no family…should have to suffer through the trauma of a cancer diagnosis and treatment. But childhood cancer is a reality. As our pediatric oncology colleagues race to find ever-more effective preventative measures, treatments, and – one day – cures, our hope is that this study will help to provide meaningful, enduring, affordable, accessible and powerful healing and comfort to the children and families who need it now.

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Executive Summary

In 2010, American Humane Association, Zoetis, and the Pfizer Foundation partnered to conduct a unique study on the impact of animal-assisted therapy (AAT) on children with cancer and their families. The goals of this collaboration are to promote innovation, evidence-based research, practice improvements, and knowledge advancement to further the field of research on human-animal interaction (HAI) and the treatment of cancer in children. This comprehensive review includes literature regarding childhood cancer epidemiology and treatment, the well-being of patients and families who are impacted by childhood cancer, the applications of AAT for various populations in need, the state of AAT effectiveness research, and the considerations that need to be made when incorporating therapy animals into clinical settings.

Children of all ages, races, genders and socio-economic strata, and their families, are affected by cancer every year. Medical advances have drastically improved the survival rates for many forms of childhood cancers; however, incidence rates have remained fairly stable for decades. At any given time, in the United States, more than 40,000 children are undergoing cancer treatment and nearly 13,500 parents each year are hit with the devastating news that their child has been diagnosed with cancer. Given that medical advances have improved survival rates, yet so many children and families continue to be affected, it is important to understand the unique physical and psychosocial issues that these children and families face due to the diagnoses, treatment, mortality, and survivorship of childhood cancer.

Children diagnosed with cancer and their families not only cope with physical issues, but are also prone to psychosocial issues including isolation, depression, trauma, stress, and fear. Child and adolescent patients generally undergo a decrease in their quality of life across all stages of active cancer treatment, and may experience depression, emotional distress, fatigue, physical pain, post-traumatic stress, social stress, and withdrawal symptoms both during and after their treatment processes. This may affect their physical health, and even when physical effects may improve over time, many psychosocial and behavioral effects remain and may impact childhood cancer survivors for the long term. These effects on children can also vary by type of cancer; patients with certain types of childhood cancer experience improvements more than others, and children with other types experience more long-term risk for ongoing behavioral and psychological problems. With both improvements in outcomes for some, along with concurrent or subsequent increases in other problems for others (even for the same children in some cases), this is truly a tumultuous time for these children and their families in a number of respects.

Not surprisingly, families of children with cancer also tend to struggle while coping with the considerable challenges of childhood cancer and its aftermath. Upon learning that their child has cancer, parents tend to experience anger, anxiety, denial or avoidance of their child's illness, distress, grief, post-traumatic stress, sleeping problems, weight gain, and decreased physical activity, all of which can greatly endanger their health and well-being. Parental distress tends to vary as a function of time from diagnosis, with parents of more recently diagnosed patients presenting higher levels of distress than parents of children who have been living with cancer for some time. The relationship between parents is also commonly impacted – both negatively and positively – by their child's cancer diagnosis and treatment, and family roles and responsibilities often change when one child in the family has cancer. Thus, siblings of cancer patients also experience psychosocial effects, including acting out, feeling left out or less important, loneliness, maturation (as a result of increased expectations and responsibilities), sorrow, and

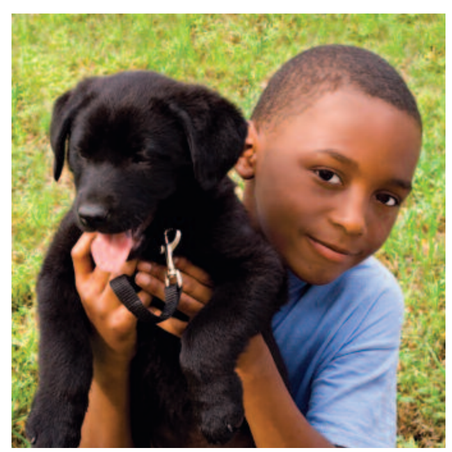
anxiety. Overall, distress experienced by one family member can negatively affect the physical and emotional wellbeing of the ill and vulnerable child with cancer.

Given that a diagnosis of childhood cancer can negatively impact both children and families on a multitude of levels, it is important for healthcare professionals to not only attend to the physical and medical needs of the child, but also to the emotional, psychological, and social needs of the entire family. One very exciting possibility is that a focus on improving children's ability to cope with stress could prove to be comprehensively beneficial to their entire family. Additionally, due to the high and stressful costs of cancer treatment, services or adjunctive interventions aimed at addressing the family's psychological needs should be both accessible and affordable. AAT is one of several adjunctive, low-cost treatment options that could potentially address the immediate and ongoing psychosocial needs of many families coping with childhood cancer.

For many families, animals and pets take center stage in their daily lives, offering companionship, solace, joy, and for some, even kinship. Increasingly, greater attention has been given to the roles that animals can play in supporting the health and emotional well-being of people in need. Many research studies have provided promising evidence that involving animals in therapeutic interventions provides benefits for many populations, such as exercise or opportunities for positive play; relaxation and reduced anxiety; unconditional support and acceptance; improved skills that lead to healthy relationships with others; enhanced social interactions; increased learning, growth, and development; and improved senses of self-esteem and confidence. For critically or terminally ill populations, such as children with cancer and their families, therapy animals also have the potential of normalizing the hospital experience, motivating active participation in the healing process, offering helpful distraction from pain or worry, decreasing blood pressure and heart rate; alleviating distress; increasing opportunities for sensory stimulation and physical touch; and decreasing depressive symptoms by offering joy, company, and something to look forward to.

Notably, the incorporation of therapy animals into healthcare treatment is a complex undertaking which requires a special consideration of myriad topics in order to ensure safe and beneficial interactions. Such topics include infectious disease control and zoonoses, human allergies, phobias and physical harm, animal well-being, therapy animal selection, handler role, participant inclusion, and service delivery protocol.

The majority of findings documenting the benefits of AAT and pet ownership have largely been anecdotal and the field has consistently struggled with developing and conducting rigorous research. While the field of HAI research has expanded enormously, it is not yet clear that the incorporation of animals in clinical settings is effective from a scientific standpoint. The *Canines and Childhood Cancer (CCC)* project intends to add to this knowledge base by examining the experiences of children and families coping with childhood cancer, and by understanding how best to integrate AAT into pediatric cancer treatment. The literature documented in this review is intended to serve as a resource to the fields of HAI and pediatric oncology, as well as a foundation for the current study examining the efficacy and impact of AAT in the context of childhood cancer treatment.



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Introduction

The literature documented in this review is intended to serve as a foundation for a major multi-site study of the efficacy and impact of animal-assisted therapy (AAT) in the context of pediatric oncology. The study itself emerged from the mutual concerns of Zoetis and American Humane Association that progress is needed to expand the evidence base for determining the effectiveness of AAT and animal-assisted activities (AAA), and especially those focused on children. Many of the research studies included in this review have provided promising evidence that involving animals in therapeutic interventions can provide benefits for many populations. These potential benefits include exercise or opportunities for positive play; relaxation and reduced anxiety; distraction from pain or worry; unconditional support and acceptance; improved skills that lead to healthy relationships with others; enhanced senses of self-esteem and confidence; and increased motivation to actively participate in the healing process. What is now needed is a more comprehensive and larger research agenda, built on rigorous premises, regarding the effectiveness of AAT in a range of settings and situations, including those that involve serious illness.

In late 2010, American Humane Association's Child Protection Research Center (now part of the Children's Innovation Institute) and Animal-Assisted Therapy Department received support from Zoetis and the Pfizer Foundation and forged a partnership to conduct a study on the impact of AAT on children with cancer (pediatric oncology patients), as well as their parents/caregivers, siblings, and other close family members. The goal of this collaborative partnership is to increase the body of research on human-animal interaction (HAI) and its relationship to the treatment of cancer in children through innovation, evidence-based research, and practice improvements. Equally important will be to foster improved communications between human and animal medical professionals and to recognize the benefits of AAT to enhance the treatment of children and families experiencing conditions like cancer. ***Fundamentally, we plan to advance our understanding of how AAT impacts the health and well-being of children with cancer and their families.***

Throughout its 135-year history, American Humane Association has celebrated the extraordinary power of the human-animal bond. Intuitively most of us know and feel that our relationships with animals enrich many aspects of our lives, health, and well-being. As the nation's voice for the protection of children and animals, American Humane Association reaches millions of people around the world every day through groundbreaking research, education, training, and services that span a wide network of agencies, organizations, and corporations. Today, American Humane Association is also leading the way in understanding HAI and its role in society. Through AAT programs, American Humane Association and the therapy animals we work with touch countless lives each year, while advancing learning, connection, and wellness. Zoetis is dedicated to transforming the care of animals for a healthier world. With operations in more than 60 countries across four geographic regions (the United States; Europe, Africa & the Middle East; Canada and Latin America; and Asia-Pacific), Zoetis is dedicated to improving the health of animals through a combination of products backed by rigorous research. Zoetis is also committed to building its strengths and continuing to bring its customers new ideas and integrated solutions, thus helping them respond to unmet, latent, and evolving animal health care needs.

Over the course of the next three years, American Humane Association and Zoetis will work with up to five healthcare settings that treat children with cancer. The specific focus of this study is to examine what medical, behavioral, and mental health impacts AAT may have for children with cancer and their families. The project plan is to conduct the study in three phases, with Phase III being a full clinical trial. This literature review represents a key product for Phase I of the study. During Phase I, American Humane Association has worked with children's hospitals to seek input from pediatric oncology staff and families of children with cancer to determine their needs and to help inform and strengthen the objectives and design of this study. During Phase II, the study's treatment and research design will be finalized, clinical sites and study participants will be selected, and project implementation and data collection will be tested.

While the activities of Phase I will contribute to defining the final study objectives, the following are several research questions that lay the groundwork for the initial steps:

Can the use of animal-assisted therapy help to reduce anxiety and depression among children with cancer?

Can the use of animal-assisted therapy improve the ability of caregivers, siblings, and other close family members to meet the many social and psychological support needs of these patients?

Can the use of animal-assisted therapy affect the psychological well-being of familial caregivers, siblings, and other close family members?

How does animal-assisted therapy affect the relationship between familial caregivers and healthcare providers, including physicians, nurses, and oncology specialists?

How can animal-assisted therapy contribute to treatment protocols in pediatric oncology?

How are the behaviors and physiology of dogs affected by their involvement in animal-assisted therapy?

Do particular traits of the dog (e.g., temperament, size, color, age, and breed) or handler (e.g., sociability, race/ethnicity, gender, and age) impact the intervention's effectiveness and, if yes, how so?

Does previous or existing pet ownership impact the effectiveness of animal-assisted therapy among children with cancer and their families?

The study is innovative on several fronts. First, the focus population and research framework involve not only pediatric patients, but extend to their familial caregivers as well. For that reason, the literature review includes research that pertains to the behavioral health of familial caregivers who are involved in providing support for long-term treatment processes. Second, all design phases call for a multi-site approach. In using this approach, the study benefits by developing an understanding of diverse treatment settings and patient populations. The results from trials can be generalized to a greater degree by using this multi-site approach. Third, the study provides a platform for investigators at each site to contribute to the study design and to focus on specific aspects of the populations of children, familial caregivers, involved animals, animal handlers, and the possible effects of treatment.

Current State of Research

During the last two decades, the field of HAI research has expanded enormously (McCardle, McCune, Griffin, Esposito, & Freund, 2011). This expansion has corresponded with the presence of animals and their handlers in a range of therapeutic settings, including hospitals, clinics, schools, behavioral health centers, residential facilities for children and adults, assisted living facilities, nursing homes, and more (Lefebvre, Peregrine, Golab, Gumley, Waltner-Toews, & Weese, 2008). Much effort has gone into developing methods and specialized training to help ensure that therapy animals are treated humanely, and interactions with patients/clients are hygienic, healthy, and safe. Organizations like Delta Society and American Humane Association have been instrumental in developing or adapting rigorous training, and improving the professional status of animal handlers, who for the most part are volunteers. What is less clear is whether the incorporation of animals in these settings is effective from a scientific standpoint (Kazdin, 2010). Much of our understanding of the effectiveness of AAT or AAA is based on anecdotal information provided through the experiences of patients, students, staff, family members, and animal handlers. A small number of scientific studies provide limited evidence-based data (Griffin, McCune, Malholmes, & Hurley, 2011; Nimer & Lundahl, 2007; Wilson & Barker, 2003).

Nevertheless, multiple research studies, many of which are reviewed here, have offered promising evidence of the benefits of involving animals in therapeutic interventions. Some of the evidence from research (across human populations with various conditions and circumstances) lends support to the effectiveness of AAT/AAA in reducing stress, improving mood, reducing depression, easing pain, and providing encouragement, but there is also evidence that AAT/AAA is not consistently tied to improvements in these conditions. There is also some preliminary thinking that human biomedical pathways might be identified that would be activated through the application of AAT/AAA. Evidence-based research concerning the effectiveness of AAT/AAA continues to lack definitiveness, with many studies being preliminary in nature (e.g., pilot studies).

Despite great strides in developing training and certification procedures for therapy animals and their handlers, there is still no consistent approach to AAT/AAA interventions. This inconsistency has been a major barrier to researching AAT/AAA effectiveness, especially because it precludes the ability to replicate the interventions. However, the absence of consistent interventions also creates opportunities to rigorously formulate and test these approaches. For example, a key aspect of the study will be to create a replicable model for effective AAT/AAA interaction. The review itself provides a major part of the foundation to improve the scientific status of research on AAT/AAA and the possible effects of treatment.

Background and Description of this Literature Review

The literature review is intended to make a unique contribution to the HAI field. To our knowledge, no comparable document exists in terms of AAT with this particular population of pediatric oncology patients and their families. From the outset, the review has figured prominently as a major product of the study, with several goals for the review having been defined.

First, the literature review was organized to provide a background to support the development of the study's research

"These potential benefits include an increased motivation to actively participate in the healing process."

design and other Phase II and Phase III activities. A range of topics were considered, including: pediatric oncology, studies of caregivers and other family members of cancer patients, studies of AAT in general, studies of AAT focused on oncology, the design of AAT interventions, health risks for the use of animals in therapeutic interventions (e.g., zoonotic infection), and studies of animal behavior and wellbeing among therapy animals.

Second, this literature review will serve as a resource to the HAI field by documenting the status of the research, the gaps in the research, and the opportunities to enhance the research base. In addition to describing the studies, the review includes an extensive set of cross-referenced materials pertinent to the topics that were included and organized in the document's "research framework" found in *Appendix A: Research Framework*.

The literature that has been identified for the review originates from a variety of sources such as books, peer- and non-peer-reviewed journals, fugitive or gray literature, and web content. Databases such as Academic OneFile, Academic Search Complete, Embase, PsycArticles, PsycInfo, PubMed, ScienceDirect and SocIndex were searched using keywords. In conducting the review, more than 200 separate documents were evaluated for content. Of the considered documents, 166 were included in the review largely based on their relevance and scientific merit.

In approaching the literature review, the reader is cautioned that the organization of material is dictated by the long-term needs of the project and the design and implementation of randomized controlled trials to test the effectiveness of AAT for children with cancer and their families. Consequently, the material was oriented to assist the research team in understanding the focus population of children with cancer, the gaps in research, and how AAT can best be applied to the focus population. The authors believe the review will be of value to HAI researchers and will serve as a source of information for other similar studies.

Brief Overview of Pediatric Oncology

Epidemiology

Childhood cancer affects a moderate portion of the children's population in the United States. Between 2001 and 2003, approximately 36,450 new cases of childhood cancer were diagnosed in the U.S., which amounts to an incidence rate of 165.92 cases per 1 million children (Li, Thompson, Miller, Pollack, & Stewart, 2008). Over the past two decades, while the incidence of cancer has increased slightly, the mortality rates from cancer have drastically decreased (National Cancer Institute (NCI), 2008). Five-year survival rates for all childhood cancers improved by more than 20 percent between 1975/1977 to 2001/2007, with rates of 58.1 percent and 82.5 percent, respectively (Howlader, Noone, Krapcho, Neyman, Aminou, Waldron, et al, 2011).

It is slightly more common for boys to be diagnosed with cancer than for girls, with age-adjusted incidence rates of 174.28 and 157.14 per 1 million, respectively (Li et al, 2008). Approximately one out of every 300 boys and one out of every 333 girls will develop some form of childhood cancer (Children's Oncology Group (COG), 2005a). Notably, unlike at other ages, there is very little difference between cancer rates between males and females in infancy (COG, 2005b).

There are clear racial and ethnic differences between cancer incidence with

Caucasian children being at a significantly greater risk of cancer than African American and Native American/Alaskan Native children (Li et al, 2008). Childhood cancer also has a geographic pattern, with children in the Northeast being at a significantly greater risk than those in the Midwest, South, and West (Li et al, 2008). Cancer diagnoses also vary by age, with infants (0-4 years of age) and adolescents (15-19 years of age) more likely to be diagnosed than children in between those age groups (COG, 2005b). While many factors affect a child's prognosis, infants tend to have less-positive prognoses than other children (COG, 2005b).

Cancer Types

There are many forms of cancer that affect children with the most common forms discussed here. For additional information on cancer types, their symptoms, and treatment options please see *Appendix B: Childhood Cancer: Types, Symptoms, Treatment and Incidence*.

Leukemia, a cancer of the blood, is the most common form of all childhood cancers (Li, 2008; NCI, 2008). Approximately 3,200 children will be diagnosed with leukemia each year in the United States (Children's Cancer Research Fund (CCRF), 2009). Leukemia is most prevalent in children under the age of 10 (CCRF, 2009; Li, 2008). There is also a significant racial and ethnic difference in leukemia diagnoses in infancy, with Caucasian children having a 66 percent higher incidence rate than African American children (COG, 2005b). Hispanic children have significantly higher rates of leukemia than non-Hispanic children (53.71 per million v. 41.37 per million) in all age groups (Li et al, 2008).

There are two major types of leukemia that affect children, acute lymphoblastic leukemia (ALL) and acute myelogenous leukemia (AML) (University of Minnesota, 2011a), with ALL cases representing 75 percent and AML representing roughly 19 percent of all leukemia diagnoses (Smith, Gloeckler, Gurney, & Ross, 1999). Five-year survival rates for children with ALL have improved significantly since 1975, with children under 15 years of age having survival rates improve from 61 percent in 1975 to 88.5 percent in 2002 (Smith, Seibel, Altekruse, Ries, Melbert, O'Leary, Smith, & Reaman, 2010). However, survival rates for older children (ages 15-19) and for infants (under 1 year of age) with ALL have not been improving at the same rates; those aged 15-19 have seen an improvement from 28.4 percent to 50.1 percent and infants from 22 percent to 62 percent (Smith et al, 2010). The five-year survival rates for AML, while they have increased, have been less dramatic than those for ALL with children under 15 years of age seeing improvements from approximately 20 percent in 1975 to 58 percent in 2002, with those children ages 15-19 seeing improvements from approximately 17 percent to 40 percent (Smith et al, 2010).

Brain tumors are the most common type of solid tumor, and are nearly as common as leukemia in children (University of Minnesota, 2011b). It is estimated that nearly 2,000 children each year are newly diagnosed with brain tumors in the United States (University of Minnesota, 2011b). Neuroblastomas are the most common form of brain tumor, making up nearly 97 percent of all brain tumors in children (Goodman, Gurney, Smith, & Olshan, 1999). Neuroblastoma is most common in children under age five and is the most common form of cancer in infants, with the majority of cases being diagnosed prior to the child turning six months of age (University of Minnesota, 2011b). Neuroblastomas have an incidence rate in infancy (0-4 years of age) that is nearly double that of leukemia (Goodman, Gurney, Smith, & Olshan, 1999). Neuroblastoma five-year survival rates have not fluctuated much for infants with rates ranging from approximately 86 percent in 1975 to 88 percent in 2002. For older children (ages 1 to 14 years), the rates are not as promising (35 percent in 1975 to approximately 65 percent in 2002), though improvements have still been made.

