EXAMINING THE PSYCHOMETRIC PROPERTIES OF THE FAMILY RESOURCE SCALE-REVISED

by

HEATHERLUN S. UPHOLD

DISSERTATION

Submitted to the Graduate School

of Wayne State University

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

2016

MAJOR: EVALUATION AND RESEARCH

Approved By:

_____

Advisor   Date

_____

_____

_____

_____

ProQuest Number: 10104994

ProQuest.

ProQuest 10104994

ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 – 1346

DEDICATION

This dissertation is dedicated to my mother, Linda, and my husband Jason. They never stopped believing that, in spite of my insistence to the contrary, I could see it through. In loving memory of my father, Mark Evans, who taught me to never leave a job unfinished.

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1 INTRODUCTION

The American Cancer Society estimated that in the year 2015, approximately 10,380 children under the age of 15 would be diagnosed with cancer and roughly 1,250 children will die (Siegel, 2015). Since 1975, there has been an annual increase of 0.6% per year in cancer diagnoses for children ages 0-19 years (Ward, 2014). Second only to accidents, cancer continues to be a leading cause of death in children in the United States (Siegel, 2015). While a diagnosis of cancer in children is uncommon, it represents a significant impact on the life of the child, their parents, and family members (Castellino, 2014; Kazak, 2012; Kurtz, 2011; Long, 2011).

Despite the increase in incidence rates, both the Centers for Disease Control and Prevention and the American Cancer Society report that the survival rate for most childhood cancers has increased to just over 80% (Barbel, 2015; Siegel, 2015; Smith, 2010; Ward, 2014). Seigel (2012), noted a 24% increase in the five-year survival rate across all pediatric cancer diagnoses in the last 30 years. Advances in treatment protocols, better management of side effects, the use of multidisciplinary teams, and clinical trials have contributed to this success (James, 2002; Patenaude, 2005). This has led to pediatric cancer being characterized as one of modern medicine's greatest success stories (Izraeli, 2004; McNeil, 2002; Smith, 2010). As the population of pediatric cancer survivors and their families has risen, so has the need to examine and understand the psychosocial aspects of childhood cancer (Grootenhuis & Last, 1997; Zebrack, 2004). Adler (2008) argued that when psychosocial needs are ignored the patient and family may suffer, which threatens the effectiveness of treatment and overall quality of life.

The significant advancements in medical protocols that resulted in higher remission and survival rates also shifted much of the child's treatment to an outpatient setting (James, 2002; Kelly, 2014; Klassen, 2010). This shift has increased the burden on parents to provide more care for their child, not only as the child's primary support, but also in helping to manage their significant medical care (Kars, 2008). This can include administering medication orally and through IV injections, sterilization of catheters, and watching for adverse reactions (Jones, 2012; Klassen, 2010). This expanded role of a caregiver is one that parents are often ill-prepared and inexperienced to handle (Sulkers, 2015).

James (2002) divided this burden into primary and secondary caregiving responsibilities. The primary responsibilities focus on caring for the child, looking after their emotional, physical, developmental, and now increased medical needs. These medical needs can include home care regimens, managing symptoms, and side effects, along with juggling health insurance requirements (Eiser, 2004; Sloper, 1996). The secondary responsibilities take the form of meeting needs that are related to caregiving but less immediate than direct care. For example, secondary responsibilities include taking care of other family members, fulfilling parental responsibilities and roles in the family, and maintaining work obligations. Adding a cancer diagnosis to these responsibilities includes helping siblings cope with the diagnosis, marital and family functioning challenges, and balancing work demands around hospital stays and clinic visits. The extent of these responsibilities can prove to be overwhelming for some parents (James, 2002; Rodriguez, 2011).

The stress resulting from increased demands and responsibilities can manifest itself in emotional and physical ways, not only at the time of diagnosis or during active treatment, but also after the weekly rigors of clinic appointments have passed. Specifically, parents have been found to experience elevated symptomatic levels of distress, anxiety, and depression at the start of active treatment and throughout treatment (Boman, 2003; Hoekstra-Weebers et al, 1998; Sloper, 1998). This is concerning for a number of reasons, including the link between parent distress and child distress (Robinson, 2007; Trask, 2003) and between parent and child anxiety symptoms (Robinson, 2007). According to Trask (2003), parents' adjustment to their child's diagnosis and treatment is significantly related to the child's overall welfare. Additionally, long-term adjustment to a cancer diagnosis was directly related to distress and family cohesion (functioning) (Alderfer, 2009b; Barakat, 1997). Parents' ability to cope with their child's cancer is critical to the health and quality of life of their child during and after treatment. In light of these challenges, it is important for researchers and healthcare professionals to understand how best to support parents of children diagnosed with cancer.

Previous research has noted several areas where families report significant needs, including financial resources (Creswell, 2013; Sloper,1996; Wakefield, 2014; Warner, 2014; Dockerty, 2003), social support (Kazak, 1997; Lindahl Norberg, 2008), family functioning (Grootenhuis, 1997; Syse, 2010), education assistance (Hobbie, 2010; Patenaude, 2005;), and marital relationship/counseling (Grootenhuis, 1997; Lavee, 2005; Robinson, 2007). Identifying, understanding, and meeting these needs are

important factors relating to the child's outcomes, and the child and family's quality of life once treatment ends.

This idea is supported by several professional organizations, including the Institute of Medicine's focus of care for the "Whole Patient" (Jacobsen; 2012; Kazak, 2012; Rosenberg, 2013), and the American Academy of Pediatrics' recommendation to include psychosocial care for both patients and their families (AAP, 2004). Jacobsen (2012) stated that the goals of psychosocial care include addressing emotional distress and improving well-being. In order to meet these goals effectively requires screening of patients and their families to determine needs (Kazak, 2012).

Thus, it is important to ensure there are accurate data collection tools in order to understand family needs, particularly with regard to psychological and sociological pathologies or strengths. The *Family Resource Scale* (FRS) was designed to measure the level of resources and needs in households with young and disabled children (Dunst, 1987, 1988). This scale offers clinicians a method to personalize intervention plans to the needs and current resources of parents of at-risk developmentally delayed preschool children (Dunst, 1986). Additionally, Dunst (1987) theorized that parents' adherence to prescribed interventions would be lessened when providers did not fully understand the resources available to families. This gap in understanding could mean that parents would potentially drop out of interventions or not participate at all if they perceived that the study requirements would be too much.

The original version of the FRS included 30-items and used a 5-point Likert scale with choices ranging from *not at all adequate* to *almost always adequate*. While several studies went on to use the FRS, very few reported any psychometric properties aside

from Cronbach's alpha (Brannan, 2006; Brody, 1998; Brown, 2000; Dinehart, 2006; Eshbaugh, 2007; Foster, 1998; Herman, 1997; Hooper, 2009; Kelley, 2000; McGrath, 1999; Maupin, 2010; Natarajan, 2014; Rhodes, 2012; Schwartz, 2011; Van Horn, 2001). The revised version resulted in a 20-item scale and 4 subscales: money, basic needs, time for self, and time for friends (Van Horn, 2001). Example questions include: food for two meals a day, good job for yourself or spouse, and time to keep in shape and looking nice.

Both the Family Resource Scale and the revised version have been used in the study of families of children with disabilities or special needs (Balakrishnan, 2011; Brannan, 2006; Candelaria, 2006; Letvak, 2002; Macias, 2007; Natarajan, 2014; Summers, 2005), families living in rural or impoverished areas (Brody and Flor, 1998; Raikes, 2005), child abuse research (Burrell, 1994), grandmothers raising grandchildren (Kelley, 2000; Kelley, 2011), intervention practices (Trivette, 2010), drug users in urban economically disadvantaged neighborhoods (Ompad, 2012), children with brain injuries (Ewing-Cobbs, 2013) and children with cerebral palsy in the country of Jordan (Almasri, 2014). To date, there are no published studies where either version is used in a pediatric cancer population. This is an important factor to address due to the unique characteristics of families and children dealing with cancer (Alderfer, 2009b). The valuable information provided by this scale coupled with the need for further work examining the psychometric properties of the scale provides the foundation for this study.

Purpose of the Study

The purpose of the study is to examine the psychometric properties of the *Family Resource Scale--revised* (Van Horn, 2001). As mentioned previously, this scale has been validated with other populations, including a multi-site longitudinal study involving former Head Start families (Van Horn, 2001), but it has not been examined within the context of a pediatric cancer environment.

Assumptions

Previous research on cancer outcomes has relied on mostly self-reported data. This study is similar in that it relies on parents' self-reported levels of resources.

Limitations:

Data collected for this study are limited to families recruited between November 2009 and January 2013 at two urban Midwestern children's hospitals. Hence, it may not be representative of family data prior to 2009 or data obtained in other regions of the country.

Method

Data for this study will be comprised of self-report questionnaires, completed by caregivers of children diagnosed with cancer.