Lymphomas, cancer within the cells of an individual's lymphatic system (University of Minnesota, 2011c), are the third most common form of cancer in children and comprise approximately 15 percent of all childhood cancers (Percy, Smith, Linet, Ries, & Friedman, 1999). There are two main types of lymphomas that affect children: Hodgkin's lymphoma and non-Hodgkin's lymphoma (University of Minnesota, 2011c). Hodgkin's lymphoma is most common in youth between the ages of 15-19 and is particularly uncommon in children under the age of five (University of Minnesota, 2011c). Early detection and treatment of Hodgkin's lymphoma leads to a cure rate of nearly 90 percent, while those with advanced stages or forms face a 50-80 percent cure rate (University of Minnesota, 2011c). Non-Hodgkin's lymphoma primarily affects children in infancy and the incidence rate is highest for females and Caucasians (Percy, Smith, Linet, Ries, & Friedman, 1999). The survival rates for both non-Hodgkin's and Hodgkin's lymphomas have improved over the past several decades (Smith et al, 2010). Five-year survival rates for non-Hodgkin's lymphoma in children under 15 years of age have increased from 44.9 percent in 1975 to 87.8 percent in 2002 (Smith et al, 2010). Similarly, those with Hodgkin's lymphomas have seen their five-year survival rates increase from approximately 91 percent in 1975 to nearly 95 percent in 2002 (Smith et al, 2010).

Sarcomas refer to a tumor of connective tissue and are an assorted group of malignancies generally identified in either the child's soft tissue or bone (Huh, Fitzgerald, Mahajan, Sturgis, Beverly Raney, & Anderson, 2011). Soft tissues include tendons, ligaments, skin, fat, and muscles. Sarcomas make up approximately 15 percent of all cancers in children and adolescents (Li et al., 2008). There are two main types of bone sarcomas that affect children: osteosarcomas and Ewing's sarcomas (Gurney, Swensen, & Bulterys, 1999). Osteosarcomas comprise approximately 56 percent and Ewing's sarcomas comprise 34 percent of all bone tumors in children (Gurney, Swensen, & Butlerys, 1999). It is most common to find osteosarcomas and Ewing's sarcomas in adolescents and young adults (National Center for Biotechnology Information, 2010; University of Minnesota, 2011d). Males also tend to be affected at a greater rate than are females (University of Minnesota, 2011d). Muscle or soft tissue sarcomas affect nearly 900 children each year with the majority of those children being diagnosed with rhabdomyosarcoma (Gurney, Young, Roffers, Smith, & Bunin, 1999). Males and African Americans tend to have slightly higher incidences of rhabdomyosarcomas and other soft tissue cancers than females or those of other races and ethnic groups (Gurney, Young, Roffers, Smith, & Bunin, 1999). Five-year survival rates for osteosarcoma have improved from approximately 40 percent in 1975 to 67 percent in 2002 (Smith et al, 2010). Five-year survival rates for Ewing's sarcoma have improved from roughly 59 percent in 1975 to just less than 76 percent in 2002 (Smith et al, 2010). Rhabdomyosarcoma has seen moderate

improvement in five-year survival outcomes since 1975 with rates improving from approximately 53 percent to 64.9 percent in 2002 (Smith et al, 2010).

Liver cancers are not common in children. The overall incidence of these types of cancers in children and adolescents aging from birth to 14 years of age is approximately 2.4 per 100,000 (National Cancer Institute (NCI), 2011). The two main types of liver cancer in children are hepatoblastoma and hepatocellular carcinoma. Hepatoblastomas typically occur in children under the age of three years, and nearly 90 percent of all liver cancers in children under the age of four are hepatoblastomas (NCI, 2011). Survival rates vary across these two cancer types with hepatoblastoma rates being near 70 percent, while hepatocellular carcinoma rates are only about 25 percent (NCI, 2011). Hepatoblastoma cases have nearly doubled over the last 25 years; while hepatocellular carcinoma cases have remained relatively stable (NCI, 2011). One contributing factor may be the increased survival rate of premature and low birth weight infants, which has been linked to the occurrence of hepatoblastoma (NCI, 2011). Hepatocellular carcinoma is rare in children, with an incidence of approximately 2.0 per 100,000; this equates to approximately 50-75 new cases per year in the United States (NCI, 2011; St. Jude Children's Research Hospital (SJCRH), 2011; Texas Children's Hospital (TCH), 2011). Hepatocellular carcinomas are nearly non-existent in children under 14 years of age with an incidence of 0.4 per 100,000 and are typically first seen in children between the ages of 12 and 14 years old (NCI, 2011; SJCRH, 2011). Children who have had multiple infections of the liver (including Hepatitis B or C), those who have a metabolic or congenital disease, and those who have been given certain medications (such as anabolic steroids) have been found to be at greater risk of developing hepatocellular carcinoma than other children (SJCRH, 2011).

Retinoblastoma is a form of cancer that affects the child's retina. The retina, or the nerve tissue that serves as lining on the inside of the eye, senses light, and also aids in transmitting images to the brain through the optic nerve (CCRF, 2011; University of Minnesota, 2011e). Retinoblastomas can affect all individuals, but the majority of cases are found in children under the age of five-years and most commonly in children younger than two-years. Retinoblastomas make up nearly 11 percent of all cancers diagnosed in the first year of a child's life (University of Minnesota, 2011e; Young, Smith, Roffers, Liff, & Bunin, 1999). There are two forms of pediatric retinoblastoma, hereditary and non-hereditary. Hereditary retinoblastomas account for 30 to 40 percent of all retinoblastoma diagnoses in the United States (CCRF, 2011). There are little gender or racial and ethnic differences in the incidence of retinoblastomas (Young, Smith, Roffers, Liff, & Bunin, 1999). Survival rates for children affected by retinoblastomas are favorable with more than a 93 percent survival rate after five-years of being diagnosed (Young, Smith, Roffers, Liff, & Bunin, 1999).

"*Childhood cancer is an issue that affects children across all ages, races, genders and socio-economic strata.*"

Kidney cancers, or malignant tumors found in the child's kidney(s) represent less than seven percent of all childhood cancer diagnoses in the United States in children under the age of 15 (Bernstein, Linet, Smith, & Olshan, 1999). Nearly 550 children under the age of 20 are diagnosed with some form of kidney cancer each year; of those, roughly 500 are diagnoses of Wilms' tumors (Bernstein, Linet, Smith, & Olshan, 1999). The other forms of kidney cancers seen in children include rhabdoid tumors, clear cell sarcomas, and renal carcinomas; together, these forms make up less than six percent of all childhood kidney cancer diagnoses (Bernstein, Linet, Smith, & Olshan, 1999). Five-year survival rates for children diagnosed with Wilms tumors are promising and have improved from 73.7 percent in 1975 to nearly 92 percent in 2002 (Smith et al, 2010).

Summary of Childhood Cancer

Childhood cancer is an issue that affects children across all ages, races, genders and socio-economic strata (COG, 2011). While there have been many advances in medical technology that have improved the overall survival rates for many cancers, the number of cases being diagnosed every year in the United States has remained constant over two decades with nearly one in every 350 people developing cancer by the age of 20 (COG, 2011; Henderson, Friedman & Meadows, 2010). At any given time, more than 40,000 children in the U.S. are undergoing cancer treatment each year (COG, 2011). With more than 35 children receiving a cancer diagnosis every day, roughly 13,500 parents a year hearing the devastating news that their child has cancer, as well as the fact that nearly one out of every 900 young adults is a cancer survivor, it is important to understand the unique medical, psychosocial and behavioral needs that these children and families face (COG, 2011; Henderson, Friedman & Meadows, 2010).

Needs of Children Coping with Cancer

According to parents, there are a handful of symptoms that cause the most problems for their children during cancer treatment. Both mothers and fathers rate emotional distress, fatigue, adequate nutrition, and pain as the most problematic areas, especially for adolescents (Poder, Ljungman, & von Essen, 2010). Of these four, pain is the most problematic. While the prevalence of most of these symptoms decreases over time, these adverse symptoms are not only acute, but also result in increases in the parents' emotional distress. Despite the fact that pain and other physical symptoms are common and burdensome side effects of cancer treatment, while physical effects subside over time, many psychosocial and behavioral effects do not. Additionally, psychosocial symptoms, such as post-traumatic stress disorder, are more common with high risk situations like pediatric cancer, and not with low risk situations like a simple planned surgery (Landolt, Boehler, Schwager, Schallberger, & Nuessli, 1998). Due to the increased survival rate among pediatric oncology patients, managing long-term effects and preserving quality of life has become a major focus. As a result, our review of children's needs examines and compares both short- and long-term effects in an ultimate effort to understand the long-lasting impact of the psychosocial and behavioral effects of cancer and cancer treatment.

Children's Needs During Active Treatment

Some researchers have specifically evaluated psychological problems during early treatment. For example, Gerali and colleagues analyzed psychological problems over the course of the initial intensive treatment, with assessments at 1, 3, and 6 months (Gerali, Servitzoglou, Paikopoulou, Theodosopoulou, Madianos, & Vasilatou-Kosmidis, 2011). Compared to control subjects, pediatric oncology patients develop psychological problems at the beginning of intensive treatment based on both parental and teacher reports. After 6 months of treatment, children had reductions in psychological problems, with child leukemia patients experiencing the most reductions. This finding signifies the importance of following the course of psychosocial and behavioral symptoms over time, as well as the effect of different types of childhood cancer on that trajectory.

Impacts on quality of life (QoL) experienced by pediatric oncology patients as an aspect of psychosocial assessment is also a subject of studies concerned with the outcomes of cancer treatment and survival. One recent study looked at overall QoL in children during different phases of active therapy for acute lymphoblastic leukemia (ALL), and found lower overall scores compared to population norms (Sung, Yanofsky, Klaassen, Dix, Pritchard, Winick, Alexander, & Klassen, 2011). More specifically, both physical and psychosocial summary scores ranged from one to two standard deviations lower than a normative population. Several factors put children at higher risk of poorer scores, including being female, being older, having lower household incomes, and having unmarried parents. Notably, the scores did not significantly vary across the stages of treatment.

Researchers have also evaluated behavioral adjustment difficulties in children and adolescents with cancer across different stages of treatment. One study assessed children and adolescents who had been receiving treatment for acute lymphoblastic leukemia (ALL) for at least one year or who were off therapy for no more than three years (Moore, Challinor, Pasvogel, Matthay, Hutter, & Kaemingk, 2003). It was found that body image alterations and mental and emotional problems that were related to treatment were in turn correlated with problematic behaviors, including depression, somatization (physical symptoms in response to psychological stress), withdrawal, and social stress. Many of these problems were at clinically significant levels signifying need of treatment. Teacher ratings were significant for somatization, learning problems, leadership problems, and poor study skills. Parent ratings were significant for somatization, adaptability problems, attention problems, withdrawal, anxiety, poor social skills, and depression. Self-report ratings were significant for anxiety and a poor attitude to school. It is noteworthy that psychosocial and behavioral problems were also significantly related to both intelligence and academic achievement, highlighting the dire need to address the psychological and behavioral well-being of children with cancer lest in turn it also interferes with their academic standing.

Not surprisingly, parenting is related to specific outcomes during active treatment for children with cancer. One study of children currently receiving treatment for cancer found that higher levels of parenting stress were associated with worse behavioral and social adjustment, though parental overprotection or perceived child vulnerability were not (Colletti, Wolfe-Christensen, Carpentier, Page, McNall-Knapp, Meyer, Chaney, & Mullins, 2008). Additionally, higher levels of perceived child vulnerability and parenting stress were correlated with worse emotional adjustment, while parental overprotection was not.

Children's Needs During Post-Treatment Stages

Given the significantly increased survival rate, and the number of treatment effects, it is not unexpected that there are a number of research studies assessing outcomes in children with cancer at the end of their course of treatment. A recent review of research examining the psychosocial well-being across pediatric oncology populations completing cancer treatment showed that positive psychosocial outcomes often occur upon treatment completion, including high self-worth, good behavioral conduct, and improved mental health and social behavior (Wakefield, McLoone, Goodenough, Lenthen, Cairns, & Cohn, 2010). Negative outcomes, including lower levels of psychological well-being, mood, liveliness, self-esteem and motor and physical functioning, as well as increased anxiety, problematic behaviors and sleeping difficulties, also occurred. It seems that the conclusion of treatment is a tumultuous time for children recovering from cancer.

Campbell and colleagues (2008) compared children and adolescents who completed treatment for ALL and healthy controls in their study, which examined the association between executive function (working memory, behavioral inhibition, cognitive flexibility, and self-monitoring) and coping and behavioral outcomes. The association of chemotherapy with reduced cortical white matter volume is in turn related to decreased performance in neurocognitive functioning, including higher order domains of executive function (EF) such as cognitive flexibility and working memory. Not only are these neurocognitive sequelae likely to impact academic achievement and learning, but also have been shown to negatively affect emotion regulation and the utilization of adaptive coping mechanisms. Based on this knowledge, these researchers sought to determine how ALL survivors' neurocognitive and psychosocial functioning compared to healthy peers, as well as to examine the association between EF, coping, and behavioral variables. They found that decreased executive functioning was associated with decreases in strategies used to cope with stress, and also additional emotional and behavioral problems. This study highlights the impact of cancer treatment on these psychosocial and behavioral outcomes, pointing to the need for interventions to ameliorate such consequences

Once treatment is complete, school phobia can inhibit successful reintegration of children back into the school setting, with a prevalence of about 10 percent in the pediatric oncology population (Henning & Fritz, 1983). While specific studies identify anxiety, depression, and bullying as more prevalent among these children upon return to school (Henning & Fritz, 1983; Lahteenmaki, Huostila, Hinkka, & Salmi, 2002), it is not clear if the increases in anxiety and depression found in children with cancer across multiple studies cited in this report make these children targets for bullying. On the other hand, we do know that with respect to parents, anxiety and fears about their children being rejected by schoolmates is associated with parents keeping their children home from school (Chekryn, Deegan, & Reid, 1986; Katz & Jay, 1984; Klopovich, Vats, Butterfield, Cairns, & Lansky, 1981; Lansky, List, & Ritter-Sterr, 1986). Given that returning to school is not only a major milestone, but also a routine that allows them to normalize back to daily living (Sullivan, Fulmer, & Zigmond, 2001), it is very apparent that addressing anxiety in both children and parents is a key focus for interventions.

There are also studies about the ongoing effects of cancer within a few years after the end of treatment. One such study looked at the mental health status of young adult childhood cancer survivors (CCSs) (Kamibeppu, Sato, Honda, Ozono, Sakamoto, Iwai, Okamura, Asami, Maeda, Inada, Kakee, Horibe, & Ishida, 2010).

They assessed depression, anxiety, post-traumatic stress symptoms (PTSS), and post-traumatic growth (PTG) among adolescent and young adult CCSs in remission for more than one year. Not to be confused with resilience, which is more about returning to previous levels of functioning, PTG is a relatively new term referring to a new personal gain after a traumatic event. In comparison to controls, survivors did not significantly differ with respect to depression or anxiety. On the other hand, while they had significantly more PTSS than controls, they also exhibited an even stronger effect for greater PTG.

Another study looked at the psychosocial adjustment of children who had allogeneic stem cell transplantation (SCT) and were at least two years post-treatment (Felder-Puig, Peters, Matthes-Martin, Lamche, Felsberger, Gadner, & Topf, 1999). In comparison to bone cancer survivors and a normative population, those receiving SCT showed high levels of anxiety, appeared to be extremely sensitive and vulnerable, and showed strong, unfulfilled needs in their love lives. However, the authors found that there were no significant differences relative to controls with respect to self-esteem, family and peer relationships, or school/vocational performance. This study suggests that patients who underwent SCT in their childhood or adolescence are at risk of developing long-term emotional or social problems.

A closer look at the predictors of outcomes in the pediatric oncology population reveals that, similar to other populations, early functioning is the best predictor of later functioning, at least with respect to some domains of well-being. In a prospective longitudinal study on cognitive and psychosocial functioning after hematopoietic stem cell transplant (HSCT), overall there was found to be stability in cognitive functioning over time (Kupst, Penati, Debban, Camitta, Pietryga, Margolis, Murray, & Casper, 2002). However, for those with changes, the strongest predictor of cognitive declines was pre-HSCT cognitive functioning. Additionally, unlike other studies, there was a low prevalence of behavioral and social problems.

Children's Long-Term Needs

Turning to what is known as the late effects of childhood cancer, or outcomes in survivors at least five years post-diagnosis, there is continued evidence of a mixture of a number of different negative psychosocial and behavioral outcomes. In a study of adolescent survivors who were at least five years post-diagnosis, there was an increased rate of sub-clinical attention deficits, emotional and externalizing behaviors, and social withdrawal problems in comparison to sibling controls (Krull, Huang, Gurney, Klosky, Leisenring, Termuhlen, Ness, Srivastava, Mertens, Stovall, Robison & Hudson, 2010). As adults, a number of physical health and substance use problems occurred at a higher rate, including physical inactivity, obesity, and stimulant use. This study points to the importance of assessing psychological problems in pediatric oncology patients, especially given the association between these symptoms and an increased risk for obesity and poor health behavior in adulthood.

> *"It is important to assess a variety of behavioral and psychological impacts of childhood cancer, as some decrease with time while others do not."*

Other studies have also analyzed childhood cancer survivors who had survived more than five years. In one, analyses revealed that while survivors scored lower on somatization, obsessive-compulsive tendencies, and anxiety, they had increased distress, interpersonal sensitivity, depression, aggression, and psychotic tendencies compared with a normative population (Michel, Rebholz, von der Weid, Bergstraesser, & Kuehni, 2010). Another study assessed a similar range of behavioral and social domains, including depression/anxiety, headstrong tendencies, attention deficits, peer conflict/social withdrawal, antisocial behaviors, and social competence. In comparison to their siblings, the pediatric oncology group was more likely to have symptoms of depression/anxiety and to exhibit antisocial behaviors (Schultz, Ness, Whitton, Recklitis, Zebrack, Robison, Zeltzer, & Mertens, 2007). Once again there is an effect of type of cancer, with leukemia and central nervous system (CNS) tumor patients scoring higher in depression/anxiety, attention deficit, and antisocial domains relative to their siblings, while survivors of neuroblastoma were significantly higher in the depression/anxiety and antisocial domains. This study highlights the fact that those with a history of leukemia, CNS tumors, or neuroblastoma may be at increased risk for adverse behavioral and social outcomes.

In another long-term study, the late effects of pediatric sarcoma therapy were measured in a sample an average of 17 years after their treatment ended (Wiener, Battles, Bernstein, Long, Derdak, Mackall, & Mansky, 2006). Both psychological distress and post-traumatic stress symptoms were measured. The Brief Symptom Inventory (BSI) was used, which assesses psychiatric symptoms (somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism) as well as three global distress indices (Global Severity Index, Positive Symptom Distress Index, Positive Symptom Total). Seventy-seven percent met clinical criteria on a global index of distress derived from a weighted sum of ratings across all psychiatric symptoms which combines information about numbers of symptoms and intensity of distress. Additionally, 12 percent met diagnostic criteria for Post-traumatic Stress Disorder as measured by the Structured Clinical Interview for DSM-IV. For these adults, their psychological distress was concomitantly associated with difficulty readjusting to work/school after treatment and employment. Outcomes did not differ based on age or time since diagnosis.