CHAPTER 2 LITERATURE REVIEW

In the mid to late 19th Century, several textbooks were published that examined pediatric medical treatment and diseases such as jaundice and scurvy (Pearson, 2002). This marked the beginning of the documented examination of blood properties in children in the United States. As Pearson (2002) noted, this provided an important understanding of age-related normal values; and without this, detecting abnormal blood elements in children would be impossible.

The early 20th Century brought even greater understanding of blood disorders and anomalies in children (Pearson, 2002). After World War II, when resources were more easily accessible, pediatric oncology became recognized as a subspecialty and the successful usage of chemotherapy in children was documented (Cantrell, 2011; Wdlff, 1991). Although advances in treatment methodologies were being made, most children diagnosed with cancer died. Documented survival rates for the 1960s show a 5-year survival rate of 28% across all pediatric forms of cancer (Izraeli, 2004; Smith, 2004).

Cancers found in children are very different from those seen in adults. Typically, adult cancers occur because of environmental effects or lifestyle choices; whereas pediatric cancers are often the result of cellular abnormalities stemming from DNA changes, some genetic syndromes, and parental smoking (Kazak, 2015a; Wiemels, 2012). The primary adult cancer sites for males and females are prostate, breast (female), and lung (Siegel, 2015). The highest incidence rates in children are for leukemia, central nervous system tumors, and lymphomas (Barbel, 2015; Ward, 2014).

Pediatric cancers are generally not preventable and do not lend themselves to early detection (McGregor, 2007; Ward, 2014). Ward (2014) attributes this in part to cancer symptoms mimicking those of other more common childhood diseases. However, pediatric cancers do respond well to chemotherapy (Eiser, 2004; Izraeli, 2004). This is reflected in the overall difference in survival rates between adults and children, where the five-year survival rate for combined adult cancers is 66% (Howlader, 2013), and 83% for children ages 0-19 (Ward, 2014). The most common type of pediatric cancer is leukemia, a form of blood cancer that begins in the bone marrow (Chan, 2010). It has two divisions, Acute (fast growing) and Chronic (slow growing), and accounts for approximately 25-30% of cancer diagnoses in children (Belson, 2007; Hunger, 2012). The primary types of Acute Leukemia are Lymphoblastic (ALL) and Myelogenous (AML) (Rytting, 2010). Chronic leukemia is rarely seen in children and is most frequently diagnosed in adults.

Acute Lymphoblastic Leukemia (ALL) is the most common form of pediatric cancer, and accounts for approximately 75-80% of all leukemia cancer diagnoses in children under the age of 20 (Rytting, 2010; Ward, 2014). In spite of this, the survival rate for children with ALL aged 1-14 years is nearly 90% (Myers, 2014; Pui, 2012; Smith, 2010; Ward, 2014). In contrast, Acute Myelogenous Leukemia is rarer with roughly 400 new diagnoses every year and a survival rate of 50-64%, which is one of the lowest survival rates amongst pediatric cancers (Rytting, 2005; Ward, 2014).

The next most frequent type of pediatric cancer is tumors of the brain and central nervous system (CNS). Examples of CNS tumors are medulloblastoma, retinoblastoma, and meningioma (Rytting, 2010). Treatment for CNS tumors most often includes

surgery and radiation with chemotherapy being used for the most aggressive tumors (Rytting, 2010). With a survival rate of 75%, these types of tumors are on the lower end of the survival spectrum (Ward, 2014) and can also result in significant physical and mental difficulties.

Lymphoma is the third most common type of pediatric cancer with boys being twice as likely to be diagnosed as girls (Ward, 2014). Non-Hodgkin's lymphoma is more aggressive than Hodgkin's lymphoma. Comparatively, children with the non-Hodgkin's form of lymphoma will receive more aggressive chemotherapy, will be inpatient for more of their treatment, and their treatment will be longer. The survival rate for a diagnosis of non-Hodgkin's lymphoma is 85%, even with the more difficult treatment regimens. Hodgkin's lymphoma has a survival rate of 91%. Very often treatment is given in an outpatient setting and lasts approximately 6 months (Ward, 2014).

McGregor (2007) argued that a strong clinical structure, multidisciplinary support from oncologists, surgeons, and radiation therapists among others has led to the stunning success in children with cancer (Patenaude, 2005). Cure (2014) added that these advances led to over 330,000 survivors of pediatric cancer in the United States, of which 75% were diagnosed within the last 30 years. This growing population adds a new dimension to pediatric cancer research that includes the quality of life of survivors (Kazak, 2007; Patenaude, 2005). It was asserted in a 1998 report by the American Cancer Society's task force on children and cancer that the high survival rate in pediatric cancer can only be justified if the child's quality of life is protected (Haase, 1998).

Pediatric cancer treatment includes numerous medical procedures, including surgery for Mediport or PICC line insertions, lumbar punctures, bone marrow aspirations, radiation, and possible stem cell/bone marrow transplant (Bustos, 2014; Kurtz, 2011). Weeks of inpatient chemotherapy treatment, then months to years of clinic appointments for continued chemotherapy, blood transfusions, and various injections can result in physical side effects. The three most prevalent include: fatigue, nausea/vomiting, as well as pain (Erickson, 2013; Hildenbrand, 2011; Hinds, 2010; Long, 2011; Myers, 2014; Redd, 2001). While not as prevalent, alopecia (hair loss), disturbed sleep, weight gain, and weight loss were also reported side effects (Baggott, 2010; Enskar, 2007; Kurtz, 2011).

Side Effects

Cancer-related fatigue (CRF) is one of the most frequently reported side effects that children experience (Baggott, 2010; Barsevick, 2013; Hinds, 2010). Commonly this stems from chemotherapy treatments, but also may result from psychological issues like depression and anxiety (Hockenberry, 2011). Hospitalized children also reported high fatigue (Hinds, 2010). Tomlinson (2013) noted that children can experience tiredness at all stages of cancer treatment.

During treatment, pediatric patients often experience a loss in appetite, along with occurrence of nausea and vomiting (Baggott, 2010; Long, 2011; Reindl, 2005; Tyc, 1997). This can be caused by chemotherapy drugs; however, sometimes it is an anticipatory response that occurs prior to the start of treatment (Baggott, 2010; Kamen, 2014; Tyc, 1997). The pharmacological response to this side effect has been managed through the use of ondansetron or granisetron combined with dexamethasone,

commonly used anti-nausea medications that are given orally (Dupuis, 2013). In addition, there are numerous studies that have examined the use of behavioral interventions to help parents and children manage nausea. These include the use of hypnosis, distraction, and imagery (Kamen, 2014; Landier, 2010).

Pediatric cancer and its treatment involve varying amounts of pain. Hain (2004) described the pain that children experience using four categories: bone, neuropathic, colicky, and soft tissue. Bone pain is localized, and a child is easily able to communicate the location of the pain. Neuropathic pain is associated with a feeling of numbness; it very often includes a larger area on the child's body. It can give the child a sensation of pins and needles or that the area has gone to sleep. Children who experience colicky pain will experience extreme pain one moment and then be completely pain free the next. Soft tissue pain is often difficult for children to communicate as it can have attributes of any and all of the aforementioned categories.

Cancer is more than physical for children; it also brings a psychological aspect. This is evident during treatment and for the rest of the child's life (Oeffinger, 2008; Tai, 2012). During treatment, children can experience emotional distress along with symptoms of anxiety and depression; they are also susceptible to stress relating to disruptions to daily life (Compas, 2014; Rodriguez, 2011).

Pediatric cancer patients very often consider treatment procedures to be more distressing than the cancer itself (Hedstrom, 2003; Hildenbrand, 2011). Children experience anticipatory anxiety when thinking about future procedures (Goldwin, 2014). This is particularly true in adolescents. Wu (2013) stated that anxiety was the most

common type of psychological problem. Kurtz (2011) added that separation from a parent or caregiver may result in increased anxiety, particularly for younger children.

In a study of 290 parents (193 mothers and 97 fathers of 199 children), Rodriguez (2011) examined the relationship of stress sources based on parent and child report. Children (n = 106; ages 10-17) reported daily/role functioning (unable to participate in things they used to do or not being able to do them as well) as being more stressful than the uncertainty of their own life. Agreement was found among mothers, fathers, and children within the same family about which stressors affect the child the most.

Further stressors children may experience include a fear of needles (Mahoney, 2010; McGrath, 2008), fear of death, feelings of uncertainty, unexpected or lengthy hospital stays, and wanting life to return to normal (Hildenbrand, 2011). For adolescents Kurtz (2011) reported that body image, sexuality, and future fertility were also sources for concern. Interestingly, depression has not been found to be a significant psychological side effect for children during treatment (Kurtz, 2011; Miller, 2009; Noll, 1997; Vannatta, 2003).