Summary of Children's Needs

It is important to assess a variety of behavioral and psychological impacts of childhood cancer, as some decrease with time while others do not. Additionally, it is also important to observe different types of pediatric cancer patients as effects differ by type of cancer. For example, while QoL has been shown to decrease across all stages of active treatment, improvements in psychological impacts also occur across active treatment and more so for children with leukemia. Furthermore, in studies of long-term effects, those with certain types of cancer are more at risk for ongoing behavioral and psychological problems.

An additional reason why it is important to assess for multiple behavioral and psychological impacts—and to do so separately as opposed to global problem scores—is that while there are times when there are improvements in some outcomes (e.g., an increase in positive psychological functioning at the end of active treatment), there has also been shown to be an increase in other problems at the same time. It is not surprising that this is a tumultuous time for children in a number of respects. Given that early functioning has shown to be a strong predictor of later functioning, any relevant measurements of functioning before treatment begins should prove useful to help identify those who are more likely to be in need.

One very exciting possibility is that a focus on improving children's ability to cope with stress could provide them with at least a small amount of relief, based on the findings that a decreased ability to cope with stress is associated with an increase in other psychological and behavioral problems. Additional research that supports this notion is that symptoms of anxiety are often associated with difficulties readjusting to work and/or school after treatment. Anxiety also keeps parents from letting their children return to school, delaying reintegration back into normal daily activities. Given the finding that pediatric oncology patients not only experience stress and anxiety as a result of this experience, but also that many experience post traumatic growth, perhaps there is a means by which an intervention could promote that growth in the area of improved coping skills.

It is important to note that children with cancer do not live or exist within their own bubbles. Rather, they are part of a larger family system, and their overall well-being depends, to a large extent, on the well-being of their parents, siblings, and other close family members. It seems that for children, both disease type and certain types of parenting (e.g., parenting stress) influence the short-term effects in pediatric oncology populations. Similarly, the physical, emotional, and social well-being of family members is also greatly influenced by how well or not well the child with cancer is coping with his/her illness. Thus, it is important to also focus on the various needs of these families, as this may reveal ways to help the entire family group manage the many challenges that accompany a childhood cancer diagnosis.

Needs of Families Coping with Childhood Cancer

Several studies have examined how parents cope with the news that their child has cancer, as well as how they continue to cope throughout their child's cancer treatment and illness trajectory. Not surprisingly, parents tend to experience a great deal of distress, anxiety, anger, denial, grief, and even trauma upon learning that their child has cancer, and these emotions have the potential of manifesting in a variety of ways (Al-Gamal & Long, 2010; Best, Streisand, Catania, & Kazak, 2001; Fotiadou, Barlow, Powell, & Langton, 2008; Norberg & Boman, 2008; Norberg, Poder, & von Essen, 2011). Namely, distress in parents has been found to have a profound, and often negative, impact on the stress, anxiety and overall health status of their children with cancer (Al-Gamal & Long, 2010; Best et al., 2001; Norberg, Poder, & von Essen, 2011; Wijnberg-Williams, Kamps, Klip, and Hoekstra-Weebers, 2006). According to Wijnberg-Williams et al. (2006), those parents who had children who had relapsed showed higher levels of anxiety and distress than did parents whose children had either survived or passed away. Additionally, parents who avoid the distress associated with their child's illness and treatment may also place their child at risk of not receiving the medical treatment they need (Best et al., 2001; Norberg, Poder, & von Essen, 2011). These important findings not only exemplify the power of the parent-child relationship, but they also underline the importance of using adjunctive therapies with parents of children with cancer throughout the treatment process (and even post-treatment) to help them cope with the anxiety and psychological distress that can affect them and their entire family for the long-term.

> *"Parents who avoid the distress associated with their child's illness and treatment may also place their child at risk of not receiving the medical treatment they need."*

Overall Parental Needs

Enskar, Carlsson, Golsater, Hamrin, and Kreuger (1997, p. 159-162) utilized semi-structured, qualitative interviews with parents of children and adolescents being treated for cancer, and identified the following eight categories of themes influencing the parents' life situation:

1. "Watching [their] child suffer," including feelings of "powerlessness around [the child's] suffering" and the "child's reactions to the disease and treatment"
2. "Being governed by [their] child's disease," including impacts to the parent's work situation and to the family's budget/finances
3. "Behaving differently as a family member," including impacts on the family's "privacy and integrity"; the parent's marital (or equivalent) relationship; siblings and other children living in the home; and raising the ill child (i.e., managing "the tendency" to overprotect and/or spoil the ill child)
4. "Experiencing strong feelings and reactions," including impacts on the parent's "self-image," "mood," and degrees of "certainty" and "uncertainty" about the future
5. "Trying to cope" with their child's illness
6. "Dealing with the reactions of others" regarding their child's illness
7. "Finding support from others," including immediate family members; friends and extended relatives; health care professionals; and "parents of other sick children"
8. "Evaluating quality of care," including the "professionalism" of medical and nursing staff; the "experience" and expertise of the organization; the "information" provided by health care personnel; and the "equipment available" on the ward

In their comparative evaluation of post-traumatic stress symptoms (PTSS), depression and anxiety in parents facing their children's cancer, Norberg and Boman (2008) found that parents were prone to developing symptoms of intrusion, avoidance, and arousal—all indicators of post-traumatic stress. Likewise, parents also experienced abnormally heightened levels of distress symptoms, such as anxiety and depression (Norberg & Boman, 2008). Notably, parental distress tended to vary as a function of time from diagnosis, with parents of more recently diagnosed patients presenting higher levels of distress symptoms than parents of long-term survivors (Norberg & Boman, 2008). In a 2003 study with similar findings, Han found that Korean mothers of children recently diagnosed with cancer were significantly more likely to report poorer psychosocial adjustment than mothers whose children had been living with cancer for some time.

In a study of anticipatory grief among 140 parents of children with cancer in Jordan, Al-Gamal and Long (2010) found that parents with children newly diagnosed with cancer (Group 1) reported more significant anticipatory grief than parents of children who had been living with cancer for 6-12 months (Group 2). Using the definition originally proffered by Rando in 2000, Al-Gamal and Long (2010, p. 1981) describe anticipatory grief as "the phenomenon encompassing the process of mourning, coping, interaction, planning, and psychological reorganization that are stimulated and begun in part in response to the impending loss of a loved one and the recognition of associated losses in the past, present and future." Parents in both groups reported that they had felt personally burdened and had experienced "drastic life changes" as a result of caring for their ill child; increased stress because of these changes; and sad longing for their life prior to their child's diagnosis (Al-Gamal & Long, 2010, p. 1985). Approximately 98.6 percent of parents in Group 1 and 84.3 percent of parents in Group 2 wished that their child's cancer diagnosis was "all a dream" (Al-Gamal & Long, 2010, p. 1985). Additionally, while parents in Group 2 also reported worry, sadness, and felt isolation, 85.7 percent of them remarked that "[this experience is] a life phase and I know we'll get through it" (Al-Gamal, 2010, p. 1985). The authors did not include the percentage of parents in Group 1 who made this remark, making it difficult to compare groups on this item. These findings suggest that coping with a child's cancer diagnosis and experiences may ease over time for some parents.

In contrast, other research suggests that parents may be particularly vulnerable to distress after the completion of their child's cancer treatment (rather than at diagnosis), when fears around recurrence may be particularly heightened (Wakefield, McLoone, Butow, Lenthen, & Cohn, 2011). In their review of 15 articles pertaining to the experiences of caregivers of pediatric oncology patients, Wakefield et al. (2011) reported that the time of post-treatment may place caregivers at risk of experiencing anxiety, uncertainty, helplessness, loneliness, and post-traumatic stress. How parents cope with their child's illness during and after the treatment process may also impact their long-term wellbeing (Norberg, Poder, & von Essen, 2011). A recent study out of Sweden found that mothers and fathers who coped by avoiding "stimuli that might elicit stressful memories and emotions associated with their child's cancer" (referred to by the authors as the "Avoiding group") during and immediately after their child's treatment had higher levels of PTSS one year after the end of treatment than parents who did not avoid these stimuli (referred to by the authors as the "Non-Avoiding group") (Norberg, Poder, & von Essen, 2011, p. 82). Receiving the news that your child has cancer is almost always a traumatic experience for parents (Norberg & Boman, 2008). However, the authors argue that when parents avoid stimuli associated with this initial trauma, they are subsequently more "vulnerable to re-traumatisation" (Norberg, Poder, & von Essen, 2011, p. 83). This assertion was supported by the study finding that avoidance early in the child's treatment trajectory was a stronger predictor of PTSS and post-traumatic stress disorder (PTSD) among bereaved parents than among non-bereaved parents (Norberg, Poder, & von Essen, 2011).

Furthermore, the authors note that avoidance can have negative impacts for both the parents and the child already ill with cancer; previous studies (e.g., Best et al., 2001) have found that parents who display avoidance behaviors may intentionally miss necessary medical appointments, or in extreme cases, could even overlook their child's negative symptoms in order to avoid distressing news (Norberg, Poder, & von Essen, 2011). Of note, the authors found that some parents who reported having PTSD one year post-treatment were not part of the "Avoiding group," indicating that there were also other factors – in addition to avoidance – that may have contributed to their PTSS, such as socioeconomic stressors (Norberg, Poder, & von Essen, 2011). The implications of these and other findings include the importance of providing psychosocial support both during and after the child's treatment process, particularly in the areas of parenting, physical and emotional fatigue, and social isolation (Wakefield et al., 2011). Likewise, Norberg, Poder, and von Essen (2011) encourage nurses and other healthcare professionals to seek interventions aimed at preventing parents' avoidance of the stressful or adverse emotions that typically accompany a child cancer diagnosis (e.g., cognitive behavioral therapy), especially given that parents prone to avoiding disease- or treatment-related distress may be less likely to reach out for help.

Predictors of optimism in parents of children with cancer have also been explored (Fayed, Klassen, Dix, Klaassen, & Sung, 2010). A recent study by Fayed et al. (2010) found that parents' individual traits (e.g., intrapsychic, social, and economic factors) had a greater influence on their level of optimism than did elements associated with their child's illness (i.e., cancer type and time since diagnosis). Positive parental intrapsychic traits in this study included self-esteem and mastery, or the sense that one is in control of one's own environment, actions, and choices. These existing intrapsychic traits, along with a lack of depression, a higher level of education, and a positive view of the child's prognosis were all predictors of parental optimism (Fayed et al., 2010). Of note, the authors found that parents' perceptions of their child's prognosis did not always correlate with those of the clinician, which could signify that these parents were unrealistically optimistic about their child's prospects (Fayed et al., 2010). Fayed et al. (2010) state that further studies are needed to investigate whether parental optimism fluctuates over the course of a child's treatment trajectory, and how optimism may impact their parenting experiences over time.

Parental Needs: Physical Health

Norberg and Boman (2008) postulate that stress may evolve for parents at any phase in the course of their child's disease and treatment, and can even interfere with their ability to attend to their health and the health of their families. At least one study has found that parents coping with the major stressor of their child's cancer diagnosis were at an increased risk of weight gain as compared to parents with healthy children (Smith, Baum, & Wing, 2005). Smith et al. (2005) measured not only body weight, but also eating behavior, physical activity, stress, and mood for both groups at two points in time. Findings from this study reveal that the parents of children with cancer gained more than 1.5 kg over a three month period compared to no weight change in the parents of healthy children. Moreover, this significant increase in weight among parents of child cancer patients was correlated with a lower amount of physical activity rather than an increase in caloric consumption (Smith et al., 2005). The strongest predictors of weight gain were the parents' reported impact of having a child diagnosed with cancer and the severity of recent life events. Overall, this study's findings highlight the important issues of stress and depression in parents who are caring for a child with cancer, and how these experiences can affect both their emotional and physical health and well-being.

Al-Gamal and Long (2010) have also documented evidence suggesting that the health and well-being of parents, including sleep patterns and physical health, are often negatively impacted by their child's diagnosis and experiences with cancer. For example, 72.8 percent of parents of newly diagnosed children self-reported that they had experienced sleeping problems since their child became sick, and 65.7 percent believed that their physical health had declined since their child's diagnosis (Al-Gamal & Long, 2010). For parents of children who had been living with cancer for 6-12 months, Al-Gamal and Long (2010) found that 30 percent of parents reported sleeping problems and 40 percent perceived a decline in their physical health. While this study certainly draws attention to the physical health risks for parents of children with cancer, it also provides insight regarding when these risks are most likely to take shape: at the beginning of the child's illness trajectory, closely after an initial diagnosis has been made.

Parental Needs: Gender Differences

While it is true that both parents confront a great deal of distress when their child has cancer, there is evidence that mothers and fathers tend to have different experiences and coping mechanisms. One prospective Dutch study, examining the psychological functioning of parents of children with cancer over a five-year period, noted interesting gender differences in their findings (Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006). The authors were interested in measuring psychological distress, stress and state anxiety (i.e., the state of anxiety where a stimulus causes us to feel temporarily anxious), and psychosomatic symptoms at four points in time from diagnosis to five years post-diagnosis (Wijnberg-Williams et al., 2006). Findings show significant decreases in psychological distress, psychosomatic complaints, and state anxiety, indicating an improved ability among both parents to cope with or adapt to their child's illness over time. That said, parents of children with cancer still exhibited higher levels of psychological distress than did those in the comparison group five years post-diagnosis (Wijnberg-Williams et al., 2006). Further, mothers generally had higher levels of state anxiety at all four points as compared to fathers, but mothers' anxiety declined more quickly than did fathers' (Wijnberg-Williams et al., 2006). Fotiadou, Barlow, Powell and Langton (2008) did not find differences between mothers and fathers in regards to levels of pessimism related to depression, life situation and coping, but did find differences related to optimism and anxiety. The researchers found that men tended to have higher mean scores of optimism and lower mean scores of anxiety than did women.

These findings are somewhat in contrast to those of a previous study conducted in 1998 by Hoekstra-Weebers, Jaspers, Kamps, and Klip. This study found no differences between mothers and fathers of children with cancer on any measurement, with the exception of coping styles; men tended to demonstrate more active problem solving when the child was diagnosed and were less palliative at 12 months than were women. Mothers also tended to use more social-support seeking activities on all measurements. There was a tendency for couples to adopt similar coping styles, with discrepancies in these coping styles being positively related to distress in fathers at the point of diagnosis (Hoekstra-Weebers, 1998). For example, both mothers and fathers used fewer problem-focused and emotion-focused coping strategies over time, although the decrease in the use of emotion-focused coping was not significant for mothers. The authors also found that symmetry in emotion-focused coping between partners was associated with higher marital quality (Hoekstra-Weebers, et al. 1998). Similarly, Al-Gamal and Long (2010) recently found no significant differences in responses between mothers and fathers of child cancer patients in Jordan. When the total and subscale scores measuring personal sacrifice, burden, sadness, longing, worry, and felt isolation were compared according to gender, the differences in responses between mothers and fathers were not statistically significant, both for parents with newly diagnosed children and those with children who had been living with cancer for 6-12 months (Al-Gamal & Long, 2010).

As is the case in other fields of family practice and research (e.g., child welfare), fathers are generally underrepresented as compared to mothers, with many studies focusing solely or primarily on the female parent's perspective. Many have postulated that this trend is because mothers typically are the primary caregivers of their children (both sick and well). However, it is noteworthy to mention that the perspectives of fathers and mothers are not necessarily equal in the existing research, at least in terms of quantity.

Parental Needs: Socioeconomic Status

Research shows that there are also differences in parental needs depending upon the family's socioeconomic status. Al-Gamal and Long (2010) found the level of family income to have a greater effect on parental anticipatory grief than parent gender, with parents of lower socioeconomic status more likely to experience higher intensity anticipatory grief than parents with higher incomes. This finding highlights the important influence of poverty on physical and emotional well-being and, according to Al-Gamal and Long (2010), the vital need for the availability of low- to no-cost support services for children with cancer.

Parents of children and adolescents with cancer have reported that they experienced decreased opportunities to work after their child became ill (Enskar et al., 1997). Fotiadou et al. (2008) found differences in levels of parental optimism according to their employment status, with parents who had decreased their hours at work in order to care for their ill child having lower optimism than those who did not change the amount of time spent at work. Of note, Fotiadou et al. (2008) found higher levels of optimism in men and people who did not have to cut back work hours, but also stated that more

women than men in this study were unemployed. In contrast, Fayed et al. (2010) found that income was not a strong predictor of optimism among parents of children with cancer.

Parental Needs: Marital or Equivalent Relationship

Overall distress and differences in coping mechanisms can often cause a wedge to grow between the parents of ill children, thus jeopardizing their healing, relationship, and the structure of the entire family group as a whole. Several studies have focused on the relationship between parents of children with chronic or terminal illnesses, and the large amount of stress and burden placed upon them. A recent and integrative literature review pertaining to the impact of childhood cancer on the marital relationship between parents noted that relationship changes (both positive and negative) usually began to take shape within a few weeks to four months after their child received a cancer diagnosis, and often fluctuated over the trajectory of the illness (da Sliva, Jacob, & Nascimento, 2010). Positive changes reported by parents included increased relationship flexibility and more cohesive support, and one study found that fathers felt their relationship with their partner actually grew stronger as a result. Negative changes primarily pertained to weakened connections (including decreased sexual intimacy) between parents due to heightened stress and more time devoted to their child's needs than to each other's (da Silva & Nascimento, 2010). In addition, stress and geographical distance between home and hospital contributed to communication difficulties between parents, which in turn affected their relationship as a whole. The authors also found that mothers and fathers reported different stress levels and coping mechanisms, with some parents stating that they felt unable to meet their partner's needs even though they expected mutual support to occur (da Silva & Nascimento, 2010). Finally, the majority of reviewed studies highlighted changes in parental roles and responsibilities; many men experienced difficulty juggling work and new home responsibilities, while some women indicated that their role as caregiver had replaced their role as wife, which ultimately affected the marriage (da Silva & Nascimento, 2010).

Hoekstra-Weebers et al. (1998) aimed to examine the association between individual parent's coping styles and their degree of marital satisfaction at three different points in their child's illness trajectory: within 14 days of their child's diagnosis (T1), six months after T1 (T2), and 12 months after T1 (T3). Overall, analyses showed that a significant increase in marital dissatisfaction over time for both mothers and fathers occurred, but that neither parent was significantly more dissatisfied than parents in the control group (volunteer couples from the Dutch community) at T3. For some couples, marital satisfaction increased with time (Hoekstra-Weebers et al., 1998). Bivariate analyses showed that emotion-focused coping for fathers was significantly and positively associated with their level of marital distress at all three points in time.

> *"The impact of a child's cancer diagnosis, as well as the significant degree of distress and turmoil it brings, often causes a restructuring of roles and responsibilities among many members of the family."*

In contrast, a mother's level of marital distress was not related to her own emotion-focused coping, but was positively associated with her partner's emotion-focused coping; they were considered other-oriented (Hoekstra-Weebers et al., 1998). For fathers, marital stress was related to their own coping style, and not that of their partners; they were considered self-oriented (Hoekstra-Weebers et al., 1998). Psychological distress for both mothers and fathers was significantly and positively related to marital satisfaction at T2 and T3, but not at T1. Psychological distress at the time of diagnosis did not impact marital satisfaction, but as time went by, the two became increasingly related. However, for fathers, acute psychological distress at T1 was associated with their future marital dissatisfaction, and consequently, their partners' as well (Hoekstra-Weebers et al., 1998).

Studies examining divorce rates among parents of children with cancer are limited, both in quantity and quality. However, one study looking at registry and census data of married couples in Norway found that childhood cancer was not associated with an increased risk of parental divorce, except in cases where the child was diagnosed with Wilms' tumor and when the mother had an education level higher than high school (Syse, Loge, & Lyngstad, 2010). Notably, the risk of divorce was slightly higher for parents of children who had received a relatively recent cancer diagnosis (within the last five years) than those whose children had been living with cancer for five years or more. However, these differences were not statistically significant, nor were they significantly higher than the divorce rates among parents of healthy children (Syse, Loge, & Lyngstad, 2010).

Family Structure's Impact on Parental Needs

This review would be remiss if it did not also acknowledge how parents from "diverse" or complex family structures cope with their children's cancer diagnosis. After all, single parents (rather than married parents) are becoming increasingly common in the United States, and it is important to attend to their individual and unique needs. Further research with this population may be especially necessary, given that single or re-partnered parents make up approximately one-third of the entire parent population, and existing conflict between parents could likely contribute to the already stressful process of making treatment decisions for a child with cancer (Kelly & Ganong, 2010).

In their 2010 study, Kelly and Ganong examined childhood cancer treatment decision-making (TDM) among parents from diverse/complex family structures, including custodial parents (identified in this study as biological parents who provided primary care), nonresidential parents, and stepparents. The authors interviewed 15 parents from eight families: seven custodial parents (six custodial mothers and one custodial father), three co-parents (all noncustodial fathers), three stepparents (two stepfathers and one stepmother), and two parents with shared custody (one mother and one father from the same family). Interviews centered on aspects of the separation/divorce, the child's cancer history, and the experience of making a specific treatment decision (Kelly & Ganong, 2010).

Kelly and Ganong (2010) identified "moving to place" as the key psychosocial process by which parents negotiated involvement in TDM for their child. This process included the following actions: "stepping up," "stepping back," "being pushed," and "stepping away" from TDM. During the stage of diagnosis, custodial and coparents tended to align by focusing on their ill child rather than on their differences with one another. However, parents often fell back into previous ways of communicating once the urgency of diagnosis had decreased (Kelly & Ganong, 2010). Communication was more stable for parents who had been separated for a longer period of time than those who had been separated for fewer than two years. The authors also found that every parent interviewed said that biological parents have an "imperative" responsibility for TDM, which motivated both biological parents to "step up" (at least initially), as well as influenced the primary caregiver to include the coparent in important treatment decisions. Notably, coparents frequently "stepped away" from the decision making process after diagnosis, leaving the primary caregiver to be the primary decision maker as well. In addition, some coparents also described "being pushed" from daily treatment decisions and information sharing by the primary caregiver, particularly after diagnosis (Kelly & Ganong, 2010, p. 7).

Stepparents described either "stepping back" or "being pushed" from the TDM process by their partners, their partner's former spouse, and/or the treatment team (Kelly & Ganong, 2010). In many cases, stepparents also "stepped up" to participate in daily decision making as time from diagnosis increased, but reported that they did not receive the same amount of information regarding the child's care as did biological parents. The authors concluded that parents of pediatric oncology patients who no longer live together generally experience greater stress when coping with their child's illness than parents who are still together and share a household. However, some parents reported that their relationship with their former spouse was actually strengthened throughout the process (Kelly & Ganong, 2010).

Restructuring of Family Roles and Responsibilities

The impact of a child's cancer diagnosis, as well as the significant degree of distress and turmoil it brings, often causes a re-structuring of roles and responsibilities among many members of the family (Syse, Loge, & Lyngstad, 2010). Whereas the family's focus may have been evenly and equally distributed among different members prior to the time of diagnosis, that attention has likely shifted to primarily center on the needs, schedule, routine, and experiences of the ill child once he/she begins to undergo cancer treatment. And with good reason—the health and well-being of the child with cancer would be endangered if things were to remain exactly the same.

Many have noted that this transition takes its toll on the healthy members of the family, including the parents and their relationship together, but also the siblings

"Parents often underestimate the hardship that their healthy child experiences when his or her sibling becomes ill."

of the patient who frequently feel left out and less important in comparison. In her study examining the experiences of siblings and parents of pediatric oncology patients, Koch (1985) describes the range of emotions siblings typically experience when their brother or sister has been diagnosed with cancer. Through interviews, these siblings describe their experiences of having a brother or sister with cancer, including:

1. Worry that their brother or sister may die and sorrow that he or she must endure their often painful illness
2. Rules prohibiting emotional expression about the situation, particularly worry and anger
3. Health and behavior problems after the diagnosis, such as exacerbated physical symptoms and "acting out" behaviors
4. Changes in family roles, especially pertaining to a new and prioritized focus on the patient; emotional caretaking among mothers and siblings; and (forced) sibling maturation
5. Increased closeness and cohesiveness between members

This early study by Koch (1985) is somewhat unusual in that it utilized the child's/sibling's perspective, rather than only the parent's opinion of how the child was coping. Emily (aged 11 years), when speaking to how her parent's priorities had changed since her half-sister Evelyn (aged 3 years) was diagnosed with neuroblastoma, remarked, "…they both worry about Evelyn. They care about her a little bit more. I don't blame them, but it seems unfair" (Koch, 1985, p. 67). Similarly, Sean (aged 8 years) summed up his feelings by stating, "I think Ian's [brother, aged 6 years, diagnosed with non-Hodgkin's lymphoma] life is more important than mine," (Koch, 1985, p. 67). Siblings also reported how their own priorities had changed as well, causing them to adopt a more cautious, caretaking, and mature role with their ill brother or sister. When asked about her sister Peggy (aged 11, diagnosed with ALL), Amy (aged 15) stated, "There are some things I feel compelled to do. Like when she gets sick, I'm going to try and stick around the house a little more and help out. And play her a game or something," (Koch, 1985, p. 67).

The impact of a child's cancer on his or her sibling may become even more pronounced if that sibling is considered a donor candidate. In their recent review examining the psychological effects of hematopoietic SCT therapy on pediatric patients, their parents and their siblings, Packman, Weber, Wallace, and Bugescu (2010) documented that sibling donors are prone to developing PTSS, anxiety, and low self-esteem. Packman and colleagues also (2010, p. 1138) report that research has pointed to the sibling donor's "overwhelming responsibility for their sibling's survival" as a key, underlying source of this psychological distress.

According to Houtzager, Grootenhuis, Caron, and Last (2005), children are often overlooked as informants of their own functioning, both in clinical practice and in research, and the degree of agreement between their reports and those of their parents is not always strong. Houtzager et al. (2005) found that parents of pediatric oncology patients tended to underestimate the adjustment problems experienced by the patient's brother or sister (especially for younger siblings), and were not always in tune with somatic complaints or problematic behaviors exhibited by their healthy child and/or children. Again, parental psychological well-being seemed to play a role in how parents observed the experiences of their children. Parents who were experiencing a great deal of distress reported more physical problems in the healthy sibling than parents who were experiencing less distress (Houtzager et al., 2005). The fact that parents often underestimate the hardship that their healthy child experiences when his or her sibling becomes ill is an indication that there may be discrepancies in the amount of attention they pay to their child with cancer and their child who is well.

Wilkins and Woodgate (2007) conducted interviews with siblings to better understand what they thought would be most helpful during their brother's or sister's bone marrow transplant process. The authors identified the following seven themes as being the most important, from the sibling's perspective:

1. Being included in the definition of "family"
2. Having others be caring
3. Having others share information with the sibling
4. Having others give the sibling choices
5. Having others help the sibling to share his or her feelings
6. Having others provide opportunities for the sibling to meet and interact with his or her peers
7. Having others create a healthy hospital environment

Given that a diagnosis of childhood cancer can negatively impact both children and families on a multitude of levels, several studies included in this review recommend that healthcare professionals not only attend to the physical and medical needs of the child, but also to the emotional, psychological, and social needs of the family in order to support the best possible outcomes for all involved (da Silva, Jacob, & Nascimento, 2010; Enskar, Carlsson, Golsater, Hamrin, & Kreuger, 1997; Grimm, Zawacki, Mock, Krumm, & Frink, 2000; Jalmsell, Kriecbergs, Onelov, Steineck, & Henter, 2010; Norberg & Boman, 2008; Norberg, Poder, & von Essen, 2011; Tremolada, Bonichini, GianMarco, Pillon, Carli, & Weisner, 2010). Additionally, due to the high and stressful costs of cancer treatment, other scholars have highlighted that the services or adjunctive interventions offered to families need to be both accessible and affordable (Al-Gamal & Long, 2010; Frank, Blount, & Brown, 1997). AAT is one of several adjunctive, low-cost treatment options that could potentially address the immediate and ongoing psychosocial needs of many families coping with childhood cancer.

The Role of Human-Animal Interactions and Animal-Assisted Therapy in Supporting Populations in Need, With a Focus on Pediatric Oncology Patients and Their Families

Overview of Human-Animal Interactions and Animal-Assisted Therapy

For many, animals and pets take center stage in their daily lives, offering companionship, solace, joy, and for some, even kinship. A 2011-2012 national survey estimated that 62 percent of U.S. households own a pet, which amounts to roughly 73 million homes (American Pet Products Association, 2011). In fact, pet ownership is currently so high that the average child in America is more likely to grow up with a companion animal than with a father (Melson, 2001). In the majority of U.S. homes, pet owners often consider their companion animals to be important members of the family (Matuszek, 2010).

Many scholars contend that the historical bond that humans and animals share is not only mutually and evolutionarily beneficial, but deep-seated as well (Wilson, 1984; Melson & Fine, 2010; Serpell, 2010). As originally hypothesized by biologist E.O. Wilson, humans have an innate need to interact with other living beings, including animals and the surrounding environment (Wilson, 1984; Fine, O'Callaghan, Chandler, Schaffer, Pichot, & Gimeno, 2010; Melson & Fine, 2010). This natural pull towards nature, or "biophilia," is one of several explanations for why so many people consider their relationships with animals to be amongst their most significant. Some scholars have also argued that it is the social support we gain from our relationships with animals that explains the power of the human-animal bond, while others point to attachment theory when describing why we feel emotionally connected to the animals in our lives (McNicholas & Collis, 2006; Wells, 2009; Zilcha-Mano, Mikulincer, & Shaver, 2011). Finally, studies that report on the biochemical benefits of human-animal interactions (e.g., decreases in blood pressure and the stress hormone Cortisol) support a "physiological basis" for the affinity that humans and animals share (Barker & Wolen, 2008; Friedmann, 1995; Odendaal, 2000, p. 278; Tsai, Friedmann, & Thomas, 2010). Whatever the explanation, it is also important to recognize that the roles of animals and our relationships with them can drastically differ depending upon our personal and cultural backgrounds and experiences (Schwartz & Patronek, 2002). Thus, therapeutic interventions that involve animals may not necessarily be appropriate for every client.

Recently, increasing attention has been given to the roles that animals can play in supporting the health and emotional well-being of people in need. Research studies have offered promising evidence that involving animals in therapeutic interventions provides benefits for myriad populations, from young children with Autism to older adults struggling with loneliness and depression (Endenburg & van Lith, 2010; Nimer & Lundahl, 2007). Therapy animals have also become commonplace in a variety of settings, including hospitals and health care facilities (Lefebvre, Peregrine, Golab, Gumley, Waltner-Toews, & Weese, 2008; Matuszek, 2010). Reported benefits of human-animal interactions (HAIs) include exercise or opportunities for positive play; relaxation and reduced anxiety; decreased blood pressure and heart rate (markers for anxiety and stress); distraction from pain or worry; unconditional support and acceptance; increased sensory stimulation and opportunities for physical touch; improved social skills that lead to healthy relationships with others; enhanced senses of self-esteem and confidence; and increased motivation to actively participate in the healing process (Fine, 2010; Friedmann, Son, & Tsai, 2010; McCardle, McCune, Griffin, Esposito & Freund, 2011; Nimer & Lundahl, 2007; Serpell, 2006; Tsai, Friedmann, & Thomas, 2010; Wells, 2009). In their meta-analysis of 49 studies pertaining to animal-assisted therapy (AAT), Nimer and Lundahl (2007, p. 225) concluded that AAT improves outcomes in four broad areas of need: Autism-spectrum symptoms, behavioral issues, emotional well-being, and "medical difficulties."

As recognition of the bond we share with animals has increasingly gained momentum and credibility, so too has the field of human-animal interaction (HAI) as a serious focus of academic and

professional pursuit. Only recently were university students given the option of majoring in "Anthrozoology," the study of our relationships with animals. Graduate programs in psychology, sociology, counseling, social work, and veterinary medicine have increasingly begun to understand how important these relationships can be, as well as the healing and learning potential that HAIs may have for people and animals in need. For example, the University of Denver's Graduate School of Social Work's Institute for Human Animal Connection is a recognized pioneer in the area of HAI education and training, as is the Center for the Human Animal Bond at Purdue University's School of Veterinary Medicine.

Defining Animal-Assisted Therapy and Animal-Assisted Activities

Animal-assisted interventions (AAI) and HAIs are considered to be umbrella terms that encompass both animal-assisted therapy (AAT) and animal-assisted activities (AAA), which are often used interchangeably in the literature and in the field (Barker & Wolen, 2008; Palley, O'Rourke, & Niemi, 2010). AAT is a type of HAI targeted at helping clients meet their specific treatment goals, which are typically set by the client's therapist, teacher or doctor depending upon their individual situation and needs. However, how AAT happens is a subject of much debate. There is a general lack of consistent, documented AAT protocols and several different definitions and terms (e.g., AAT, animal-facilitated therapy, canine visitation therapy, pet therapy, pet-facilitated psychotherapy, etc.) to describe AAT have been proffered (Kruger & Serpell, 2006; Friedmann, Son, & Tsai, 2010; Matuszek, 2010). For example, some in the HAI field support the notion that in order for an intervention to be considered AAT, it must include at least four participants: the client; the therapist, doctor, or other helping professional; the animal handler; and the therapy animal (Kruger & Serpell, 2006; Delta Society, 2008). Following this model, many animal-handlers volunteer their time and work with professionals when providing AAT. Other schools of thought assert that the helping professional can also serve as the handler, and believe this may even be the best option as the professional is likely to be specially trained to work with the population being served. Others argue that having an individual play the dual roles of professional and handler places both the client and the animal at risk, since the individual is unable to give their undivided attention to either participant. Complicating matters further, some in the field are proponents of more than one model and/or do not differentiate between them when referring to AAT practice.

While AAT is a goal-directed intervention, animal-assisted activities (AAA) are often much less formal. For example, AAA are often characterized by brief therapy animal visits in hospitals and do not typically match the same animal and client for all sessions. Further, AAA visits tend to be more "spontaneous" in nature than AAT visits, which often presents challenges when attempting to evaluate the efficacy of AAA (Barker & Wolen, 2008; Kruger & Serpell, 2006, p. 23).

While AAT and AAA have historically included many types of therapy animals (e.g., dogs, cats, horses, rabbits, guinea pigs, birds, fish, dolphins, etc.), most interventions and research in the field involve specially trained and registered therapy dogs (Granger & Kogan, 2006; Friedmann, Son, and Tsai, 2010; Nimer & Lundahl, 2007). Therapy animals differ from service animals in that they are not legally defined by federal law; are not owned by the client as a pet in their home; are not responsible for the client's safety and wellbeing; and are typically subjected to less specialized training (i.e., service dogs are often trained to help people with specific disabilities, such as guide dogs for people with visual impairment). Both AAT and AAA are considered to be adjunctive interventions; rather than serving as stand-alone treatment options, they are primarily designed to complement more traditional modes of therapy.

Animals as Catalysts for Rapport and Social Interaction

One of the earliest claims in the field of AAT/AAA was made in 1969, when child psychologist Boris Levinson accidentally discovered that the mere presence of his dog, Jingles, in therapy sessions seemed to alleviate much of the anxiety and resistance previously exhibited by his young clients (Fawcett & Gullone, 2001). Levinson believed that Jingles "enabled more rapid establishment of rapport between himself and his clients" by alleviating the clients' mistrust of the therapeutic process and by improving their impressions of the professional (Fawcett & Gullone, 2001, p. 126; Mallon, Ross, Klee, & Ross, 2010). In this sense, Jingles served as an "extension" and co-therapist to Levinson (Fine, 2010, p. 174). Likewise, in a 1983 study conducted by Lockwood, research subjects rated people depicted in images with animals as significantly friendlier and less threatening than those where an animal was not present (Friedmann & Tsai, 2006). In contrast, Turi (1994) found that knowing that a therapist owned a pet was not

shown to significantly influence elementary school children's perceptions of the therapist's friendliness and/or the safety of the therapeutic milieu. However, it is important to note that the children surveyed in Turi's study were exposed only to videotaped sessions of the therapist and the "pet animal" and did not witness a physical HAI, a limitation Turi herself acknowledges (Turi, 1994, p. 96).

Animals have been shown to ease other social interactions as well, and are often considered to be social catalysts or "lubricants" (Fine, 2010, p. 172; Nimer & Lundahl, 2007). Studies examining populations from every walk and stage in life have demonstrated animals' ability to initiate and ease interactions between human beings. Animals often make humans more approachable, and they provide a topic for relaxed and enjoyable conversation (Fine, 2006). What is more, increased social interactions with other people have the potential of greatly reducing feelings of loneliness and isolation (Fine, 2006; Fine, 2010). In a study done with older adults living in long-term care facilities, residents who received weekly visits from a therapy dog and its handler were shown to display significantly reduced degrees of loneliness in comparison to those who did not receive the intervention (Banks & Banks, 2002). It is important to note that the study population was self-selected and may have been motivated to participate due to pre-existing desires to experience companionship (Banks & Banks, 2002). Indeed, more than 95 percent of participants had previously owned a pet and virtually all residents expressed a desire for current pet ownership, which long-term care facilities generally prohibit (Banks & Banks, 2002).

"The presence of animals, who are often considered to be non-judgmental and unconditionally devoted, has been documented to help individuals feel safe, accepted, and supported."

Animals as Sources of Unconditional Acceptance and Social Support

In addition to serving as a catalyst for rapport-building and social interaction, Jingles likely reduced some of the anxiety felt by Levinson's clients by providing a non-judgmental and "neutral" living being on which to focus, thus distracting the youth from their immediate problems (Kruger & Serpell, 2010, p. 39). Studies have shown that simply observing (e.g., fish swimming in aquariums) and/or petting an animal can temporarily reduce one's blood pressure and regulate one's heart rate, both of which can considerably moderate anxiety in stressful situations (Fawcett & Gullone, 2001; Friedmann, Son, & Tsai, 2010). Edwards and Beck (2002) also found that introducing aquariums at mealtimes in specialized units serving individuals with Alzheimer's disease (AD) caused this population to eat more, thus increasing their weight and nutritional intake and decreasing the amount of nutritional supplements needed. The authors found that the aquariums provided a calming stimulus for individuals with AD to focus their attention, and that those who observed the fish were more alert and sat longer with their meals (Edwards & Beck, 2002).

The presence of animals, who are often considered to be non-judgmental and unconditionally devoted, has been documented to help individuals feel safe, accepted, and supported, especially when disclosing painful and private aspects of their lives (Mallon, 1994). Reichert (1998) has observed this benefit of AAT in her work with sexually-abused children. Reichert states that her clients often use the therapy animal as a "transitional object" when they express their feelings and tell their stories "through the animal" (i.e., "I wonder if Riley is scared at night") rather than communicating directly with her (i.e., "I am scared at night") (Reichert, 1998, p. 178). Similarly, in a study conducted with youth at Green Chimneys, a residential-treatment farm and school in New York state that utilizes animal-assisted interventions and humane education, Mallon (1994) found that children also felt safe to confide in the farm animals about their concerns because they knew they would not be judged for what they said, and that their information would be kept secret (Mallon, 1994). This effect may be especially important for children living in homes where conflict, abuse and/or violence is present, as the pet may be the only family or household member whom with the child feels safe and supported (Strand, 2004).