After treatment ends, Robison (2014) noted five categories for health-related quality of life in childhood cancer survivors: growth and development, organ function, fertility and reproduction, carcinogenesis, and psychosocial. Outcomes relating to the survivor's growth and development range from skeletal maturation to their intellectual functioning. The general functioning of organs can be compromised particularly the heart. Survivors may be unable to have children, or the health of their offspring may be diminished. Another issue faced by survivors is the threat of recurrence or the

development of a new cancer. The psychosocial components included mental health, education, employment, health insurance, social interactions, chronic symptoms, and physical and body image. Fedele (2013) found that when compared with controls or healthy siblings, survivors had increased rates of posttraumatic stress disorder, more physical limitations, and lower rates of marriage.

Using data and publications from the Childhood Cancer Survivor Study, Gurney (2009) found similar results and reported that long-term childhood cancer survivors faced significant challenges in the areas of education, employment, relationships, emotional health, and physical disabilities. Pediatric cancer survivors are at a greater risk for chronic health conditions and an overall decreased lower level of health-related quality of life. These can be related to unhealthy life-style behaviors including limited physical activity, tobacco-use, poor diet, and a high body mass index among others (Badr, 2013; Oeffinger, 2008).

The diagnosis and treatment of cancer are very stressful events, not only in the life of the child, but also for the child's family and can have long long-lasting effects (Harper, 2013; Hedstrom, 2003; Jones, 2012; Kazak, 2015b; Kazak and Noll 2004; Long, 2011; Vami et al, 2000). Serving as the central support for their child, parents are at risk for psychological challenges and strain (Best, 2001; Goldbeck, 2001; Vrijmoet-Wiersma, 2008). Areas where families experience major disruption include: daily activities, family dynamics and functioning, self-identity, physical and mental health, and the parents' role (Jones, 2012; Long, 2011).

The unpredictable nature of cancer can cause significant chaos for parents. Meitar (2004; p 230) divides the time after diagnosis into three separate periods:

reorganization, stabilization and end of treatment. The child's specific diagnosis, family characteristics and dynamics determine the length of time it takes to reach each category.

During reorganization parents often struggle to meet the needs of their ill child while adjusting to a new normal. Unexpected clinic appointments, lengthy hospital stays, administering medications, as well as monitoring and managing side effects, can lead to parents having to alter their normal activities and routines (Flury, 2011; James, 2002; Vrijmoet-Wiersma, 2008). Alderfer (2009a) stated that a family's ability to adapt and adjust to the disruptions and challenges associated with their child's cancer is critical. This is also a very stressful and distressing time for parents. McCarthy (2012) studied 220 parents and noted that two weeks after diagnosis 63% of mothers and 60% of fathers exhibited significantly high rates of acute stress disorder (ASD) symptoms. Patino-Fernandez (2008) found similar results with more than 50% of mothers and 40% of fathers experiencing significant levels of acute stress disorder immediately following their child's cancer diagnosis.

Bona (2014) found that in a sample of 71 families of children with advanced (progressive, recurrent or nonresponsive) cancer, 94% of caregivers reported work disruptions. Families also reported experiencing difficulties related to financial resources (Bona, 2014; Tsimicalis, 2011). This is not only because of work disruptions but extra costs in the form of travel to clinic appointments, purchasing food during hospital stays, and supportive care medications not covered by insurance (Williams, 2013). Creswell (2013) found that parents of children with cancer depressive symptoms were strongly and independently associated with financial struggles. In a study of 206 parents of

children in active treatment for ALL, socioeconomic status was found to predict child quality of life (Gupta, 2014). Long (2011) noted that socio-demographic factors may have an effect on outcomes.

The period of stabilization offers parents a time to find equilibrium. It is well established that parents' distress decreases over time (Sulkers, 2015). This is reflected in McCarthy's (2012) finding that when measured 6-8 months post diagnosis, only one fifth of parents were noted to meet PTSD criteria. Meitar (2004; p 231) stated that during this time parents' use of various coping strategies increased their sense of control (Sulkers, 2015).

The end of active treatment brings mixed emotions for parents, including the fear of relapse and overall uncertainty about the future health of their child (Wakefield, 2011). Wakefield (2011) reviewed 15 published articles that examined parents' responses to the ending of their child's cancer treatment. Parents experienced feelings of vulnerability, because their child was no longer being seen by medical staff as frequently, thus making them more responsible to watch for warning signs of relapse or late effects of treatment. Moore (2009) noted the critical role that parents play in helping their child successfully re-enter school.

Despite the trauma and stress in the initial diagnosis and treatment of the disease, after treatment ends most families and children return to near normal psychological levels (Goldwin, 2014; Kazak; 2007; Kazak, 2012; McCarthy, 2009). Patenaude (2005) compared several behavioral studies on psychological adjustment and found most survivors did not significantly differ from population norms on anxiety, depression, or self-esteem. This may be due to adjustment over time, which gives

families the opportunity to employ coping strategies and treat their child's cancer as more of a chronic illness (Jones, 2012; Kazak, 2003).

There was, however, a small subset of approximately 25-30% of families who did not return to normal psychological levels (Barrera, 2014; Long, 2011; Marsland, 2013; Streisand, 2003). In general, parents with higher psychological stress after their child finished treatment also had lower amounts of social support and less family cohesion (Kurtz, 2011). There is a well-established link between child well-being and parent emotional health and the psychosocial health of the family as a whole (Kazak, 2011). Myers (2014) noted that family functioning predicted emotional functioning in children. They also found that family functioning was a modifiable variable when combined with family-based interventions.

There is a growing body of research that advocates for the use of screening for psychosocial risk in children with cancer and their families (Barrera, 2014; Kazak, 2012; Kazak, 2015b; Peterson, 2014). Pai (2014, pg 1) defined psychosocial risk as "a constellation of individual, family, social, and economic factors that when considered collectively increase the likelihood that an individual or their family members will experience difficulties managing the challenges of cancer and its treatment. These difficulties may manifest as psychological symptoms or as diminished academic/professional, social, or family functioning of either the patient or a family member." The purpose of identifying risk in this manner is to help providers identify families who may be less equipped to handle the stress of a chronic illness. Providers could target interventions to provide a more patient-centered approach (McCarthy, 2009). Patenaude & Kupst (2005, pg 19) summarized one of the goals of pediatric

cancer research as "who might benefit from which psychosocial support intervention when."

One way to identify needs and provide targeted interventions is to identify family resources at diagnosis and at various points during the treatment experience.

Family Resource Scale

The Family Resource Scale (FRS) was originally designed as a clinical assessment to assist practitioners in developing interventions for families of children with disabilities (Dunst, 1987, 1988). Previous methods of looking at socioeconomic status (SES) included income, caregiver education, and caregiver employment status among others. The FRS broadened the concept of resources through the caregiver's perspective of the adequacy of categories relating to basic needs, money, time for self, and time for family.

A description of the *Family Resource Scale* (FRS) and its psychometric properties was first published in 1987 (Dunst, 1987). The article stated that the 30-item scale was developed to measure the adequacy of resources in households with young children (Dunst, 1987). Respondents answered using a five-point Likert scale of adequacy where 1=not at all adequate, 2=seldom adequate, 3=sometimes adequate, 4=usually adequate and 5=almost always adequate. The higher a participant's score the better resourced they are. The individual items in the scale focused on topics like food and shelter, financial resources, time for family, extra family support, childcare, specialized child resources, and luxuries.

The rationale behind the creation of the scale was the assumption that families who were lacking in resources would be less likely to adhere to interventions that were

not geared toward meeting basic needs. Two studies were reviewed in the initial article; the first had 28 participants who were well-educated professionals accustomed to working with developmentally challenged preschoolers and their families. The hierarchical ordering of the scale was reviewed in addition to the test-retest reliability of the rank orderings. Results indicated that the scale was ordered approximately from the most basic need to the least basic need, and the mean correlation of the test-retest rankings was 0.70 (sd=0.17, P<0.0001). The time between the test-retest participant responses was two months.

The second study included in the Dunst (1987) article examined the reliability and validity of the scale when used with 45 mothers of developmentally at-risk preschool aged children. The average correlation between the 30-items resulted in a coefficient alpha of 0.92, using the total scores from the scale produced a coefficient alpha of 0.97. When administered 2-3 months apart, the test-retest reliability resulted in a stability coefficient for the total scale scores of r=0.52 (P<0.001). Partial correlation analysis of the total scores from the FRS predicted total scores from the *Health and Well-Being Index* and the *Personal Allocation Scale*. Factor analysis indicated that independent aspects of resources and needs were being measured.

The *Family Resource Scale* was used in several studies after this original paper was published, but few reported any psychometric properties beyond Cronbach's alpha (Anderson, 2007; Bennett, 2002; Brody, 1998; Brody, 1999; Brown, 2000; Dunst, 1988; Herman, 1997; Kelley, 2000; Kelley, 2011; Macias, 2007; Misra, 2001; Slaughter-Acey, 2013; Silovsky, 2011; Whittaker, 2011). Three studies examined the reliability and validity of the scale (Brannan, 2006; Rhodes, 2012; Van Horn, 2001).