The non-judgmental traits of animals may also encourage children to perceive their relationship with an animal as having "lasting quality and permanence" (Fine, 2006, p. 183). An animal's "unconditional positive regard" for humans not only fosters feelings of trust for a child, but also provides them with a sense of relationship stability, reliability, and/or consistency (Fawcett & Gullone, 2001, p. 129). Likewise, once a trustworthy bond has been formed between a person and an animal, the development of mutual support between the two can occur. Evidence has shown that animals are often the most important, if not the only, source of social support for people with few relationships and connections with others. According to a recent study, men living

with HIV/AIDS (an illness that can be marked by social stigma and isolation) were more likely to be clinically depressed if they either did not have a pet or were not attached to their pet (Siegel, Angulo, Detels, Wesch, & Mullen, 1999).

The Role of Animals in Human Health and Well-Being

Many in the medical field have long recognized the important role that animals can play in promoting the health and well-being of human beings. In 1860, Florence Nightingale commented, "A small pet is often an excellent companion for the sick, for long chronic cases especially. A pet bird in a cage is sometimes the only pleasure of an invalid confined for years to the same room" (Palley, O'Rourke, & Niemi, 2010, p. 199). Research also shows that owning pets may even have the power to prolong one's lifespan (Friedmann, Katcher, Lynch, & Thomas, 1980; Wells, 2009). In 1980, Friedmann, Katcher, Lynch, and Thomas examined the association between pet ownership and one-year survival rates among adult patients discharged from a coronary care unit. The authors found that of the 78 patients who were still alive one year post-discharge, 50 (or 64 percent) owned at least one pet (Friedmann et al., 1980). Of the 14 patients who did not survive one year post-discharge, only three (or 21 percent) of them were pet owners. Despite some limitations, this study's findings suggest that a strong bond between a human and an animal, such as a pet, can have positive effects on one's mental and physical health, and that these effects may be especially pronounced if the individual is lacking other sources of social support.

Research has also shown that walking dogs can have positive effects on people's health, namely their level of physical activity and their weight. Coleman, Rosenberg, Conway, Sallis, Saelens, Frank, and Cain (2008) found that a higher proportion (53 percent) of dog owners who walked their dog met national recommendations for minutes of moderate to vigorous physical activity than dog owners who did not walk their dog (33 percent) and people who did not own dogs (46 percent). Additionally, there were significantly fewer obese dog owners who walked their dogs than obese dog owners who did not walk their dogs or obese non-dog owners (Coleman, et al., 2008). Of note, neighborhoods tended to be more walkable (i.e., more sidewalks and/or paths, thus increasing one's sense of security and enjoyment during walks) for dog owners who walked their dogs than for dog owners who did not.

The State of Animal-Assisted Therapy Research

Since the late 1970s, HAIs have been the focus of many research studies in both the U.S. and abroad. However, the majority of study findings documenting the benefits of AAT, AAA, and pet ownership have largely been anecdotal and the field has consistently struggled with developing and conducting rigorous research (Johnson, Odendaal & Meadows, 2002; Kazdin, 2010). Additionally, most AAT research has examined the benefits that are observed while in the "context of the therapeutic milieu," rather than studying the longevity of these outcomes or if they are transferable to other situations (Kruger & Serpell, 2006). Many argue that this lack of evidence-based research has hindered the ability of HAIs to be recognized as serious and effective treatment modalities for people in need, particularly by those in the medical and health care fields (Palley, O'Rourke, & Niemi, 2010). For example, Wilson and Barker (2003, p. 23) assert that rigorous research supporting AAT/AAA programming must also outline "valid cost effectiveness estimates" for the practice to be recognized and prioritized in organizational planning and budgeting procedures, and possibly even by outside insurance providers. In fact, Palley, O'Rourke, and Niemi (2009, p. 206) argue that if AAT was recognized as a legitimate and cost-effective treatment modality, it could "advance health care in many ways for many patients." Wilson and Barker (2003) also propose that it is the multi-dimensional nature of HAI research that presents the most challenges, particularly in regard to the various types of HAI interventions and how they are practiced; the many populations that may be eligible to receive an HAI intervention; and facilities or settings that may be equipped or prepared to incorporate HAI programming.

In their 2002 article, Johnson, Odendaal, and Meadows (p. 432) identify the following as issues with developing and conducting HAI research:

1. Gaining access to clinical settings and ensuring that the research does not overly add to staff workload
2. Obtaining Institutional Review Board (IRB) approval to conduct the study in a safe and ethical fashion
3. Effectively managing zoonotic and infection concerns at the facility
4. Recruiting and randomly selecting a large and culturally diverse study sample to participate
5. Choosing study instruments, while making efforts to avoid the pitfall of exhausting study participants with "overzealous batteries"
6. Implementing the study without contaminating study groups or over-burdening facility staff

To manage these and other concerns, Johnson et al. (2002) recommend that HAI researchers first conduct a pilot study before engaging in a full research trial.

While much anecdotal evidence exists surrounding the benefits of AAT and AAA, there is still much work to be done in the area of HAI research, including examining the effectiveness of AAT with people who have—or have been touched by—serious illness. Evidence concerning the effectiveness of AAT/AAA with the pediatric oncology population is limited, with most research coming from pilot studies and/or being preliminary in nature. Likewise, the majority of AAT/AAA studies with the pediatric oncology population have occurred outside of the United States, making it difficult to generalize the studies' methodology, design, and findings on a broad scale. While these preliminary studies have laid the foundation for research in this area, most of them have generally lacked the methodological rigor necessary in evidence-based research, thereby leaving significant gaps that must be filled.

Potential Applications of Animal-Assisted Therapy in Addressing the Needs of Children and Families Coping with Pediatric Cancer

Animal-Assisted Therapy's Impact on Children with Cancer

One of the primary challenges that children with chronic or terminal illnesses often face is adapting to their new life as a patient. The once "normal" and healthy child may now primarily be seen in terms of his or her illness, and/or as fundamentally different from his or her peers. This can be confusing and isolating for children, especially as they grow and begin to identify who they are in the world. Moreover, since the clinical environment is so different than that of the child's home, and one that is often associated with pain, uncertainty and anxiety, the hospitalization process can be quite daunting for children newly diagnosed with cancer and other diseases (Wu, Niedra, Pendergast, & McCrindle, 2002).

Normalizing the Hospital Experience

Integrative and adjunct treatment modalities, such as animal-assisted therapy (AAT) and animal-assisted activities (AAA) have shown promise in normalizing the hospitalization experience for patients and their families (Bardill & Hutchinson, 1997; Gagnon, Bouchard, Landry, Belles-Isles, Fortier, & Fillion, 2004; Skeath, Fine, & Berger, 2010). Several studies with hospitalized children have revealed that having a therapy dog present during treatment or on the ward makes the hospital feel less foreign and more “like home,” in part because dogs are familiar and representative of the child’s everyday environment (Bardill & Hutchinson, 1997, p. 20; Wu, et al., 2002). In a recent study examining the impact of a ward dog named Graham on hospitalized adolescents living in an inpatient psychiatric unit, findings reveal that patients felt Graham made the milieu seem not only more like home, but more “familylike” as well (Bardill & Hutchinson, 1997, p. 20). Likewise, because dogs often represent happy companionship and/or imply friendliness and acceptance, patients were made to feel less “crazy” upon arrival to the psychiatric unit once they knew that Graham was also a resident (Bardill & Hutchinson, 1997, p. 20). One patient commented, “That feel of home was somewhere here thanks to Graham,” while another noted, “Graham helps give people a feeling that they are not locked up in this place” (Bardill & Hutchinson, 1997, p. 20). Gagnon, Bouchard, Landry, Belles-Isles, Fortier, and Fillion (2004, p. 222) also found that therapy dogs had a normalizing effect on pediatric oncology patients, with children having an improved acceptance of hospitalization, as well as a sense of being more “normal” and “less ill,” as a result of therapy with the dogs. Both parents and nurses reported that hospitalization seemed to be a happier event for children who received the animal-assisted intervention, with many children even talking about “loving the hospital” (Gagnon et al., 2004, p. 222).

In addition to helping normalize the hospital experience, therapy dogs have also been noted to provide comfort to children undergoing hospital treatment by reminding them of life, interests and relationships outside of the clinical environment (Sobo, Eng, Kassity-Krich, 2006). Sobo, Eng, and Kassity-Krich (2006, p. 56) refer to this process as the engagement, recruitment, or reactivation of “cognitive schemas regarding home and pet companionship.” In their study looking at the effectiveness of canine visitation therapy (CVT) on pain management in hospitalized children, Sobo et al. (2006) reported that one child thought that visits from the dog may be especially helpful for children who have

dogs at home, as the dog serves as a strong reminder of their own dogs. Similarly, Skeath, Fine, and Berger (2010) stress that health care providers should make efforts to understand the importance that a pet may have in the life of a hospitalized patient who now cannot interact with his/her animal companion as often or in the same ways as he/she did prior to getting sick.

Motivating Active Participation

The normalization of the hospital experience has the potential of leading to an increase in motivation among children to actively participate in treatment. In the counseling and mental health fields, there is a growing body of evidence indicating that the opportunity to interact with therapy animals can help motivate clients to comply with the therapeutic process, to engage with their therapist, and to retain that motivation overtime (Barker & Wolen, 2008; Kale, 1992; Mallon, Ross, Klee & Ross, 2010). A recent exploratory study examining the impact of including dogs in adolescent anger management therapy found that youth participants felt that the dog motivated them to stay engaged in the therapeutic process (Lange, Cox, Bernert & Jenkins, 2007).

Other studies have found similar results in hospital settings (Bardill & Hutchinson, 1997; Gagnon, et al., 2004). In a recent study with pediatric cardiology patients, patients listed “motivation to get better” or “motivation to stay optimistic” among the most important benefits of being visited by a therapy dog (Wu et al., 2002, p. 360). Similarly, Gagnon et al. (2004, p. 222) found that more than half of the 16 parents of children with cancer in their study sample reported seeing an improvement in treatment compliance, as well as “motivation to continue with hospitalization” in their children after they were visited by a therapy dog.

“Rather than focusing solely on the unpleasant situation at hand, children are given the opportunity to interact with another living being that provides them with joy and comfort.”

Increased motivation to actively participate in the treatment or therapeutic process implies that these patients may also have experienced future orientation, or the ability to see beyond their current situation as a cancer patient. Excitement or anticipation about the next visit with an animal indicates that the patient may be experiencing hopeful optimism for future events, something that is often hard to come by when you are living with a chronic or terminal illness. In their study with adult cancer patients receiving inpatient treatment, Johnson, Meadows, Haubner, and Sevedge (2003, p. 55) found that, when compared to patients who received either a visit from a “friendly human” or a session of “quiet reading,” patients who received a visit from a therapy dog and its handler were more likely to tell others about their experience, look forward to similar future sessions, and remember the visit after returning home from the hospital.

Providing Helpful Distraction

In addition to the normalization of the hospital environment, one of the primary benefits of animal-assisted interactions in clinical settings is the distraction from pain, worry, anxiety, and unhappiness that animals can provide for patients and their families (Matuszek, 2010). Rather than focusing solely on the unpleasant situation at hand, children are given the opportunity to interact with another living being that provides them with joy and comfort. For example, Wu et al. (2002) found that 61 percent of pediatric cardiology patients and 40 percent of their parents stated that the dogs’ presence served as a pleasant distraction from the reality of hospitalization. Likewise, Moody, King, and O’Rourke (2002) found that staff on a pediatric medical ward had expected that visits from dogs would distract patients from their illness prior to the implementation of a dog visitation program, and that these expectations were realized post-intervention.

Sobo et al. (2006) suggest that AAT serves to distract child patients from pain perception, thus increasing their comfort level throughout the necessary treatment process. From interviews with children and their parents exploring their reactions to the CVT intervention, Sobo et al. (2006, p. 55-56) identified the following eight themes:

1. The dog provided distraction from pain/situation
2. The dog brought pleasure/happiness
3. The dog is fun/entertaining
4. The dog reminds the child of home
5. The child enjoys snuggling/contact with the dog
6. The dog provides company
7. The dog is calming
8. The dog eases pain

For parents, the most prominent theme was that of distraction, with one parent noting that “it’s so good for children to have something to take their minds off the pain” (Sobo et al., 2006, p. 55). Distracting the patient from the often unpleasant and painful experience of receiving treatment has the benefit of easing the treatment process for all involved, thus contributing to a less stressful and potentially more successful treatment session.

Recently, one study found that children/youth aged 3-17 years who received an AAT intervention in an acute care pediatric setting experienced a significant decrease in pain when compared to children who did not interact with a therapy dog (Braun, Stangler, Narveson, & Pettingell, 2009). Additionally, respiratory rates significantly increased in the AAT group, but the groups did not differ when it came to other vital signs, such as blood pressure and pulse. The authors suggest that interacting with the therapy dog may have caused a release of endorphins (which generate positive feelings) and lymphocytes (which enhance the immune system) for children in the AAT group, thus contributing to their significant reduction in pain level (Braun et al., 2009). This study indicates that the benefits of AAT may reach far beyond helpful distraction, and that the interaction itself may also have the capacity to significantly ease the pain and discomfort commonly experienced by pediatric patients.

Alleviating Distress

Some research has found that the presence of a companion animal can help to lessen the distress experienced by children during medical examinations (Hansen, Messinger, Baun, & Megel, 1999). Hansen et al. (1999) measured both physiological variables (e.g., systolic, diastolic, and arterial blood pressures; heart rates; and fingertip temperatures) and behavioral variables (i.e., videotapes were assessed for signs of behavioral distress, including crying, screaming, physical resistance, and “verbal statements of fear”) amongst children who had a companion dog present during their routine physical examination and children who did not (Hansen et al., 1999, p. 144). While there were no significant differences between the two groups in terms of physiological measures, children displayed significantly less behavioral stress when a dog was present during their examination (Hansen et al., 1999). In contrast, a study with similar measurements (i.e., physiologic arousal through fingertip temperatures and behavioral distress) found that the presence of a dog did not affect the behavioral distress of children undergoing dental procedures (Havener, Gentes, Thaler, Maler, Baun, Driscoll, Beiraghi, & Agrawal, 2001). Physiologic arousal also remained unchanged. In their pilot study of anxiety among children visiting the dentist, Schwartz and Patronek (2002) identify several methodological considerations for future research in this area, including the age of the children; whether they have pets at home; their experience with animals, which is often dependent upon where they live (i.e., urban vs. rural geographical and cultural areas); the impact of how their anxiety was measured (i.e., children may have acted differently because they knew they were being videotaped); and the personality of the therapy dog.

Elevating Mood

Patients who have been diagnosed with chronic or terminal illnesses are at a great risk of experiencing depression, especially as their disease and/or treatment progresses. Withstanding grueling and often painful treatment procedures, combined with the anxiety and grief that typically accompanies major lifestyle, and physical ability changes, has the potential of increasing a person's likelihood of becoming depressed. In a longitudinal study examining adults with physical disabilities/chronic illnesses, Turner and Sameul (1988) found that adults with physical disabilities are at a dramatically elevated risk of suffering from depression symptoms than those who are not disabled. Moreover, physical disability and/or chronic illness and pain increased the risk for depression regardless of the gender or age of the affected individual (Turner & Sameul, 1988).

AAT and AAA have been shown to have positive impacts on the moods of clients, including hospitalized children and adolescents. In a recent study examining the reactions of pediatric patients, their families, and medical staff to the introduction of and incorporation of AAA into Italy's Anna Meyer Children's Hospital, Caprilli and Messeri (2006) found that children self-reported their mood to be pleasurable due to the therapy dog's presence, with many of them creating drawings featuring dogs after the visits had taken place. Another study comparing the effects of pet therapy versus those of play therapy on children undergoing hospitalization (33 percent of children in the sample were hospitalized for hematology/oncology issues) indicated that while nurses and parents believed the children to be happier at the end of both types of therapy than they were prior to the intervention, children who received pet therapy were still rated as happier than those in the play therapy group (Kaminski, Pellino, & Wish, 2002).

Offering Social Support

Closely related to the topic of mood elevation is social support. AAT has long been recognized as an intervention that provides social support and unconditional affection for those in need. Not only is cancer frightening and confusing, but it also can make young patients feel separate from their peers in a way that they may have never experienced before in their lives. They are now known as the "kid with cancer"; they look different, have special needs, and they cannot always engage in the activities they used to do before they got sick. What is worse, they are frequently separated from their peers and their everyday lives at school and in the community, with more and more people treating them as a patient rather than as a "normal" child. This can have profound implications for how children identify themselves, what they believe about themselves, and how they relate to those around them, all crucial elements of

"Children self-reported their mood to be pleasurable due to the therapy dog's presence, with many of them creating drawings featuring dogs after the visits had taken place."

healthy growth and development. Because animals naturally accept us for exactly who we are, and do not pass judgment on us based on our social standing, appearance, or health status, they may be capable of providing both direct social support through companionship, and indirect social support by acting as lubricants or "catalysts for human-human interaction" and socialization (McNicholas and Collis, 2006, p. 54).

Fine and Eisen (2008) allude to this benefit in the true story of Alexann, a six-year old cancer patient who shared a tremendous bond with her therapy dog, Gleason. In preparation for Valentine's Day, Alexann, Gleason, and Gleason's handler, Sue, left the hospital to attend a card-making party with other children. According to the study, Gleason served as "a kind of bridge for the other children to use in approaching [Alexann]," allowing everyone to feel more comfortable with one another. Alexann eventually began to feel so "normal" and supported that she removed her wig and hat, revealing the bald head caused by her chemotherapy treatment. Alexann's parents responded to this particular outing with Gleason and Sue by expressing their gratitude that Alexann could leave the hospital and "be just another kid on the 'outside,'" for a day (Fine & Eisen, 2008, p. 151).

In addition to providing empirical evidence supporting the relationship between physical disability and depression, the study conducted by Turner and Sameul (1988) was foundational because it identified two primary targets in which to focus intervention efforts: social support and mastery (Turner & Sameul, 1988). Across all age categories, only degrees of social support and mastery were shown to consistently contribute to levels of depression in research subjects. Although factors and symptoms such as chronic strain and eventful stress were strongly correlated with incidences of depression, they also tended to vary over time and by the age of the individual. According to this study's findings, improvements in social support and mastery are likely to reduce the risk and the severity of depression in people with disabilities and chronic illnesses. Given that AAT has been shown to enhance levels of both social support and mastery for populations in need, it arguably could be an apt adjunct therapy to reduce their levels of depression as well.

In their study of the impact of a dog visitation program on pediatric cardiology patients and their families, Wu, Niedra, Pendergast and McCrindle (2002, p.) note that 19 percent of the patients identified "the giving of unconditional love by the dogs" as the most important benefit of the program. Similarly, young patients living in a psychiatric unit commented on the supportive benefits of Graham—the resident ward dog—by saying, "Sometimes you can talk to him when you can't talk to anybody else. He doesn't judge you. He can't say, 'Oh you're stupid,'" (Bardill & Hutchinson, 1997, p. 21).

Animal-Assisted Therapy's Impact on Families of Patients

AAT/AAA has been practiced with a variety of adult populations, from the elderly to the chronically ill or physically disabled to those struggling with mental health issues, such as veterans living with PTSD. Currently there is a general lack of literature describing how AAT impacts the families of patients with chronic or terminal illnesses. In other words, while many studies rely on parental reports of how they think the AAT interaction did or did not benefit the pediatric patient, the literature identified has very little to offer in terms of how AAT affects the patient's parents and other close family members. In describing the effects of AAT for families of children with cancer, this review will primarily focus on research concerning how AAT and other HAIs impact and address the needs of adults.

Animal-Assisted Therapy's Impact on the Caregivers of Pediatric Patients

According to Enskar et al. (1997), parents' responses to and feelings about their child's cancer depend to a great extent on their child's responses and feelings. Thus, interventions that noticeably and effectively raise the mood of pediatric patients may likely do the same for their parents, siblings, and other family members. In a study evaluating whether dog visits help patients receiving treatment in a pediatric cardiology inpatient unit and their families adjust to the stress and unfamiliarity of hospitalization, Wu, Niedra, Pendergast, and McCrindle (2002) found that parents self-identified seeing their child happy with the dogs as a primary reason why the pet visitations made them happy. However, Wu et al. (2002) found no correlation between the parent's reported feelings and those of their children. Wu et al. (2002) also found that 52 percent of parents considered relief to be the most important pet visit benefit, 16 percent chose the giving and receiving of unconditional love, another 16 percent felt they personally received no benefit, 12 percent identified the facilitation of social interaction, and 4 percent thought that having the dogs serve as objects for the projection of feelings was the most important benefit. All participants (including patients and their parents) wished to be visited by the dog again in the event of a future hospitalization, with 100 percent considering the AAT program to be beneficial and 60 percent saying they would recommend a pet visit to anyone.

These findings are consistent with several other studies that document parents' favorable opinions and support of the AAT their ill child received during the treatment process (Bouchard, Landry, Belles-Isles, & Gagnon, 2004; Caprilli & Messeri, 2006; Sobo, Eng, & Kassity-Krich, 2006). In one of the few studies specifically examining the impact of AAT on children with cancer, Bouchard, Landry, Belles-Isles, & Gagnon (2004) administered questionnaires to both parents and nursing staff to measure their overall satisfaction with the intervention. Both parents and nurses provided overwhelmingly positive responses, with parents reporting that visits with the dog provided their child with comfort, happiness, and encouragement. Nurses provided similar responses, and even indicated that the dog visits made their own work with patients easier.

Animal-Assisted Therapy and Depression

As discussed earlier in this review, parents of children with cancer often experience significant and acute depression when their child becomes sick, particularly in the time period shortly after their child has been diagnosed. Several studies have examined if animals, whether they be therapy or companion animals, have an impact on depression levels in adults. In a recent meta-analysis of five studies examining AAA and AAT with adults, Souter and Miller (2007) found an aggregate effect size that was statistically significant, indicating that AAA and AAT yield improvements in depression among adults. The authors also identified several limitations in current AAA/AAT research (e.g., the common absence of random assignment, the lack of focus on whether the positive effects of AAA/AAT can be attributed to the dog or the handler, the need to assess the long-term impacts of AAA/AAT, etc.) and suggested that addressing these gaps is crucial to understanding why AAA/AAT may be effective at decreasing depression. Of note, four out of the five studies included in Souter and Miller's (2007) meta-analysis were conducted with the nursing home population.

Contrary to popular belief, some research has shown that AAA/AAT and/or pet ownership are not necessarily more effective than other interventions at decreasing depression for adults in need (Barker & Dawson, 1998; Bolin, 1987; Fila, 1991; Johnson, Meadows, Haubner, & Sevedge, 2008; Lutwack-Bloom, Wijewickrama, and Smith, 2005). For example, a 1987 report from the National Institutes of Health (NIH), which addressed a national probability sample of approximately 1,200 older adults, concluded that "no direct association was found between pet variables (pet ownership and attachment) and reported illness status or levels of depression" (NIH, p. 3).

A more recent study focused on the impact of dog visitation (AAA), human visitation, and quiet reading with adult cancer patients receiving outpatient radiation therapy (Johnson, et al., 2008).

> *"Owning a pet may be particularly helpful as the illness (or the illness of a loved one, arguably) progresses and the individual must confront issues concerning their own (or their loved one's) mortality."*

The authors utilized a longitudinal, pre-test/post-test research design, assessing the mood (which included anxiety, depression, fatigue, tension, and vigor), self-perceived health, and sense of coherence among participants in all three cohorts at two points in time: prior to receiving the AAA/friendly human/quiet reading intervention (T1) and four weeks later at the end of the last session (T2). Study findings included no significant differences between or within groups in regards to mood or sense of coherence. However, the AAA group's post-test scores showed numeric increases in anger/hostility, slight increases in depression/dejection, decreased fatigue, decreased vigor, and increased confusion when compared to their pre-test scores. The friendly human visitor group showed no change in anger/hostility scores, lower depression/dejection scores, decreased fatigue scores, increased vigor scores, and lower confusion scores. The quiet reading group experienced a decrease in anger/hostility, depression/dejection, vigor, and confusion scores, as well as no change in fatigue scores. In terms of emotional health, participants in the friendly human visitor and quiet reading groups believed that their emotional health declined during the study, whereas those in the AAA group believed it had improved (Johnson et al., 2008).

The exit questionnaires administered at T2 revealed that participants in all three groups believed their sessions were helpful and beneficial (especially early in the treatment trajectory), with most indicating they would recommend the intervention to other patients. The authors stated that this finding is especially noteworthy for those in the AAA group, as their numeric scores suggest that their experiences may not have been as positive as those in the quiet reading cohort. The authors also emphasized that healthcare professionals should know that while patients with cancer may want and benefit from dog visitation, positive outcomes may not be measurable for this population (Johnson et al., 2008). At the very least, patients may value dog visits for their calming effect and for their role in helping to provide distractions from illness and treatment. However, visits from dogs and their handlers may be just as beneficial as visits from humans for some adult cancer patients.

In a similar study done with elderly residents at two long-term care settings, Lutwack-Bloom et al. (2005) examined the effects of visits from a dog and its handler versus visits from a human without the dog present over a six month period. The authors found a significant and positive change in mood for residents who received visits from a dog and its handler. However, similar to previous studies, depression did not improve significantly over the six-month period for those receiving dog visits.

In addition to AAA/AAT, other studies examining HAIs have specifically focused on the relationship between pet ownership and depression. For example, a 1999 study using data collected from questionnaires determining the impact of pet ownership on depression levels for persons living with HIV/AIDS, found that receiving an AIDS diagnosis was associated with high levels of depression, particularly for those who either did not have a pet or were not attached to their pet (Siegel, Angulo, Detels, Wesch, & Mullen, 1999). People living with HIV/AIDS often lack concrete and consistent social support networks, due to emotional isolation because of others' discomfort with the illness and/or how it was contracted, as well as physical isolation (i.e., the inability to leave their homes for social interaction due to being weak and/or immuno-compromised). Thus, owning and attaching to pets may provide a way for people living with HIV/AIDS to promote their emotional well-being by receiving support in a non-judgmental, undemanding, and unconditional fashion. Owning a pet may be particularly helpful as the illness (or the illness of a loved one, arguably) progresses and the individual must confront issues concerning their own (or their loved one's) mortality (Siegel et al., 1999).

Special Considerations for Implementing Animal-Assisted Therapy in a Pediatric Oncology Setting

Animal-Assisted Therapy Implementation

The incorporation of therapy animals into healthcare treatment is a complex undertaking which requires special consideration of myriad topics in order to ensure safe and beneficial interactions. Such topics include controlling infection, selecting participants, and establishing protocols. Guidelines and standards regarding animal-assisted therapy (AAT) and human-animal interaction (HAI) have been published by several agencies, including Delta Society (1996), the International Association of Human-Animal Interaction Organizations (1998), Centers for Disease Control and Prevention (Sehulster & Chinn, 2003), American Journal of Infection Control (Lefebvre et al., 2008), and the American Veterinary Medical Association (2011). In addition to the benefits of AAT, there are several risk factors and contraindications to consider, such as zoonotic and infectious disease transmission, human allergies and phobias, and negative impacts on the animal.

Infectious Disease Control and Zoonoses

According to the Centers for Disease Control (2010), although animals carry germs, people are not likely to become ill from interacting with dogs. In AAT sessions, which occur in a controlled environment, Brodie, Biley, & Shewring (2002) concluded that zoonoses, allergies and bite hazards are minimal. For example, in a six-year period more than 4,000 patient exposures to therapy dogs, Arkansas Children's Hospital in Little Rock did not find a single infection or adverse reaction from a patient or employee (Yamauchi & Pipkin, 2008). Another study of AAT in a children's hospital in Italy found that the presence of infections did not increase in wards visited by a therapy dog (Caprilli & Messeri, 2006). Hines and Fredrickson (1998) also found limited evidence of the transmission of zoonotic diseases in AAT.

According to Johnson (2010), AAT with medical patients does involve a risk of zoonotic disease transmission. The physical examination of 102 visitation dogs with no known health issues in a study conducted by Lefebvre et al. (2006) found zoonotic agents in 80 percent of the dogs. Pathogens reported in visitation dogs included Clostridium difficile, Escherichia coli, Salmonella, Pasteurella multocida, Malassezia pachydermatis, Giardia, Toxocara canis, and Ancylostoma caninum.

Furthermore, Lefebvre et al. (2006, p. 757) posit that the increasing commonality of AAT in healthcare settings "emphasizes the need to develop appropriate risk assessment and infection control measures." Facilities that garner AAT services for their clients need to ensure that policies and procedures are in place to support safe and effective AAT service delivery (Guay, 2001). In general, more information is needed regarding the transmission of zoonotic diseases in AAT (Lefebvre et al., 2006) since, although there is a lack of evidence that infection rates rise as a result of AAT, this may be due to a lack of injuries, lack of central reporting registries or failure to recognize zoonotic diseases (Friedmann, Son, and Tsai, 2010).

When interacting with animals, special precautions should be taken to protect people who are immuno-compromised. According to the Centers for Disease Control (2010) "people who are more likely to get diseases from dogs include infants, children younger than five years old, organ transplant patients, people with HIV/AIDS, and people being treated for cancer." However, in a study of existing literature on zoonoses by Hemsworth and Pizer (2006, p. 126), it was concluded that immuno-compromised people are not at any additional risk by interacting with pets than they would be by interacting with other people and the environment.

Although risk of disease transmission between humans and animals in AAT exists, it can be greatly mitigated by "taking simple measures, including careful selection of animal and client, thorough planning and allocation of responsibility, rigorous health care of the animal and informed practices by all involved" (Brodie, 2002, p. 454). These simple measures include people washing their hands with soap and water after touching animals and avoiding rough play with cats and dogs (Centers for Disease Control, 2010; Pets Are Wonderful Support, 2009).

Guidelines for animal-assisted interventions in health care facilities published by the American Journal of Infection Control (Lefebvre et al., 2008) recommend animal handlers be required to carry an alcohol-based hand sanitizer and require all people who interact with the therapy animal to practice hand hygiene both before and after touching the animal in order to help reduce disease transmission. In addition, Robinson and Pugh (2002) noted the importance of best practice approaches including preventive health care, diet, and dog management to reduce the risk of zoonoses transmission.

Human Allergies and Physical Harm

In addition to concerns about disease transmission, a common concern regarding AAT is allergic reactions of participants and others exposed to the therapy animal. "The proteins found in a pet's dander, skin flakes, saliva, and urine can cause an allergic reaction or aggravate asthma symptoms in some people. Also, pet hair or fur can collect pollen, mold spores and other outdoor allergens," (American Academy of Allergy, Asthma & Immunology, 2011). However, in regard to children, exposure to dogs and cats early in life can help mitigate allergies later in life (Beck, 2011). The Centers for Disease Control (Sehulster & Chinn, 2003) recommend several precautions to reduce allergic reactions to animals including bathing the animal within 24 hours of a therapy session, grooming the animal immediately before a session, and having the animal wear a therapy vest to block loose hair.

In terms of potential physical harm to participants, such as dog bites, scratches or tripping over the dog, typically there is minimal risk due to the therapy animal screening and training that is involved (Friedmann, Son and Tsai, 2010)

Animal Well-Being

The well-being of the therapy animal is as equally salient to the practice of AAT as human health and well-being. No matter how appropriate the animal may be for AAT service, "animal fatigue, overwork, and burnout can occur with therapy animals," (Beck, 2011, p. 48). The International Association of Human-Animal Interaction's Prague Declaration (1998) regarding AAT emphasizes the need for safeguards to be in place to ensure the well-being of the animal.

Therapy animals are frequently eager to please their owners and the owner must be familiar enough with the animal's behavior to recognize subtle cues that the animal is tired or uncomfortable (Serpell, Coppinger, Fine, & Peralta, 2010). Stress signals in canines can include "increased performances of body shaking, crouching, oral behaviours, yawning, restlessness and a low posture," (Beerda et al., 1998, p. 376). In order to help ensure a mutually beneficial interaction, only animals that seek and enjoy interaction with individuals they encounter should serve as therapy animals (Granger & Kogan, 2000).

Granger and Kogan (2000, p. 231) posit that "limiting the time an animal is 'on duty' and keeping the animal safe from accidents or aggressive client behavior are major responsibilities of the human team member." In a survey of AAT practitioners conducted by Iannuzzi and Rowan (1991), respondents stated that they recognized signs of fatigue in their therapy dog when sessions lasted longer than one hour. Likewise, Lefebvre et al. (2008) concur that therapy sessions should be limited to one hour in length.

To date, few studies have specifically evaluated what bearing AAT may have on therapy dogs. Saliva sampling is a non-invasive and accurate method of measuring cortisol hormone levels in order to assess canine stress (Dreschel & Granger, 2009). According to Haubenhofer and Kirchengast (2006, p. 166), "Cortisol is an essential hormone and is considered to be a major indicator of altered physiological states in response to physiological arousal in most mammals, including humans and dogs."

In a 2007 study examining cortisol secretion responses of dogs and handlers in relation to AAT sessions, Haubenhofer and Kirchengast (2007) found that AAT was a source of increased canine cortisol concentrations, independent from the handler's associated emotions. Haubenhofer and Kirchengast (2007) concluded that increases in canine cortisol may have been due to the novelty of the situations that therapy dogs encountered when beginning an AAT session, and suggested that they may need a certain amount of time after each session for rest and recreation. Thus, an increased understanding of how AAT sessions impact therapy dogs will assist the AAT field in its ongoing development of best practices and ethical standards that ensure the well-being of therapy animals.

Therapy Animal Selection

Published guidelines regarding the selection of animals for AAT include, but are not limited to, the following topics and corresponding recommendations:

1. Species: Include only domestic companion animals that are household pets; avoid reptiles, amphibians, nonhuman primates; exclude recently domesticated species and other animals that cannot be litter trained (Sehulster & Chinn, 2003; Lefebrve et al., 2008; Johnson, 2010).
2. Age: Exclude dogs and cats younger than one year (Lefebrve et al., 2008; Johnson, 2010).
3. Animal origin: Include only animals with known medical and behavioral histories (AVMA); exclude animals that come directly from animal shelters or with a permanent home for less than six months (Lefebrve et al., 2008; Johnson, 2010).
4. Training method: Include only domestic animals which have been trained and will continue to be trained using techniques of positive reinforcement (International Association of Human Animal Interaction Organizations, 1998; American Veterinary Medical Association, 2011). Therapy animals should only wear humane equipment, i.e., no choke chains, prong collars or other punitive training aids that may cause pain or discomfort to the animal (Delta Society, 1996).
5. Health issues: Exclude animals that are fed a raw-meat diet, are immuno-compromised, or lack complete annual vaccinations certified by a licensed veterinarian (Lefebrve et al., 2008; Johnson, 2010).
6. Wellness: Animals should receive regular vaccinations; parasite prevention and control; selected screening for common diseases and conditions; preventive medical, dental, nutritional, and behavioral care, including environmental enrichment; and an assessment of genetic health when appropriate (American Veterinary Medical Association, 2011).
7. Affiliation: Exclude animals that are owned by handlers who are not affiliated with a visitation group nor registered by an AAT training program (Lefebrve et al., 2008; Johnson, 2010).
8. Temperament evaluation: Ensure participating animals have passed a temperament evaluation at least every three years that is specifically designed to assess their behavior under conditions which they will encounter in the setting they will be visiting (Lefebrve et al., 2008).

A criticism of the standard selection procedures for therapy animals as practiced by many organizations is that although AAT has expanded to chaotic and unpredictable settings, typical selection protocols use "a single procedure that attempts to determine the appropriateness of an animal/handler team in any type of environment with little or no regard for the different applications that might be utilized within any given

> *"Findings suggest that a strong bond between a human and an animal, such as a pet, can have positive effects on one's mental and physical health, and that these effects may be especially pronounced if the individual is lacking other sources of social support."*

environment," (Fredrickson-MacNamara & Butler, 2010, p. 115).

The Role of the Animal-Assisted Therapy Handler

The animal is only one part of the equation in providing safe and effective AAT. The handler must be skilled in presenting their therapy animal and advocating on his/her behalf. Their duties encompass preparation before the visit such as training, grooming and veterinary care. Service delivery duties include working to meet the participant's goals while concurrently making continuous assessments regarding the safety of the environment and appropriateness of interaction with clients. Post-visit, the handler is responsible for documentation as well as attending to the animal's needs (Fredrickson-MacNamara & Butler, 2010).

In addition to published guidelines for therapy animal selection, published guidelines also exist for AAT handlers. Recommendations emphasize the importance of formal training for AAT handlers including, but not limited to, education in the areas of animal behavior, humane handling, infection control, animal training, and AAT (Sehulster & Chinn, 2003; Lefebrve et al., 2008; Johnson, 2010). Similar to the criticism of the lack of expansion of animal selection procedures over time, Granger and Kogan (2000) cite the need for increased depth and extensiveness in handler training as the field continues to proliferate and encompass more people, animals and settings.

Selection of Appropriate Participants for Animal-Assisted Therapy

Delta Society (1996) recommends AAT participant selection procedures that take into account the facility environment, including activity level, population characteristics, and how these factors may impact AAT.

In terms of age of participants, the Centers for Disease Control and Prevention (2010) state that children younger than five years old are more likely than older people to get diseases from animals since young children are more likely to put their hands in their mouths and less likely to wash their hands thoroughly. This finding underscores the importance of infection control procedures that are practiced and controlled in healthcare settings, especially among populations that include young children. Specific goals of AAT and corresponding activities may also be dependent upon the age of the participant and their developmental level.

Further, healthcare providers should ensure that people who are allergic to animals, have a fear or phobia of animals or are otherwise uninterested in coming in contact with the therapy animal are identified to the handler with instructions to avoid such individuals (Lefebvre et al., 2008; Delta Society 2008). In regard to specific populations that may benefit from AAT, according to Johnson (2010, p. 29), "patients may benefit from AAA if they are experiencing anxiety-inducing disease states or treatment protocols, such as patients with cancer undergoing chemotherapy or radiation treatments."

Service Delivery of Animal-Assisted Therapy

Literature regarding the delivery of AAT services ranges from basic guiding principles to specific best practices. The International Association of Human-

Animal Interaction Organizations (1998) supports the overarching principle that the interaction is designed to be mutually beneficial and that "basic standards are in place to ensure safety, risk management, physical and emotional security, health, basic trust and freedom of choice, personal space, appropriate allocation of program resources, appropriate workload, clearly defined roles, confidentiality, communication systems, and training provision for all persons involved."