In a large (n=13,505) multi-site, longitudinal invention study, Van Horn (2001) thoroughly examined the psychometric properties of the FRS. Factor analysis resulted in 20 items with four separate factors; this was further examined with confirmatory factor analysis with alphas ranging from .72 to .84. The four subscales that were identified were Basics, Money, Time for Self, and Time for Family. Van Horn (2001) asserted that the revised version of the FRS would be easier for respondents to complete, yet would still apply to a broad population.

Brannan (2006) compared two samples of parents whose children were receiving mental health services. The first group (n=984) were recruited through a military insurance program near army bases located in Georgia, North Carolina, and Tennessee. The second group (n=1,026) included children who received mental health care through a community mental health program at 20 sites across the United States. Internal consistency resulted in six factors (Basic Needs, Housing and Utilities, Benefits, Social Needs, Child Care, and Extra Resources) that were verified by confirmatory factor analysis.

Rhodes (2012) conducted an exploratory factor analysis with a sample of 162 families with children attending an outpatient clinic in a pediatric teaching hospital that yielded 4 factors with eigenvalues bigger than 1. When using varimax rotation, three factors were noted (Basic Needs, Additional Financial Needs, and Time for Self or Family).

Pub Med and Google Scholar searches for research studies that used the *Family Resource Scale-revised* with families of children diagnosed with cancer returned no results. This missing information is the basis for this research.

CHAPTER 3 METHODOLOGY

Design

This research is based on archival data collected as part of an ongoing NIH-funded R01 study "Resources, Parent-Child Communication and Adjustment to Pediatric Cancer," (Penner: PI; NCI #R01CA138981-05). Penner (2009) studied the relationship between resources, parent-child communication, and adjustment to childhood cancer and did not involve any treatment intervention. Penner's study is ongoing, and so far data has been collected from 135 families. They were recruited from Children's Hospital of Michigan in Detroit (n = 58) and St. Jude's Children's Research Hospital in Memphis, TN (n = 77). The current study will focus on the psychometric properties of the *Family Resource Scale*-Revised, based on from the data from Penner (2009).

Purpose

The purpose of this study is to determine the reliability and validity of the Family Resource Scale-revised by assessing parents whose children were receiving treatment for their pediatric cancer diagnosis in an urban setting. Specifically the aims are to determine the measurement properties of the FRS-r, including exploratory factor analysis to examine the subscales, and confirmatory methods.

Participants

The families that participated in this study were recruited from the Hematology/Oncology clinic at Children's Hospital of Michigan in Detroit, Michigan, and St. Jude Children's Research Hospital, in Memphis, Tennessee. Eligibility requirements included: children must have been diagnosed with cancer at least one month and at most 18 months prior to recruitment. Children must be aged 3 to 12 years old. Both the

children and their caregivers must be able to speak English; adults must also be able to read English. Additionally, the child must receive some type of painful medical procedure (e.g., Port access, IV starts, lumbar punctures, bone marrow aspirations, and intra-muscular injections).

Data Collection

The data were collected at three points. Demographic information such as gender, ethnicity, education, and income was collected through an interview that was conducted immediately following participant consent. The initial assessment involved a series of questionnaires that were given to caregivers on the day of consent. The scales that were used to collect baseline information focused on the caregiver's perspective of herself or himself and included responses to the following instruments: Social Skills Inventory (Riggio, 1989), Resilience (Block, 1996), Adult Trait Anxiety was measured using a subscale from the State-Trait Anxiety Inventory (Spielberger, 1977), and the Family Resource Scale-Revised (Van Horn, 2001). The second set of instruments was divided into three age groups of 3-6, 7-9 and 10-12 and examined the caregivers' perceptions of their child. Several scales were used, including the Children's Behavior Questionnaire for ages 3-6 (Rothbart, 2001), the Temperament in Middle Childhood Questionnaire for ages 7-9 (Simonds, 2004), the Early Adolescent Temperament Questionnaire for ages 10-12 (Ellis, 2001), and age appropriate versions of the Child Behavior Checklist (Achenbach, 1999).

The next data collection point included three treatment assessments that occurred on days when the child was receiving a painful procedure in the hospital clinic. State Anxiety (Spielberger, 1977) data were collected from the caregiver both before

and after each of the procedures. Ratings of parent and child distress and child cooperation were collected from the caregiver and the medical staff performing the procedure. Child self-rating of distress was also collected once the procedures had been completed using the FACES scale (Wong, 1988). These interactions were videotaped and varied in length from 15 minutes to multiple hours.

Two follow-up assessments were collected three months and six months after the last taped procedure. Parents completed several measures about themselves including the Perceived Stress Scale (Cohen, 1983), the Brief Symptom Inventory (Derogatis, 1993), and the Impact of Events Scale-Revised (Weiss, 1997). Parents also completed age appropriate versions of the Child Behavior Checklist (Achenbach, 1999) and cancer version of the PedsQL™ quality of life assessment (Varni, 2004) at each of these follow-up assessments.

Psychometric Analysis

Descriptive statistics will be computed for demographic variables and subscale variables from the Family Resource Scale-revised. Cronbach's alpha will be used to estimate the internal consistency of the scale. Item, subscale, and total subscale means, variances, intercorrelations (point-biserial), and similar statistics if item is deleted will be computed via SPSS.

To determine internal factor structure as evidence of construct validity, exploratory factor analysis will be conducted. A principle components extraction (based on Eigenvalues greater than 1 and a visual inspection of the scree plot), varimax rotation, and items displayed sorted by size with values less than |.4| suppressed will be conducted via SPSS.

Data Analysis

Demographic variables of income, employment and education will be correlated with individual variables from the FRS-r and subscale scores via SPSS. The significance of the correlations will be based on setting nominal alpha to 0.05. This is due to the small sample size of the study. Differences between parent gender and ethnicity, as well as child gender and ethnicity, cancer type and treatment site, will also be examined.

CHAPTER 4 RESULTS

Child Demographics

The sample included 144 children; 87 were male (60%) and 57 were female (40%). Average age for children was 6.35 years (range 3-12 years; sd 3.01). Child ethnicity was divided between 4 categories: 106 White (74%), 26 Black (18%), 6 Hispanic (4%), 6 Biracial or Other (4%). Most children had a diagnosis of ALL (n=117; 81%), with Wilm's tumor being the second most common diagnosis (n=7; 5%).

Parent Demographics

There were 123 mothers (85%), and 21 fathers (15%) in the sample with an average age of 33.81 years (range 20-54 years; sd 6.94). Parent ethnicity included: 107 White (75%), 25 Black (17.5%), eight Hispanic (5.6%), three American Indian/Alaska Native or Other (2%), and one parent declined to state his or her ethnicity. Most parents indicated they were currently married or had a domestic partner (n=98; 69%), with 25 (17%) stating they were divorced/separated/widowed and 20 (14%) who never married, one parent declined to answer this question.

The majority of parents reported having a high school diploma or less (n=49; 44%), 30 (20.8%) had completed less than two years of college, 22 (15.3%) completed an Associate's degree or Trade school, five (3.5%) completed 3-4 years of college but did not graduate, 27 (18.8%) received a Bachelor's degree, 11 (7.7%) parents had a Master's, Doctoral or Professional degree. Out of 140 parents, 54 (38.6%) reported having an annual household income of greater than $60,000, 43 (31%) between $20,000 - $59,000, and 43 (31%) had an income of less than $19,000.

Most parents owned a vehicle (n=132; 92%), and 53% (n=75) of parents reported that they were currently unemployed. Over two-thirds of children received their treatment at St. Jude Children's Research Hospital (n=97; 67%), with 47 (33%) children being seen at the Children's Hospital of Michigan.

Scale

Descriptive statistics for the twenty individual items of the Family Resource Scale-revised resulted in means from the highest of 4.84 (sd=.55) if the family had indoor plumbing/water to the lowest mean of 2.30 (sd=1.36) for money to travel/vacation. These scores were based on a five point Likert scale of adequacy where 1=not at all adequate, 2=seldom adequate, 3=sometimes adequate, 4=usually adequate and 5=almost always adequate. The mean total FRS-r score was 3.28 (sd=.69) and subscale means were 4.70 (sd=.55) for basic needs, 3.07 (sd=1.16) for money, 4.08 (sd=.90) for time for family, and 3.34 (sd=.91) for time for self.

The Shapiro-Wilk test was used to examine normality. Results indicated that the data were not normally distributed; all items had a $p<0.05$ (see Table 1).

Table 1

Tests of Normality (n=138)

	Shapiro-Wilk		
	Statistic	df	Sig.
Q1. BN1	.440	138	.000
Q2. BN2	.460	138	.000
Q3. BN3	.470	138	.000
Q4. BN4	.423	138	.000
Q5. BN5	.309	138	.000
Q6. M1	.739	138	.000
Q7. TS1	.894	138	.000
Q8. BN6	.591	138	.000
Q9. TS2	.909	138	.000
Q10. TF1	.855	138	.000
Q11. TF2	.743	138	.000
Q12. TS3	.904	138	.000
Q13. BN7	.391	138	.000
Q14. TS4	.768	138	.000
Q15. TS5	.904	138	.000
Q16. TS6	.911	138	.000
Q17. M2	.904	138	.000
Q18. M3	.903	138	.000
Q19. M4	.871	138	.000
Q20. M5	.844	138	.000

a. Lilliefors Significance Correction

Correlations

Demographic variables of income, and education resulted in several statistically significant positive correlations (p<.05) with individual items from the FRS-r. Household

income correlated statistically significantly with food for two meals a day (r=.232; p<.01), enough clothes for your family (r=.184; p<.05), good job for yourself or spouse (r=.496; p<.001), time to get enough sleep/rest (r=.202; p<.05), furniture for your home/apartment (r=.244; p<.01), time to be by yourself (r=.183; p<.05), money to buy things for self (r=.420; p<.001), money for family entertainment (r=.386; p<.001), money to save (r=.416; p<.001), and travel/vacation (r=.397; p<.001). Income correlated with the total scale score (r=313; p<.001), and the subscales basic needs (r=.225; p<.01), and money (r=.481; p<.001). The subscales of time for family and time for self were not statistically significantly correlated.

Child age did not significantly correlate with the total scale score or any subscales. However, parent age was statistically significantly negatively correlated with the subscale time for family (r=-0.235; p=0.005).

Six individual items statistically significantly correlated with the variable education: food for 2 meals a day (r=.212; p<.01), good job for yourself or spouse (r=.281; p<.001), money to buy things for self (r=.255; p<.01), money for family entertainment (r=.208; p<.01), money to save (r=.167; p<.05), and travel/vacation (r=.222; p<.01). The only subscale score that significantly correlated with level of parent education was money (r=.256; p<.01). The basic needs subscale was not quite statistically significant (r=.158; p<.06).

Wilcoxon-Mann-Whitney test comparing treatment site with FRS-r total scale score and subscale scores resulted in no significant relationships. No significance was found when parent gender or child gender was examined along with subscale or the FRS-r.

Only the basic needs subscale resulted in a statistically significant relationship when compared with parent (p=.01) or child (p=.001) ethnicity. Due to the small sample sizes of the other reported ethnicities only the ethnicities of black and white were used. Chi^2 results indicate a statistically significant relationship between annual household income and child ethnicity (x^2 (5) =12.667, p<0.05). Significance was also found between income and parent ethnicity (x^2 (5) =11.561, p<0.05).

The Kruskal-Wallis test indicated a statistically significant effect of the level of income on the total scale score (x^2 (5) =21.01, p=0.001) and the subscales of basic needs (x^2 (5) =18.10, p=0.003) and money (x^2 (5) =36.07, p=0.000). Further comparisons of these relationships using Wilcoxon-Mann-Whitney test resulted in statistically significant differences. Controlling for Experiment-Wise type 1 error inflation provided an alpha level of α=0.003. For the total scale score income levels greater than $100,000 differed significantly from the levels $40,000-59,000 (U=46.00, p=0.002, r=0.54), $20,000-39,000 (U=46.50, p=0.000, r=0.60), $10,000-19,000 (U=47.50, p=0.001, r=0.56), and less than $10,000 (U=41.50, p=0.000, r=0.62). The income range of $60,000-100,000 did not differ significantly.

For the basic needs subscale only the $10,000-19,000 income range differed from reported incomes greater than $100,000 (U=46.50, p=0.001). For the money subscale income above $100,000 differed from values $40,000-59,000 (U=33.00, p=0.000), $20,000-39,000 (U=26.50, p=0.000), $10,000-19,000 (U=30.00, p=0.000), and less than $10,000 (U=22.50, p=0.000). Income between $60,000 and $100,000 differed from $10,000-19,000 (U=206.00, p=0.000).

Kruskal-Wallis test was used to examine parent level of education and the FRS-R and subscales. Respondents were offered 11 levels of education options ranging from no formal schooling, some elementary school, some middle school, some high school, completion of a high school diploma/GED, and so forth up to completion of doctorate. A binned variable was created resulting in three categories: high school diploma/GED or lower level of education; 1-4 years of college or completion of Associate's degree or Trade school; and finally completion of a Bachelor's degree or above. The binned education level resulted in three significant relationships with the subscales of basic needs, money and time for family.

These relationships were further examined using Wilcoxon-Mann-Whitney. Controlling for Experiment-Wise type 1 error inflation provided an alpha level of α=0.02. Parent's level of education and adequacy of basic needs differed significantly between high school diploma/GED or less and Bachelor's degree or above (U=695.50, p=0.02; r=0.28). Examining parent education and income resulted in a positive Chi^2 relationship (x^2 (10)=36.610, p=0.000). Parent's level of education and adequacy of money differed significantly between Bachelor's degree or above and some college or Associate's degree (U=679.00, p=0.002; r=0.67) also high school diploma/GED or less (U=562.00, p=0.002; r=0.34). The time for family subscale produced a significant relationship with parent' level of education for the categories of some college or Associate's degree and high school diploma/GED or less (U=1029.00, p=0.02; r=0.23).

Further analysis was completed for all items on the *Family Resource Scale-revised*. All 20 variables were examined including mean and standard deviation (Table

2; Figure 1). Summary statistics for item means and variance were calculated (Table 3), and also scale statistics (Table 4).

Table 2

Item Statistics (n=138)

	Mean	sd
Q1; BN1	4.812	0.476
Q2; BN2	4.688	0.781
Q3; BN3	4.703	0.719
Q4;BN4	4.768	0.631
Q5; BN5	4.877	0.443
Q6; M1	4.029	1.301
Q7; TS1	3.609	1.042
Q8; BN6	4.507	0.938
Q9; TS2	3.007	1.247
Q10; TF1	3.841	1.082
Q11; TF2	4.326	0.881
Q12; TS3	3.297	1.192
Q13; BN7	4.797	0.594
Q14; TS4	4.188	1.015
Q15; TS5	3.167	1.224
Q16; TS6	2.862	1.141
Q17; M2	3.188	1.253
Q18; M3	3.290	1.263
Q19; M4	2.638	1.398
Q20; M5	2.362	1.356
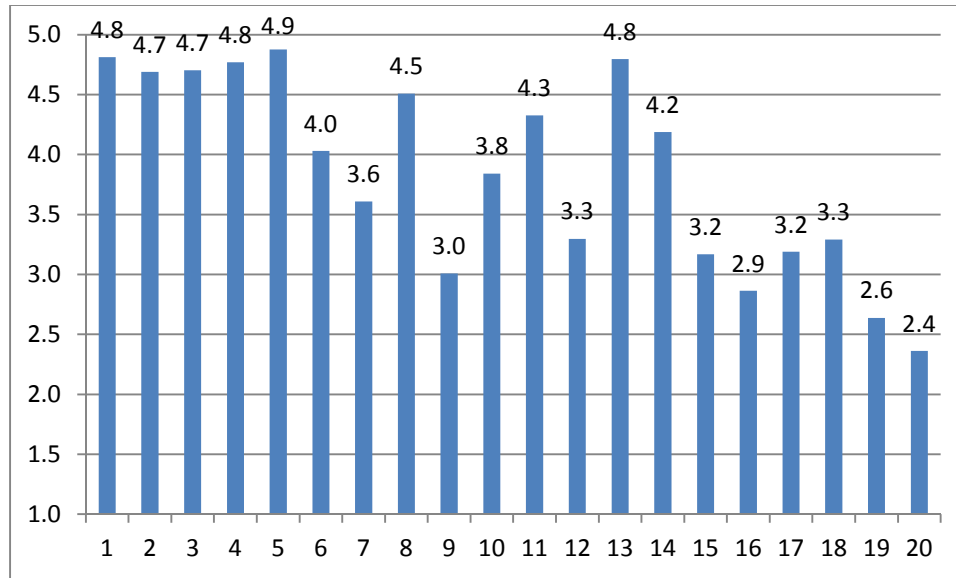
Figure 1. FRS-r Item Means

Table 3

Summary Item Statistics

	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N
Item Means	3.848	2.362	4.877	2.514	2.064	0.679	20
Item Variances	1.084	0.196	1.955	1.759	9.956	0.314	20

Table 4

Scale Statistics

Mean	Variance	Std. Deviation	N
76.9565217	181.400	13.46846523	20

Cronbach's Alpha across all items was 0.927. Cronbach's alpha by item is listed in Table 5. Removal of any of the individual items would result in the same or a lower value for Cronbach's alpha.