The American Veterinary Medical Association (2011; Delta Society, 1996; IAHAIO, 1998) emphasizes the need for adequate preparation before an AAT program is implemented. Preparation should include:

1. Knowledge of AAT concepts, AAT certification programs, and national/state/local laws that pertain to visiting animals
2. Role definition for participants as well as a mechanism for regular communication between all
3. Establishment of policies and procedures to mitigate risk and ensure the safety of participants
4. Delivery of training for handlers and staff
5. Assurance of confidentiality
6. Inclusion of a veterinarian to ensure the health and well-being of animals

Additional specific recommendations regarding AAT service delivery in healthcare facilities include topics such as standards for animal evaluators, influenza vaccination and other human health screening, leashing and transportation of the animal, incident procedures, and other guidelines for managing appropriate contact between therapy dogs and people (Lefebvre et al., 2008).

Conclusion

Purpose of the Review

In concluding this review of the research pertaining to AAT and pediatric oncology, it is useful to place the information in the context of its purpose. The review was conducted to meet two broad goals: 1) to inform the research plan and design for the remainder of the effectiveness study described above, and 2) to provide a resource to help understand the status of HAI research within this domain.

To begin, the review discussed the kinds of pediatric cancers, their epidemiology, and the basic medical treatments associated with each type. These descriptions were developed primarily to provide a basis for meeting the first objective. For instance, among the forms of cancer, leukemia and particularly ALL was determined to be the most common and the one for which advances in treatment have led to improved survival. The relative size of the population and the consistency of treatment may provide an optimal focus population for studies of behavioral health conditions and outcomes. While it is premature to conclude that the study should indeed focus on this population, the information regarding childhood cancers will be applied to making that determination.

"The opportunity to interact with therapy animals can help motivate clients to comply with the therapeutic process, to engage with their therapist, and to retain that motivation overtime."

An underlying hypothesis concerning AAT in the context of pediatric oncology is that it most likely operates to facilitate improvements in psychosocial conditions among children with cancer. It is generally believed that children with cancer are at a greater risk for psychological problems, and the literature supports this belief. The review considered the nature of the behavioral health impacts of cancer and cancer treatment on the quality of life for children. Among the many observed conditions identified by the research are a wide range of short and long term conditions including anxiety, depression, withdrawal, eating disorders, fatigue, sleeping difficulties, and poor academic performance. Other longer term outcomes are also reported including higher rates of substance abuse, obesity, attention deficits, and antisocial behavior. Concerns are also identified in the literature regarding the presence of parental stress associated with behavioral difficulties for children. While not surprising, these studies clearly point to the need to offer effective psychosocial interventions where AAT may be an appropriate adjunctive part of treatment.

Since childhood diseases typically include the child's family, there is also a potential behavioral health impact for family members as well. Similar to the literature regarding children, the literature on primary caregivers of children receiving cancer treatment indicates that psychosocial conditions include distress, anxiety, fatigue, anger, anticipatory grief, stress, weight gain, declines in physical health, and post-traumatic stress. In addition, families may be more susceptible to separation and divorce, social isolation, financial stress, underemployment, and difficulties in meeting the needs of other family members. Siblings experience grief, health problems, behavior problems, and changes in roles which in some instances may be positive. Further, parents may not be prepared to recognize or appropriately intervene in addressing behavioral or related problems of their other children due to the needs of the child with the disease. AAT is well-suited to situations involving families since interactions with animals can be planned with both individuals and groups, such as entire family units. Some of these interactions may have an important role to play in alleviating psychosocial conditions beyond the child with the disease.

It is also possible that AAT/AAA interventions may create conditions that trigger endocrinological or neurological functions which in turn may affect the course of human disease or behavior (Schuller & Al-Wadei, 2010; Uvnäs-Moberg, Handlin & Petersson, 2010). However, these associations require further work to determine if the findings have a clear relationship to improving either medical or behavioral health outcomes.

A major area of research formulation is focused on defining and clarifying more precisely what an effective therapeutic intervention involving AAT is. While the literature supports the value of professionalizing AAT interventions through training and certification, there has been less attention paid to what the intervention consists of. The literature does, however, speak to the challenges with conducting rigorous research. In fact, many of the challenges described in the literature can be applied to the design and development of the study being planned as a part of this effort.

When it comes to studies of AAT/AAA in the context of implications for cancer treatment, the literature is limited, but highly suggestive of its benefit. One primary hypothesized benefit of AAT/AAA supported by some research is the non-judgmental nature of the interactions, which may lead to improvements in social adjustments to the disease on the part of both patients and caregivers. Other effects for which there is some support for populations other than children include prolonged life spans, and improved mental health and social support. For pediatric patients, though not necessarily those with cancer, studies have shown some evidence for normalization of the hospital experience, motivating children to participate in treatment, reducing stress and improving mood during treatment, and enhanced social support. For caregivers and families of children undergoing medical treatment, this review identifies very few directly pertinent studies in the research literature. Nevertheless, a few studies have shown that parents respond very positively to the presence of animals as a part of their children's treatment and were able to identify how they thought the animals improved the treatment process. That said, there is also a case to be made that improvements in adult behavioral health functioning as a result of AAT/AAA generally are also supported by the research, which may have implications regarding the capacity of caregivers to support their children with a disease and other family members.

Finally, the review also covered the conditions, criteria, and approaches that need to be considered in involving animals in AAT/AAA interventions, particularly in hospital or clinical settings. Concerns range from zoonotic disease vectors to the humane and ethical treatment of animals engaged in the therapeutic process.

Limitations of the Review

The scope of this review was limited to the consideration of materials and domains of research activity, and internal and external expertise that were consistent with the goals of the review and our search methods. Consequently, the process may have missed some key studies, methods, or information that may have contributed to the review.

Gaps in the Research

Despite much progress in the development of HAI research which has implications for pediatric cancer treatment, there are large gaps in the literature and many limitations in the existing research. These gaps also present opportunities for new research, and improvements in the methodologies and rigor of ongoing research efforts. As anticipated, this review did identify a range of studies that have attempted to address the efficacy of AAT in a similarly broad range of settings.

Significant gaps that were identified are fundamental concerns related to the internal and external validity of AAT/AAA research generally. For AAT/AAA research to progress with populations of children in medical treatment settings, a great deal of attention is needed to define and systematically develop protocols for therapeutic interaction. Further, these protocols are likely to be more effective if they are coupled with positive outcomes for children and families for which there is existing evidence for improvement. Of course it is also informative to have results showing no effects, or even iatrogenic effects. Unfortunately, there is scant evidence for attaining any of these outcomes so far, which in turn suggests a need for a long term iterative process that would help to rule in or out the effectiveness of systematically applied protocols.

In addition to protocols, a systematic program of data collection and valid and reliable instrumentation is also needed. Particularly for work with children, behavioral health and quality of life instrumentation are major concerns since they must be attuned to the child's level of physical, emotional, and cognitive development. It is not clear that standard instrumentation currently available is consonant with the likely impacts of AAT/AAA for children or their families. When it comes to the identification and introduction of instrumentation in these studies some, and perhaps considerable, attention to instrument adaption and development is needed.

There is almost no research on the behavior of animals in clinical settings that would help clarify the appropriateness and related ethics associated with the use of animals as a form of therapeutic intervention. This is a separate concern from guidelines and regulations. Research questions extend to concerns about what types of animals or breeds of dog, what basic dispositions and behaviors are optimal, and what the short and long term impacts are on the therapy animal's health and well-being.

These gaps and others are also opportunities and suggest directions for further research. It has been recognized that threats to internal and external validity of AAT/AAA studies are difficult to address (Kazdin, 2010). Nevertheless, it should be possible to design studies that take greater advantage of our increased understanding of the potential effects of AAT/AAA interventions and that focus on those aspects that are most likely to yield results. Key issues like overcoming the difficulty of "blind" participation of staff and children participating in random control trials will continue to be a challenge.

In formulating the study design, the intent is to take advantage of these opportunities to the extent possible by synthesizing them into a design considerations framework for the research project. The review is a fundamental part of the effort to identify more precise research questions, an optimal intervention protocol, instrument battery, random assignment design, data collection program, and data analysis plan. In that regard, the information compiled here has met the basic goal of informing the design process and moves the project that much closer to being able to implement the Phase II and Phase III components of the study.

The review also documents the status of AAT/AAA research in the somewhat narrow band of work that has been done with respect to adjunctive treatment of children with medical conditions, specifically cancer. Clearly, there is considerable room for additional research, but also for a clearer conceptualization of how animals can be appropriately integrated into an overall intervention framework for improving the health status of children and their families, and elevating the role of animals in promoting healthy and humane communities.

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Appendix A: Research Framework

This appendix includes snapshots of the categorization of the literature used throughout the review. To use, please find the area of interest (such as "Behavioral Health: Anxiety" or "Effects of Human Animal Interactions") as well as the individuals within that area (such as "Child" or "General"); the numbers in the cells then correspond to items in the reference list.

Individuals	Behavioral Health (Psycho/Social)														
	General	Anxiety	Depression	Stress & PTSD	Distress	Quality of Life (QOL) (self perceived health)	Coping	Fatigue	Parental Cooperativeness (Morale/Staff Trust/Treatment Compliance, etc.)	Parental Protection (Over Protection)	Acting Out	Withdrawal/ Isolation	Family Functioning (relationships, marital satisfaction, roles)	Cognitive Functioning	Information (Treatment, Progress, etc.)
Child	53, 156	81, 38, 127, 117, 159, 163	110, 68, 81, 108, 127	18, 81, 158, 117, 159	124, 68, 108, 158	1, 13, 144, 81	18			28, 21, 83, 86, 94	28, 89	110, 89		90	
Caregiver	45	1, 13, 45, 116, 117, 159	37, 45, 116, 135	1, 29, 116, 117, 135, 159	116, 117, 156, 159	1	1, 29, 35, 70, 117	156	13, 117, 35, 85			1	29, 35, 45, 70, 85, 144		35
Siblings		119	87, 119	119		87, 160				87		71, 87			

Individuals	Effects of Human Animal Interactions											
	General (biophilia, definitions, pet ownership, etc.)	Oncology	Physiological Effects (Cortisol, Heart Rate, Blood Pressure, etc.)	Hospitals (and/or Outpatient Facilities)	Socialization	Trust/Openness	Medical Health (Physical Activity, Appetite, etc.)	Distress	Mood	Loneliness	Depression	Anxiety
General	104, 84, 56, 115, 162, 106, 103, 107, 130, 44, 105, 157, 166, 128, 120, 88, 50, 30, 55, 148, 79, 84, 161,	78, 15, 19	9, 36, 48, 50, 78, 118, 147, 16, 19	98, 103, 7, 52, 134, 138, 92, 109, 138, 16	42, 43, 44, 105, 115, 149	42, 101, 124, 141	34, 115	62, 65, 128,	92, 103, 138, 149, 19	6, 33, 42, 44	8, 14, 33, 39, 78, 100, 114, 133, 139,	36, 88, 103

Individuals	Human Animal Interaction Program Implementation							
	General	Infectious DiseaseControl and Zoonoses	Human Allergies, Phobias and Physical Harm	Animal Well Being	Therapy Animal Selection	The Role of the Animal Assisted Therapy Handle	Selection of Appropriate Participants for Animal Assisted Therapy	Service Delivery of Animal Assisted Therapy
General	4, 30, 75, 98, 129	17, 19, 20, 50, 58, 66, 69, 77, 122, 125, 164	2, 50, 129	10, 11, 32, 55, 63, 64, 74, 75, 95, 132	4, 30, 47, 75, 77, 95, 129	47, 55, 77, 98, 129	20, 30, 31, 77, 95	4, 30, 75

Individuals	Medical Health (Bio)			
	General (Pediatric Oncology)	Fatigue/ Sleep Problems	Appetite (Weight Gain/Loss)	Physical Activity/Fitness
Child	99, 111, 112, 113, 72, 22, 23, 24, 25, 26, 146, 151, 152, 153, 154, 137, 55, 59, 60, 122, 73, 141, 166, 12, 67			
Caregiver		1	135	135

Appendix B: Childhood Cancer Types, Symptoms, Treatment and Incidence

Cancer Type	Symptoms	Treatment Options	Incidence
Acute Lymphoblastic Leukemia (ALL)	The earliest symptoms of ALL are often similar to the common cold or flu. However, ALL is persistent and the child may also begin to bruise more easily (University of Minnesota, 2011a). Symptoms of ALL can include fever, fatigue, weakness, pain in joints or bones, enlarged lymph nodes, and bruising (University of Minnesota, 2011a).	Three different therapy options are available for treating ALL in children: chemotherapy, radiation, and bone marrow transplantation. Chemotherapy is the most widely-used primary treatment for children with ALL (University of Minnesota, 2011a). Often, for ALL patients, these drugs are also injected into the child's spinal fluid and/or brain fluid (University of Minnesota, 2011a). Radiation is sometimes used for children with ALL. This form of therapy is not widely used in ALL patients, unless the leukemia can be found in the central nervous system or other special cases (University of Minnesota, 2011a). The third treatment option for children with ALL is bone marrow transplantation. This treatment is done in conjunction with chemotherapy and sometimes radiation. There are four phases of treatment for ALL, including: remission induction chemotherapy (about 1 month), consolidation or central nervous system prophylaxis with chemotherapy, and sometimes radiation (up to two months), intensification therapy with chemotherapy (can occur once or twice and can last for about two months), and maintenance therapy of chemotherapy rounds (girls average two years and boys average three) (University of Minnesota, 2011a).	Age-Adjusted Incidence Rate for 0-14 years: 40.5 per million; Age-Adjusted Incidence Rate for 0-19 years: 35.0 per million

Cancer Type	Symptoms	Treatment Options	Incidence
Acute Myelogenous Leukemia (AML)	The earliest symptoms of AML are, like ALL, often similar to the flu and other common viral and bacterial illnesses. The most common symptoms include: fever, chills, bleeding or bruising easily, fatigue, and joint or bone pain (National Cancer Institute, 2011).	Four treatment options are available for treating AML: chemotherapy, radiation, bone marrow transplantation, and cord blood transportation (University of Minnesota, 2011b). Chemotherapy is the most widely-used primary treatment for children with AML (University of Minnesota, 2011b). This systemic treatment involves giving the child cancer-fighting drugs through such methods as oral administration, injected into the vein or injected into a muscle. Often, for AML patients, these drugs are also injected into the child's spinal fluid and/or brain fluid (University of Minnesota, 2011b). Radiation is sometimes used for children with AML. Radiation involves the patient being exposed to concentrated forms of radiation (such as x-rays) to kill cancerous cells (University of Minnesota, 2011b). This form of therapy is not widely used in AML patients, unless the leukemia can be found in the central nervous system or other special cases (University of Minnesota, 2011b).The third treatment option for children with AML is bone marrow transplantation. In this procedure the leukemic bone marrow is replaced with healthy marrow. This treatment is done in conjunction with chemotherapy and sometimes radiation. The chemotherapy and/or radiation are delivered in high doses until the leukemic marrow is killed (University of Minnesota, 2011b). Healthy marrow is collected from an eligible donor and then transplanted into the child through a vein (University of Minnesota, 2011b). The final treatment option for children with AML is cord blood transplantation. Very few centers exist that are capable of performing this procedure (University of Minnesota, 2011b). Using stem cells, the child grows new healthy bone marrow to replace the diseased marrow that is killed with chemotherapy and radiation (University of Minnesota, 2011b). There are three phases of treatment for AML: remission induction chemotherapy, consolidation, and intensification. The remission induction phase generally occurs for one month, the consolidation phase lasts for approximately two months, and finally the intensification phase lasts for approximately nine months (University of Minnesota, 2011b).	Age-Adjusted Incidence Rate for 0-14 years: 7.8 per million; Age-Adjusted Incidence Rate for 0-19 years: 8.3 per million

Cancer Type	Symptoms	Treatment Options	Incidence
Neuroblastoma	Generally, symptoms of neuroblastomas include dark circles around eyes and/or protruding eyes, pale skin coloring, enlarged abdomen and more rarely, watery diarrhea and uncontrollable muscle and eye movements (University of Minnesota, 2011c).	Four types of treatments are available to use either exclusively or in combination depending upon the stage and characteristics of the neuroblastoma (University of Minnesota, 2011c).Whenever possible, surgery to remove the cancer is performed (University of Minnesota, 2011c). Radiation and/or chemotherapy can be used to both decrease the size of the tumor or tumors and to kill cancer cells (University of Minnesota, 2011c). In many cases, bone marrow transplants are used to replace the diseased marrow which is killed using either radiation or chemotherapy (University of Minnesota, 2011c).	Age-Adjusted Incidence Rate for 0-14 years: 10.0 per million; Age-Adjusted Incidence Rate for 0-19 years: 7.6 per million

Cancer Type	Symptoms	Treatment Options	Incidence
Osteosarcoma	Common symptoms of osteosarcoma include pain and swelling in a child's arm or leg or other bone (Kids Health, 2011). Sometimes, a broken arm or leg may be the first visible sign of the cancer (Kids Health, 2011).	The two most common forms of treatment for osteosarcomas include chemotherapy and surgery (Kids Health, 2011). Chemotherapy is typically used for any tumor that is reasonably likely to spread to other areas of the body (Kids Health, 2011). After the initial induction chemotherapy, the cancer is then surgically removed and, if necessary, reconstruction of the bone is completed; however, if the child's tumor is unable to be removed in its entirety then an amputation may be necessary (Kids Health, 2011). Once the tumor has been removed and/or the limb has been amputated, additional chemotherapy will be administered to target any microscopic cancer cells that may be present throughout the child's bloodstream and other organs (Kids Health, 2011). The total length of treatment for osteosarcomas typically lasts about one year after the initial diagnosis (Kids Health, 2011).	Age-Adjusted Incidence Rate for 0-14 years: 4.1 per million; Age-Adjusted Incidence Rate for 0-19 years: 5.2 per million

Cancer Type	Symptoms	Treatment Options	Incidence
Rhabdomyosarcoma	There are numerous possible signs and symptoms of rhabdomyosarcoma but the most common possible sign is a lump or other type of swelling that continues to grow in size and that may cause the child pain (University of Minnesota, 2011e). Depending upon where the cancer is occurring, other symptoms may be present as well. Headaches, swelling of the eyes, trouble with urination or bowel movements, blood in the child's urine and bleeding of the nose, throat, vagina, or rectum are all potential symptoms of rhabdomyosarcoma (University of Minnesota, 2011e).	There are typically three treatment options for children with rhabdomyosarcoma: surgery, chemotherapy, and radiation (University of Minnesota, 2011e). Depending upon the location of the cancer, treatment options may vary. However, surgery is almost always used to the greatest extent possible with chemotherapy and radiation serving as alternative therapy options (University of Minnesota, 2011e).	Age-Adjusted Incidence Rate for 0-14 years: 5.4 per million; Age-Adjusted Incidence Rate for 0-19 years: 4.8 per million

Cancer Type	Symptoms	Treatment Options	Incidence
Hodgkin's Lymphoma	Children who may be experiencing Hodgkin's lymphoma may show signs of a consistently swollen lymph node for a time period of more than three weeks in the child's neck, groin, or armpit area (University of Minnesota, 2011d). These enlarged lymph nodes are typically not painful and therefore may go unnoticed by the child or caregiver (University of Minnesota, 2011d). Other potential symptoms may include: night sweats, chills, fatigue, weight loss, severe itching, and persistent fever (University of Minnesota, 2011d).	There are three standard treatment options for children diagnosed with Hodgkin's lymphoma: chemotherapy, radiation, and targeted therapy (University of Minnesota, 2011d). Targeted therapy uses specialized drugs or other materials to attack the cancerous cells while leaving the noncancerous cells unaffected (University of Minnesota, 2011d). Other treatments are currently being tested for use with children with Hodgkin's lymphoma (University of Minnesota, 2011d).	Age-Adjusted Incidence Rate for 0-14 years: 6.3 per million; Age-Adjusted Incidence Rate for 0-19 years: 12.3 per million