Table 5

Item-Total Statistics (n=138)

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Q1; BN1	72.14	175.906	0.417	0.927
Q2; BN2	72.27	170.898	0.484	0.925
Q3; BN3	72.25	172.088	0.466	0.926
Q4;BN4	72.19	173.658	0.441	0.926
Q5; BN5	72.08	176.161	0.429	0.927
Q6; M1	72.93	157.163	0.691	0.921
Q7; TS1	73.35	161.893	0.694	0.921
Q8; BN6	72.45	165.271	0.632	0.923
Q9; TS2	73.95	156.895	0.735	0.920
Q10; TF1	73.12	163.300	0.612	0.923
Q11; TF2	72.63	170.322	0.448	0.926
Q12; TS3	73.66	161.628	0.605	0.923
Q13; BN7	72.16	175.274	0.367	0.927
Q14; TS4	72.77	164.676	0.603	0.923
Q15; TS5	73.79	160.445	0.628	0.923
Q16; TS6	74.09	160.816	0.666	0.922
Q17; M2	73.77	155.844	0.767	0.919
Q18; M3	73.67	154.895	0.793	0.919
Q19; M4	74.32	153.095	0.761	0.920
Q20; M5	74.59	156.637	0.675	0.922

Further analysis was completed for each of the 4 subscales; basic needs, money, time for self and time for family. Cronbach's alpha was computed for each subscale as well as item and scale statistics of mean, variance and standard deviation. The Spearman-Brown prophecy was also calculated to determine if any change in reliability would occur when only items from the subscale were examined.

The basic needs subscale had 7 items, 142 responses and Cronbach's alpha of 0.854. The Spearman-Brown Prophecy (20) analysis resulted in 0.944. As noted in table 6, item mean equaled 4.718 with a variance of 0.013. The overall subscale mean was 33.028 with a standard deviation of 3.655 (Table 7).

Table 6

Summary Item Statistics

	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Item Means	4.718	4.507	4.859	0.352	1.078	0.013	7
Item Variances	0.511	0.250	0.876	0.626	3.510	0.046	7

Table 7

Scale Statistics

Mean	Variance	Std. Deviation	N of Items
33.028	13.361	3.655	7

Next, the 5 items from the money subscale were reviewed. There were 143 responses and Cronbach's alpha was 0.929. The Spearman-Brown Prophecy (20) analysis resulted in 0.981. The summary statistics note item means of 3.064 with a

variance of 0.432 (Table 8). The overall subscale mean was 15.322 with a standard deviation of 5.809 (Table 9).

Table 8

Summary Item Statistics

	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Item Means	3.064	2.315	4.014	1.699	1.734	0.432	5
Item Variances	1.733	1.577	1.947	0.370	1.235	0.025	5

Table 9

Scale Statistics

Mean	Variance	Std. Deviation	N of Items
15.322	33.741	5.809	5

The time for family subscale included two items, and 143 respondents. Cronbach's alpha was 0.807, and Spearman-Brown Prophecy (20) was 0.977. The item means (4.091), and other summary statistics are compiled in Table 10. The scale mean for the two items was 8.182 and a standard deviation of 1.806, as noted in Table 11.

Table 10

Summary Item Statistics

	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Item Means	4.091	3.860	4.322	0.462	1.120	0.107	2
Item Variances	0.973	0.783	1.163	0.380	1.486	0.072	2

Table 11

Scale Statistics

Mean	Variance	Std. Deviation	N of Items
8.182	3.262	1.806	2

The last subscale pertained to six parent questions relating to time for self. There were 142 responses, Cronbach's alpha was 0.881, and the Spearman-Brown Prophecy (20) was 0.961. Item means for the 6 questions was 3.350, with a variance of 0.232 (Table 12). The scale mean for the two items was 20.099 and a standard deviation of 5.474 (Table 13).

Table 12

Summary Item Statistics

	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Item Means	3.350	2.852	4.176	1.324	1.464	0.232	6
Item Variances	1.325	1.026	1.553	.528	1.514	0.047	6

Table 13

Scale Statistics

Mean	Variance	Std. Deviation	N of Items
20.099	29.962	5.474	6

The internal consistency of the scale and subscales results were assessed and alpha levels ranged from good, α=0.807, to excellent/strong α=0.929 (Table 14). The Spearman-Brown prophecy was applied to the subscale correlations to determine

reliability when the number of items is decreased. The results showed very high reliabilities ranging from 0.944 to 0.981(Table 14).

Table 14

Summary of Internal Consistency Reliabilities

	#Items	Cronbach Alpha	Spearman-Brown (20 items)
FRS Total Scale	20	0.927	n/a
Basic Needs	7	0.844	0.944
Money	5	0.929	0.981
Time for Family	2	0.807	0.977
Time for Self	6	0.881	0.961

Factor Analysis

A principle components factor analysis of all 20 variables was conducted using varimax (orthogonal) rotation and a forced four factor structure. The first iteration (Table 15) resulted in the subscale money loading on component 1 as well as the variables TS1, TS2 and TS6 which also loaded on component 2. The subscales time for family and time for self loaded together on component 2; items TS1, TS2 and TS6 dual loaded on component 1. Component 3 validated the basic needs subscale except for items BN1 and BN7 which loaded on a separate factor.

Table 15

Rotated Component Matrix[a]

	Component			
	1	2	3	4
Q17; M2	0.874			
Q20; M5	0.871			
Q19; M4	0.868			
Q18; M3	0.807			
Q6; M1	0.553			
Q16; TS6	0.527	0.496		
Q11; TF2		0.805		
Q15; TS5		0.760		
Q10; TF1		0.760		
Q12; TS3		0.740		
Q14; TS4		0.695		
Q9; TS2	0.437	0.616		
Q7; TS1	0.407	0.564		
Q2; BN2			0.865	
Q5; BN5			0.777	
Q8; BN6			0.734	
Q3; BN3			0.686	
Q4;BN4			0.685	
Q13; BN7				0.782
Q1; BN1				0.781

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 5 iterations.

A second factor analysis was conducted after items TS1, TS2, and TS6 were deleted, because they loaded on two factors. Results from this second and final iteration showed the subscales of money, basic needs 1 (items BN2-BN6), basic needs 2 (items BN1 and BN7) and the merged subscales time for family and time for self being validated (Table 16).

Table 16

Rotated Component Matrix[a]

	Component			
	1	2	3	4
Q17; M2	0.885			
Q20; M5	0.879			
Q19; M4	0.872			
Q18; M3	0.826			
Q6; M1	0.570			
Q11; TF2		0.829		
Q10; TF1		0.769		
Q15; TS5		0.752		
Q14; TS4		0.718		
Q12; TS3		0.710		
Q2; BN2			0.868	
Q5; BN5			0.775	
Q8; BN6			0.743	
Q3; BN3			0.692	
Q4;BN4			0.679	
Q1; BN1				0.807
Q13; BN7				0.771

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 5 iterations.

The resulting 4 factors explained 70.915% of the variance for the 17 items (Table 17). The first factor, consisting of 5 items relating to money, explained 22.619% of the variance. The variance explained by factors 2 and 3 had similar percentages of 19.591 and 19.519 respectively. Factor 4 which contained 2 items explained 9.185% of the variance.

Table 17

Total Variance Explained

Component	Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %
1	3.845	22.619	22.619
2	3.330	19.591	42.210
3	3.318	19.519	61.729
4	1.561	9.185	70.914

Extraction Method: Principal Component Analysis.

A comparison of correlations among factors before and after varimax rotation provides several important relationships. Components 1, and 4 note very strong positive correlations, component 2 resulted in a very strong negative relationship (Table 18).

Table 18

Component Transformation Matrix

Component	1	2	3	4
1	0.635	0.510	0.519	0.259
2	-0.055	-0.706	0.693	0.137
3	-0.770	0.471	0.379	0.203
4	0.000	-0.141	-0.327	0.934

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

The scree plot and Eigenvalues are presented in Figure 2. It is suggested, based on the descent of the curve, that 4 or possibly 5 factors explain the most of the variability.
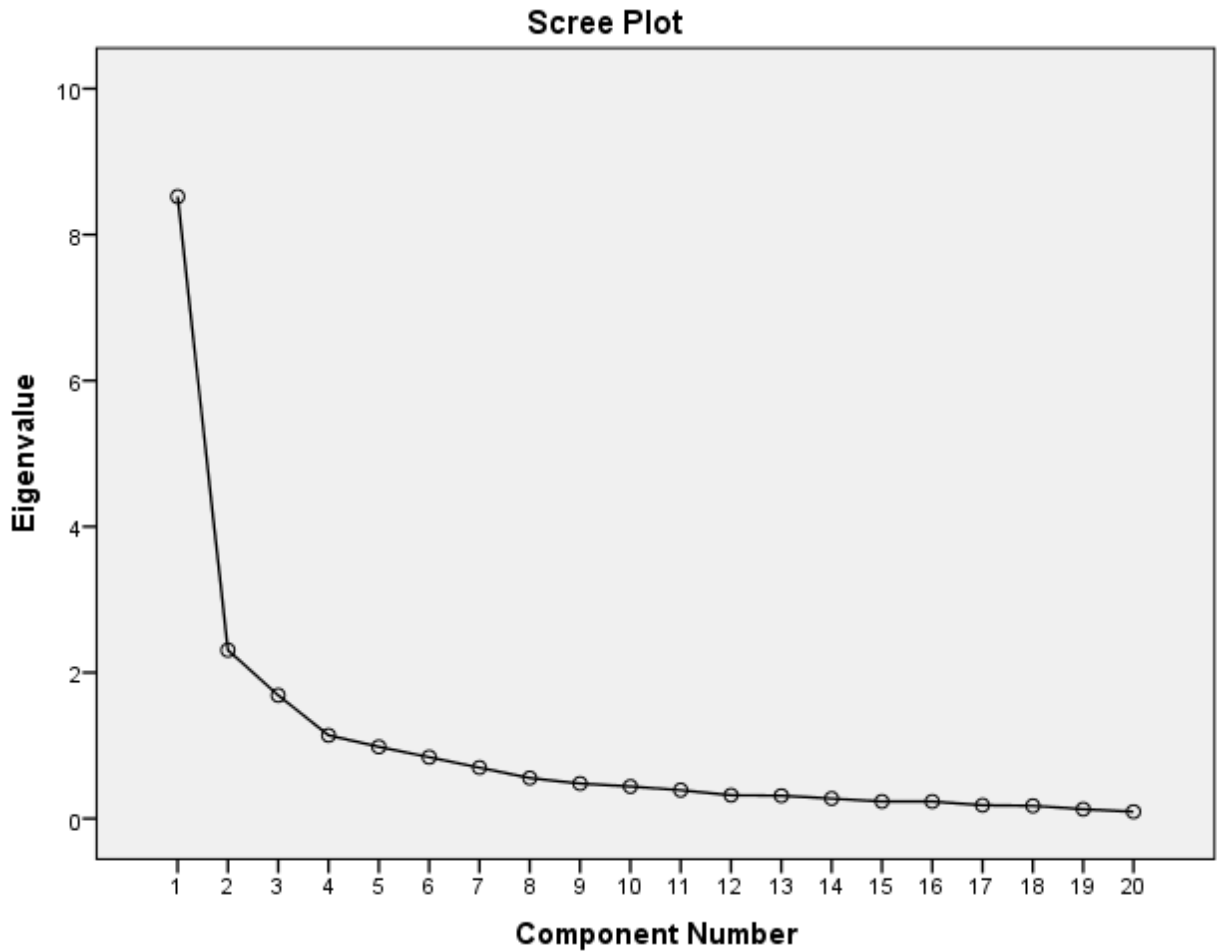
Figure 2. Eigenvalue/Scree Plot

A forced factor extraction was conducted limiting the number of components to three for the first iteration. All values less than |.4| were suppressed. This resulted in items MI, TS1, TS2, and TS6 double loading. Similar results were found when the factors were forced into 4 factors. After the four double loaded factors were removed the remaining items loaded on to 3 components and explained 64.782% of the variance (Table 19; Table 20). Correlations were strongly positive for components 1 and 3 and virtually no relationship was found for component 2 when comparing the rotated and non-rotated component values (Table 21).

Table 19

Rotated Component Matrix[a]

	Component		
	1	2	3
Q2; BN2	0.801		
Q5; BN5	0.790		
Q3; BN3	0.729		
Q8; BN6	0.716		
Q4;BN4	0.709		
Q1; BN1	0.495		
Q20; M5		0.877	
Q17; M2		0.875	
Q19; M4		0.872	
Q18; M3		0.818	
Q11; TF2			0.826
Q10; TF1			0.778
Q15; TS5			0.770
Q14; TS4			0.725
Q12; TS3			0.698
Q13; BN7			0.412

Extraction Method: Principal Component Analysis.

 Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 5 iterations.

Table 20

Total Variance Explained

Component	Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %
1	3.533	22.083	22.083
2	3.444	21.524	43.607
3	3.388	21.175	64.782

Extraction Method: Principal Component Analysis.

Table 21

Component Transformation Matrix

Component	1	2	3
1	0.571	0.607	0.553
2	0.735	-0.078	-0.673
3	0.366	-0.791	0.491

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

A second forced factor extraction was conducted limiting the number of components to five. This resulted in items BN1, BN2, BN5, TS2, and TS6 double loading in the first iteration. After the five items were deleted, the second iteration produced three items that double loaded on two components. These items were TF1, TF2, and M1. These items were removed and the third iteration was conducted using the remaining 12 items (Table 22). The five factor format explained 83.708% of the variance (Table 23). All five of the components had strong to very strong positive correlations when comparing the rotated and non-rotated component values (Table 24).

Table 22

Rotated Component Matrix[a]

	Component				
	1	2	3	4	5
Q19 M4	0.878				
Q20 M5	0.874				
Q17 M2	0.873				
Q18 M3	0.845				
Q2 BN2		0.848			
Q3 BN3		0.819			
Q8 BN6		0.803			
Q15 TS5			0.812		
Q12 TS3			0.774		
Q14 TS4			0.737		
Q13 BN7				0.933	
Q7 TS1					0.846

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 6 iterations.

Table 23

Total Variance Explained

Component		Rotation Sums of Squared Loadings	
	Total	% of Variance	Cumulative %
1	3.436	28.631	28.631
2	2.364	19.702	48.333
3	2.193	18.271	66.604
4	1.089	9.074	75.678
5	0.964	8.030	83.708

Extraction Method: Principal Component Analysis.

Table 24

Component Transformation Matrix

Component	1	2	3	4	5
1	0.691	0.450	0.465	0.190	0.260
2	-0.223	0.859	-0.442	0.033	-0.128
3	-0.647	0.137	0.602	0.440	0.081
4	0.221	-0.176	-0.278	0.831	-0.391
5	-0.080	-0.100	-0.386	0.281	0.870

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

CHAPTER 5 DISCUSSION

The purpose of this study was to determine the reliability and validity of the *Family Resource Scale-revised* by assessing parents whose children were receiving treatment for their pediatric cancer diagnoses in an urban setting. Several methods were used to examine the properties of the FRS-r, including exploratory factor analysis to examine the subscales, and confirmatory methods.

As mentioned in previous chapters, the original intent of the scale was to give researchers and interventionists a broader understanding of the socioeconomic resources available to families (Dunst, 1987; 1988). Van Horn (2001) argued that when assessing the resources available to families' variables such as time and social support should be considered in addition to income and parent education. It was also noted that a family's perception of their status may offer more information than assessing income and education levels alone. This is important information for researchers and interventionists caring for pediatric cancer patients and their families.

Demographics

Demographics for both parents and children were calculated to understand the make-up of the sample. The majority of children were male, just over 6 years old, white, and had a diagnosis of ALL. The majority of parents were female (mothers), nearly 34 years old, white, and reported being married or living with a domestic partner. Not quite half had completed high school/GED or less, just more than half were unemployed and nearly all parents owned their own vehicle. Annual household levels of income were roughly evenly distributed into thirds: $60,000 and above, $20,000-$59,000 and then $19,000 or less. Most children received treatment at St. Jude Children's Research

Hospital. This information is important when comparing the results of this research with other studies that report psychometric properties of the FRS-r.

Descriptive statistics for the scale were computed to examine the means for each individual item, the four subscales and the total scale score. This was done to check for outliers in the data and also to understand what areas parents reported as being more adequate or less adequate. The item that had the largest mean, if the family had indoor plumbing/water, was expected and is understandable in today's environment. However, not all families reported that their indoor plumbing/water was always adequate. The item that had the smallest mean, money for travel/vacation, is also expected. This could be seen as discretionary funds that could be limited while the child is in active treatment, particularly with over half of parents reporting that they were unemployed.

The normality of the data was examined using Shapiro-Wilk test, because the sample size was less than 2000. Results indicated that the individual items were not normally distributed. Thus non-parametric tests were used to examine relationships in the data.

Correlations were used to identify and examine the strength of relationships between FRS-r subscales and demographic variables. Results for this research note several expected positive correlations. The demographic variable of income correlated statistically significantly for the FRS-r subscales of basic needs and money. These results were as expected so that the higher the level of household income the more adequate the families levels of money and coverage of basic needs.

Results from the Wilcoxon-Mann-Whitney test produced significance for a relationship between the subscale of basic needs and parent ethnicity and child ethnicity. Parents who indicated that their or their child's ethnicity was white also had higher adequacy of basic needs. Similarly, Chi^2 analysis noted a significant relationship between parent and child ethnicity and the demographic variable of income.

The Kruskal-Walls test results examining income noted significance with the total scale score and the subscale scores of basic needs and money. More in depth understanding was needed for this area and the Wilcoxon-Mann-Whitney test was used to determine where the levels of income differed. Parents whose income was above $100,000 differed in the level of adequacy of total resources available to them when compared to parents whose income was below $59,000. This is an understandable result as the higher levels of income would result in more readily available resources. An examination of income and the basic needs subscale noted that parents who reported their income as $10,000-$19,000 differed from families whose income was above $100,000. This is an interesting result because no significant difference was noted for families whose income was below $10,000. This may indicate that families with a reported income under $10,000 may have a better support network or more access to social services to meet the basic needs of their families. Families with an annual income of $10,000-$19,000 may be experiencing a decrease in income due to the loss of job or a decrease in pay.