Cancer Type	Symptoms	Treatment Options	Incidence
Non-Hodgkin's Lymphoma	Children who are suffering from non-Hodgkin's lymphomas may exhibit a variety of non-specific symptoms, such as: fever, chills, swelling of lymph nodes, weight loss, and night sweats (University of Minnesota, 2011e).	If non-Hodgkin's lymphoma is diagnosed, three possible treatment options exist for children: chemotherapy, radiation, and bone marrow transplantation (University of Minnesota, 2011e). The most common primary treatment option for children with non-Hodgkin's lymphoma is chemotherapy (University of Minnesota, 2011e). Chemotherapy can systematically treat the child's entire body (University of Minnesota, 2011e). Radiation is not as common as chemotherapy, but can be used to help reduce the size of the tumor and to kill cancerous cells (University of Minnesota, 2011e). Bone marrow transplants are not widely used for all cases of non-Hodgkin's lymphoma at this point, but clinical trials are underway to determine if this treatment option is viable for some patients, particularly those who have recurrent cases (University of Minnesota, 2011e).	Age-Adjusted Incidence Rate for 0-14 years: 6.5 per million; Age-Adjusted Incidence Rate for 0-19 years: 8.8 per million

Cancer Type	Symptoms	Treatment Options	Incidence
Hepatoblastoma	There are a variety of symptoms that may be present if a child has been affected by a hepatoblastoma. These symptoms vary depending on the location and size of the tumor, as well as if the tumor has spread to other areas of the child's body (LPCH, 2011). Symptoms may include: pain that may or may not be associated with a swollen abdomen or mass within the abdomen, vomiting, fever, weight loss, jaundice, back pain, and anemia (LPCH, 2011).	The treatment options for childhood hepatoblastoma are dependent upon certain factors, such as the child's age and the stage of the disease. Typically, the treatment of hepatoblastoma includes removing the largest amount of the tumor possible, without impeding liver function (LPCH, 2011). Other treatment options include chemotherapy and liver transplantation (LPCH, 2011).	Age-Adjusted Incidence Rate for 0-14 years: 2.2 per million; Age-Adjusted Incidence Rate for 0-19 years: 1.6 per million; In infants under the age of 1 year old, the incidence rate is 10.5 per million

Cancer Type	Symptoms	Treatment Options	Incidence
Hepatocellular Carcinoma	The most common symptom associated with hepatocellular carcinoma is a mass in the child's abdomen (TCH, 2011). Other symptoms may include abdominal swelling, nausea, vomiting, pain around the abdomen, jaundice (a yellowing of the eyes and/or skin), and weight loss (SJCRH, 2011; TCH, 2011)	The treatment options that exist for hepatocellular carcinoma are not extensive and chemotherapy is generally not useful for this type of cancer unless the cancer has spread to other areas of the body (SJCRH, 2011). The most common and preferred treatment strategy is to remove the tumor(s) through surgery (SJCRH, 2011; TCH, 2011). If the tumor(s) cannot be removed safely, five options currently exist: treatment with sorafenib (a specialized form of chemotherapy), chemoembolization, chemical injection, radiofrequency ablation, or liver transplantation (SJCRH, 2011; TCH, 2011).	Age-Adjusted Incidence Rate for 0-14 years: .4 per million; Age-Adjusted Incidence Rate for 0-19 years: .8 per million

Cancer Type	Symptoms	Treatment Options	Incidence
Wilms Tumor	There are few symptoms associated with Wilms' tumor, but a child with this type of cancer may experience blood in their urine, unexplained fever, swelling, pain,a or a lump in their abdomen (University of Minnesota, 2011e). Often the parent and child do not notice any physical symptoms, but rather the child's physician will feel a mass during a routine examination (CCRF, 2011).	There are three common treatment options for children with Wilms' tumor that may be used singly, sequentially, or together depending upon the child's staging and histology type (CCRF, 2011). These treatment options include: surgery with partial nephrectomy or nephrectomy, chemotherapy, and radiation therapy. Partial nephrectomies are not commonly performed on children, but involve removing the cancerous tumor as well as a portion of the kidney near the tumor (CCRF, 2011). Nephrectomies are the most common form of surgical treatment for children with Wilms' tumor and involve the entire kidney being surgically removed (CCRF, 2011). Given the physiology of the kidney, the remaining kidney will perform the necessary functions of filtering blood and producing waste and, in children, will continue to grow an additional capacity of 10-20 percent to help accommodate this extra burden (CCRF, 2011).	Nearly 550 children under the age of 20 are diagnosed with some form of kidney cancer each year; of those, roughly 500 are diagnoses of Wilms tumors (Bernstein, Linet, Smith, & Olshan, 1999)

Cancer Type	Symptoms	Treatment Options	Incidence
Retinoblastomas	Given the young age of the children affected by this form of cancer, it is quite common that the child's parents are the first to notice any signs of possible retinoblastoma. The most common symptoms include: leucocoria, in which one or both of the child's pupils appears white and is sometimes identified through photographs; the crossing of one or both eyes; white spots on the child's iris or irises; red, irritated or swollen eyes; and poor vision (CCRF, 2011b).	There are six common treatment options available for children with retinoblastoma: chemotherapy, cryotherapy, thermotherapy, photocoagulation, enucleation, and radiation therapy (CCRF, 2011b; University of Minnesota, 2011f). In cases of retinoblastoma, chemotherapy generally seeks to reduce the size of the tumor(s) to enable the physician to use other forms of treatment more readily (University of Minnesota, 2011f). In cryotherapy, extreme cold is used to kill cancerous cells within the child's eye (CCRF, 2011b; University of Minnesota, 2011). In thermotherapy, a high-intensity laser is directed through the child's pupil to heat the tumor and damage the cancer cells (University of Minnesota, 2011f). Photocoagulation is similar to thermotherapy as it utilizes a laser; however the intent of photocoagulation is to kill the blood supply to the cancerous tumor (CCRF, 2011b). Enucleation is a surgical operation to remove the child's eye and the tumor affecting the eye (CCRF, 2011b; University of Minnesota, 2011f). Enucleation is common in cases where the child will most likely lose their vision and/or if the tumor is rather large in size (University of Minnesota, 2011f). Radiation therapy can also be used to stunt the growth of tumors, decrease the tumor size and kill cancerous cells, and can either be done with an implanted device or an external machine (CCRF, 2011b; University of Minnesota, 2011f).	Age-Adjusted Incidence Rate for 0-14 years: 4.2; Age-Adjusted Incidence Rate for 0-19 years: 3.1; in infants under the age of 1 year, the incidence rate is 25.3 per million

Appendix C: Potential Psychosocial Instruments to be Utilized

KEY
Embedded in Pediatric Oncology Literature
Systems of Care Literature

Measurement Tool	Adult	Child	Age Range	Conditions Appropriate	Subscales	# of Citations (Instrument Manual or Development/Psychometric Properties Article)
Beck Depression Inventory	☑	☑	13 – 80 years	In line with the depression criteria of the Diagnostic and Statistical Manual of Mental Disorders — Fourth Edition(DSM–IV)	21 items to assess the intensity of depression in clinical and normal patients. Each item is a list of four statements arranged in increasing severity about a particular symptom of depression. These new items bring the BDI–II into alignment with DSM–IV criteria.	4737
Behavior Assessment System for Children – 2nd Edition (BASC-2)		☑	Ages 2 years, 0 months through 21 years, 11 months for the TRS and PRS (Teacher and Parent); Ages 6 years, 0 months through college age for SRP (Self-Report)	Ideally suited for use in identifying behavior problems as required by IDEA, and for developing FBAs, BIPs, and IEP	Teacher and Parent Scales: Activities of Daily Living, Adaptability, Aggression, Anxiety, Attention Problems, Atypicality, Conduct Problems, Depression, Functional Communication, Hyperactivity, Leadership, Learning Problems, Social Skills, Somatization, Study Skills, Withdrawal; Child Self-Report Scales: Alcohol Abuse, Anxiety, Attention Problems, Attitute to School, Attitude to Teachers, Atypicality, Depression, Hyperactivity, Interpersonal Relations, Locus of Control, Relations with Parents, School Maladjustment, Self-Esteem, Self-Reliance, Sensation Seeking, Sense of Inadequacy, Social Stress, Somatization	709
Behavior Problem Index (BPI)		☑	4 – 17 years	Parent self-report; used for discriminating between children who have received clinical treatment and those who have not; behavior sysndroms such as antisocial, etc.	Externalizing - Aggressive Behavior; Internalizing - Sad or Withdrawn Behavior	
BERS-2: Behavioral and Emotional Rating Scale – Second Edition		☑	5 years to 18 years, 11 months	Designed for use in schools, mental health clinics, juvenile justice settings, and child welfare agencies, theBehavioral and Emotional Rating Scale, Second Edition(BERS-2) helps to measure the personal strengths and competencies of children	Interpersonal strength, involvement with family, intrapersonal strength, school functioning, affective strength, and career strength	53
Brief Smptom Inventory 18	☑		18 years and older (Parent/Caregiver)	Used to measure psychological distress and psychiatric disoder in medical (adult oncology) and community populations	Somatization, Depression, Anxiety, Global Severity Index (overall psychological distress)	390
Brisbane AAT Acceptability Test (BAATA Test)	☑		18 years and older (Clinicians/Staff)	When implementing an AAT program in a hospital or medical setting	Adverse Impact, Ward Climate, Dog Acceptibility	11
Cancer Knowledge Scale						
Caregiver Needs Survey (modified version of Home Cancer Caregiver Needs Survey)	☑			Individuals who have cared for an individual with cancer	http://www.surveymonkey.com/s.asp?u=697321065866	35
Child Behavior Check List (CBCL)		☑	1 year, 6 months to 5 years; 6 – 18 years	Using the CBCL as a diagnostic screening tool would result in a large number of cases being missed by the screen. Although the CBCL is unlikely to accurately identify children with specific diagnoses, it could be used as a triage tool to inform practitioners if an in-depth structured diagnostic interview is necessary.	Construct(s) Measured: Aggression, Hyperactivity, Bullying, Conduct problems, defiance and violence; Subscales: Aggressive Behavior, Anxiety, Depression, Attention Problems, Delinquent Rule-Breaking Behavior, Social Problems, Somatic Complaints, Thought Problems, Withdrawn, Externalizing, Internalizing	1098
Child Health Questionnaire		☑	5 – 18 years	Comparing groups of children within HMOs, doctor's offices, schools, including onsite clinics, clinical trials, and large population based research efforts (e.g., Medicaid)	Physical functioning, bodily pain or discomfort, general health, change in health, limitations in schoolwork and activities with friends, mental health, behavior, self-esteem, family cohesion, limitations in family activities, emotional or time impact on the parent.	543

Measurement Tool	Adult	Child	Age Range	Conditions Appropriate	Subscales	# of Citations (Instrument Manual or Development/Psychometric Properties Article)
Child Medical Fear Scale						
Child Vulnerability Scale		☑	4 – 8 years	Children undergoing any type of medical procedure or office visit	Perceived vulnerability	73
Children's Attributional Style Questionnaire		☑	9 – 12 years	Children that may be experiencing or at risk of experiencing depressive symptoms	Internalizing-Externalizing; Stable-Unstable; Global-Specific	150
Children's Depression Inventory		☑	7 – 17 years	A variety of situations including schools, guidance clinics, pediatric practice and child psychiatric settings	Negative Mood, Interpersonal Difficulties, Negative Self-Esteem, Ineffectiveness, Anhedonia	1189
Coping Health Inventory for Parents	☑		Adult (Parent)	The CHIP is a 45-item instrument designed to measure parents' response to management of family life when they have a child who is seriously and/or chronically ill.	Maintaining family integarion, cooperation and an optimistic definition of the situation; Maintaining social support, self-esteem and psychological stability; Understanding the medical situation through communication with other parents and consultation with medical staff	86
Ecocultural Family Interview-Cancer (EFI-C)						
Family Adaptability and Cohesion Evaluation Scale (FACES)	☑	☑	12 years and older	For use in evaluating communication styles, family interactions and flexibility in the home, office, medical setting, etc.	Balanced Cohenion and Flexibility, Disengaged and Enmeshed, Rigid and Chaotic, Family Communication and Family Satisfaction	961
McMaster Family Assessment Device	☑	☑	12 years and older	Screening instrument to evaluate family functioning	Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, Behavior Control, General Functioning	1149
Family Inventory of Life Events & Changes	☑			Assess cumulative family life changes	Cohension, Organization, Control, Conflict	2917
Family Routines Inventory						
Goldberg General Health Questionnaire	☑		Adolescence through Adulthood	Screens for non-psychotic disorders	The inability to carry out normal functions and the appearance of new and distressing psychological phenomena	4616
Hospital Anxiety and Depression Scale	☑	☑	Adolescence through Adulthood	Commonly used by doctors to determine the levels of anxiety and depression that a patient is experiencing	Anxiety, Depression	9671
Hospital Stress and Coping Interview						
Hospital Stress Scale						
Kidcope		☑	7 – 18 years	Assess cognitive and behavioral coping strategies	Distraction, Social Withdrawal, Wishful thinking, Resignation, Self-Criticism, Blaming Others, Problem-Solving, Emotional Regulation, Cognitive Restructuring, Social Support	
Life Orientation Test-Revised	☑			Used to distinguish optimism from neuroticism (trait anziety, self-master, self-esteem)	Optimism	1540
Marwit and Meuser Caregiver Inventory (MM-CGI) Childhood Cancer						
Observational Scale of Behavioral Distress (OSBD)		☑	3 – 13 years	Children undergoing any type of medical procedure	http://jpepsy.oxfordjournals.org/content/12/4/	103
Orientation to Life Questionnaire (OTLQ)	☑		Adult (Parent)	Utilized to determine the sense of coherence among individuals	Individuals at end of life or facing life-threatening illnesses	

Measurement Tool	Adult	Child	Age Range	Conditions Appropriate	Subscales	# of Citations (Instrument Manual or Development/Psychometric Properties Article)
Paffenbarger Activity Questionnaire						
Parent Perceptions of Uncertainty Scale						
Parent Protection Scale						
Parenting Stress Index (Short Form)	☑		18 – 60 years	Identify parent child problem areas in parents of children ages 1 – 12 years	Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child	195
Pearlin Mastery Scale	☑		Adult (Parent)	Measure of self-concept and references the extent to which individuals perceive themselves in control of forces that significantly impact their lives		
Pediatric Parenting Stress (PIP)						
Profile of Mood States (POMS)	☑		18 years and older (Parent/Caregiver)	It is an ideal instrument for measuring and monitoring treatment change in clinical, medical, and addiction counseling centers. It is also well-suited to clinical drug trials because its sensitivity to change allows you to accurately document the effects of drugs on mood state.	Tension-Anxiety, Anger-Hostility, Fatigue-Inertia, Depression-Dejection, Vigor-Activity, Confusion-Bewilderment	2492
Psychosocial Adjustment to Illness Scale	☑		18 years and older (Parent/Caregiver)	Interview designed to assess the quality of a patient's psychosocial adjustment to a current medical illness or the sequelae of a previous illness. With slight variations in format, the PAIS may also be usedto measure the nature of spouses', parents' or other relatives' adjustment to the index patient's illness, or their perceptions of the patients' adjustment to his/her own illness	Health Care Orientation, Vocational Environment, Domestic Environment, Sexual Relationships, Extended Family Relationships, Social Environment and Psychological Distress	485
PTSD Checklist Civilian Version	☑		18 years and older (Parent/Caregiver)	Screening instrument to assess for PTSD in the general population	PTSD	193
Quality of Life for Children with Cancer (QOLCC)						
Recent Life Changes Questionnaire						
Revised-Children's Manifest Anxiety Scale		☑	6 to 19 years	Ideal for routine screening	Physiological Anxiety, Worry, Social Anxiety, Defensiveness, Inconsistent Responding	778
Reynolds Child Depression Scale		☑	11 to 20 years	Ideal for routine screening in adolescents	Depression: Dysphoric Mood, Anhedonia/Negative Affect,Negative Self-Evaluation,Somatic Complaints	148
Rosenberg Self-Esteem Scale	☑		High scool age through adulthood	A unidimensional measure of global self-esteem in the general population	Self-esteem	474
Satisfaction with Life Scale	☑		18 years and older	Older adults, prisoners, individuals under inpatient care, abused women, psychotherapy clients, college students, etc.	Assesses the positive aspects of an individual's life experiences	4250

Measurement Tool	Adult	Child	Age Range	Conditions Appropriate	Subscales	# of Citations (Instrument Manual or Development/Psychometric Properties Article)
Schoolagers' Coping Strategies Inventory		☑	8 – 12 years	Ideal for routine screening	Measures the frequency and effectiveness of child's coping strategies	65
Severity of Illness Scale		☑		Pediatric Oncology	Severity of illness	
Social Skills Rating System		☑	3 – 18 years	Children with behavior and interpersonal skills problems	Social Skills: Cooperation, Empathy, Assertion, Self-Control, Responsibility; Problem Behaviors: Externalizing Problems, Internalizing Problems, Hyperactivity; Academic Competence Scale: academic functioning	1762
State-Trait Anxiety Inventory (adults)	☑		18 years and older (Parent/Caregiver)	The inventory's simplicity makes it ideal for evaluating individuals with lower educational backgrounds. Adapted in more than forty languages, the STAI is the leading measure of personal anxiety worldwide.	State Anxiety and Trait Anxiety	3455
State-Trait Anxiety Inventory for Children (STAI-C)		☑	9 to 12 years	While especially constructed to measure anxiety in nine- to twelve-year old children, the STAIC may also be used with younger children with average or above reading ability and with older children who are below average in ability.	State Anxiety and Trait Anxiety	379
Symptom Checklist	☑	☑	13 years and older	Community population, psychiatric population	Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, Psychoticim; Global Severity Index: psychological distress; Positive Symptom Distress Index – intensity of symptoms;	319
Teacher Report Form		☑	6 – 18 years	General population	Academic performance, adaptive functioning and behavioral emotional problems	1709
The Revised Children's Manifest Anxiety Scale		☑	6 – 19 years	General population	Psychological Anxiety, Worry, Social Anxiety, Defensiveness, inconsistent Responding Index	778
The Uncertainty Scale for Kids						
Three Factor Eating Questionnaire	☑		Older teens/young adults through adulthood	General population	Cognitive Restraint, Uncontrolled Eating	1576
Wechsler Intelligence Scale for Children-Revised (WISC-R)		☑	6 – 16 years	General population	Verbal, Performance, Full Scale	3890
Wide Range Achievement Test-Revised		☑	5 – 18 years	General population	Sentence Comprehension, Word Reading, Spelling, Math Computation	88
Youth Information Questionnaire		☑	11 – 18 years	General population	Acculturation, Coercion, Peer Relations, Symptomatology, Suicidality, Neighborhood Safety, Presenting Problems, Employment Status	
Youth Self-Report		☑	11 – 18 years	Mainly used to assess aggression in clinical and non-clinical populations	Competence, Somatic Complaints, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems, Delinquent Rule Breaking Behaviors, Aggressive Behaviors, Internalizing, Externalizing, Total Problems, DSM-Oriented Scales	2746
Zung Self-Rating Depression Scale	☑		18 years and older	Screening tool for depression	Depression	

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