The relationships between the variable income and the total scale score and subscales of basic needs and money were further examined using ANOVA test and Tukey's HSD post hoc test. Families with income levels above $100,000 differed in the

overall adequacy of resources when compared to families whose income was below $39,000. Results for the basic needs subscale noted a difference in levels of adequacy for income between $10,000 and $19,000 and $60,000 and above. Analysis for the subscale money noted income levels of $100,000 and above differing from all other levels of income. Parents who reported an income level between $60,000 and $100,000 differed from those who reported their income as being below $39,000. These results demonstrate that families who report more income also have more adequate resources, are able to meet the basic needs of their families and have more money. Conversely, families who report lower income levels have fewer resources.

Similarly, Kruskal-Wallis test noted that parents' level of education was related to the subscales of basic needs, money and time for family. Wilcoxon-Mann-Whitney test revealed significance for parents with an education level below a high school diploma or GED and those with a Bachelor's degree or above when compared with the basic needs subscale. Higher levels of education have been related to higher levels of income and thus more adequate levels of resources. Significance was found for level of education above Bachelor's degree versus any educational level below that when considering the subscale of money. The higher the parent's level of education the more adequately they reported their levels of money. This relationship has been well documented in research particularly with respect to health disparities and parental coping (Braveman, 2010; Gage-Bouchard, 2013). The time for family subscale noted a significant difference for the two lowest levels of education. There are only two questions included in this subscale which may not provide a full understanding of the level of time for family that parents in this situation may have.

Cronbach's alpha was used to examine the internal consistency of the scale across all items. The resulting alpha was (α=0.927), signifying that items were closely related. This level is slightly above the suggested maximum alpha level of 0.90 indicating that some of the items may be redundant (Streiner, 2003; Tavakol, 2011). When the individual subscales were examined, the Spearman-Brown Prophecy was used to predict the reliability if more items were added. The Spearman-Brown Prophecy coefficients for all four of the subscales were quite high, ranging from 0.944 to 0.981. The results emphasize the high level of internal consistency and reliabilities of the scale and its subscales.

A further examination of the internal structure of the scale was conducted using Principal Components Analysis (PCA). PCA resulted in a three factor, 16-item model explaining 64.782% of the variance and a 17-item four factor model where 70.915% variance was explained. A 12-item, five factor model was also computed that explained 83.708% of the variance.

The items that loaded on the first factor of the three factor structure included 6 of the 7 items in the basic needs subscale. The seventh item, telephone or access to a phone, loaded onto the third component. The third component was a combination of 3 items from the time for self subscale and both items from the time for family subscale. The second component consisted of four items relating to money.

These results confirm that the *Family Resource Scale-revised* is a reasonably valid measure for estimating the level of resources families of children in treatment for pediatric cancer. Combining the time for family items and the items from the time for self

subscales is a minor adjustment. The four and five factor models explain more variance but some of the subscales only consist of one item.

Continued understanding of this scale with pediatric cancer populations in other geographical settings would be recommended. Also, having parents complete the scale at diagnosis, once induction is complete, when treatment ends, as well as during survivorship would be helpful information because of the possibility that levels of resources may change over time. The relationships between the adequacy of resources and parent and child levels of distress and anxiety should also be examined.

APPENDIX A

WAYNE STATE UNIVERSITY

IRB Administration Office
87 East Canfield, Second Floor
Detroit, Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
http://irb.wayne.edu

NOTICE OF EXPEDITED AMENDMENT APPROVAL

To: Louis Penner
Oncology
Karmanos Cancer Institute

From: Dr. Deborah Ellis or designee *C. Tolomdek, PhD* IMB
Chairperson, Behavioral Institutional Review Board (B3)

Date: September 21, 2015

RE: IRB #: 033309B3E

Protocol Title: 2009-016: Resources, Parent-Child Communication and Adjustment to Pediatric Cancer

Funding Source: Sponsor: NATIONAL CANCER INSTITUTE

Protocol #: 0903006891

Expiration Date: November 02, 2015

Risk Level / Category: 45 CFR 46.404 - Research not involving greater than minimal risk

The above-referenced protocol amendment, as itemized below, was reviewed by the Chairperson/designee of the Wayne State University Institutional Review Board (B3) and is APPROVED effective immediately.

- Protocol - Other changes made which include use of a new data analysis plan. A secondary data analysis of the existing data which will examine the psychometric properties of one of the instruments used in the study, the Family Resource scale-revised (FRS-r). To determine internal facture structure as evidence of construct validity, exploratory factor analysis will be conducted. Demographic variables of income, employment and education will be correlated with individual variables from the FRS-r and subscale scores via SPSS. Differences between parent gender, and ethnicity as well as child gender and ethnicity, cancer type and treatment site will also be examined.

APPENDIX B

FAMILY RESOURCE SCALE-Revised

		Never Adequate	Seldom Adequate	Sometimes Adequate	Frequently Adequate	Always Adequate
1.	Food for 2 meals a day.	1	2	3	4	5
2.	House or apartment.	1	2	3	4	5
3.	Enough clothes for your family.	1	2	3	4	5
4.	Heat for your house or apartment.	1	2	3	4	5
5.	Indoor plumbing/water.	1	2	3	4	5
6.	Good job for yourself or spouse.	1	2	3	4	5
7.	Time to get enough sleep/rest.	1	2	3	4	5
8.	Furniture for your home/apartment.	1	2	3	4	5
9.	Time to be by yourself.	1	2	3	4	5
10	Time for family to be together.	1	2	3	4	5
11	Time to be with children.	1	2	3	4	5
12	Time to be with spouse or close friend.	1	2	3	4	5
13	Telephone or access to a phone.	1	2	3	4	5
14	Someone to talk to.	1	2	3	4	5
15	Time to socialize.	1	2	3	4	5
16	Time to keep in shape and looking nice.	1	2	3	4	5
17	Money to buy things for self.	1	2	3	4	5
18	Money for family entertainment.	1	2	3	4	5
19	Money to save.	1	2	3	4	5
20	Travel/Vacation.	1	2	3	4	5

(Dunst, 1987, 1988; Van Horn, 2001)

REFERENCES

Achenbach, T. M. (1999). The Child Behavior Checklist and related instruments.

Alderfer, M. A., Mougianis, I., Barakat, L. P., Beele, D., DiTaranto, S., Hwang, W.-T., … Kazak, A. E. (2009). Family psychosocial risk, distress, and service utilization in pediatric cancer. *Cancer*, *115*(S18), 4339–4349. http://doi.org/10.1002/cncr.24587

Alderfer, M. A., Navsaria, N., & Kazak, A. E. (2009). Family functioning and posttraumatic stress disorder in adolescent survivors of childhood cancer. *Journal of Family Psychology*, *23*(5), 717–725. http://doi.org/10.1037/a0015996

Almasri, N. A., Saleh, M., & Dunst, C. J. (2014). Family resources for families of children with cerebral palsy in Jordan: Psychometric properties of the Arabic-Family Resources Scale. *Child: Care, Health and Development*, *40*(3), 354–362. http://doi.org/10.1111/cch.12087

Anderson, K. J., & Minke, K. M. (2007). Parent Involvement in Education: Toward an Understanding of Parents' Decision Making. *The Journal of Educational Research*, *100*(5), 311–323. http://doi.org/10.3200/JOER.100.5.311-323

Ater, J., & Weinberg, J. (2010) Brain Tumors: Chemotherapy and Investigational Therapy. In K. W. Chan, & R. Raney, Jr (Eds.) *Pediatric Oncology* (pp 51-64). Springer Science & Business Media.

Badr, H., Chandra, J., Paxton, R. J., Ater, J. L., Urbauer, D., Cruz, C. S., & Demark-Wahnefried, W. (2013). Health-related quality of life, lifestyle behaviors, and intervention preferences of survivors of childhood cancer. *Journal of Cancer Survivorship*, *7*(4), 523–534. http://doi.org/10.1007/s11764-013-0289-3

Baggott, C., Dodd, M., Kennedy, C., Marina, N., Matthay, K. K., Cooper, B. A., &
Miaskowski, C. (2010). Changes in Children's Reports of Symptom Occurrence
and Severity During a Course of Myelosuppressive Chemotherapy. *Journal of
Pediatric Oncology Nursing*, *27*(6), 307–315.
http://doi.org/10.1177/1043454210377619

Balakrishnan, A., Stephens, B. E., Burke, R. T., Yatchmink, Y., Alksninis, B. L., Tucker,
R., … Vohr, B. R. (2011). Impact of very low birth weight infants on the family at
3 months corrected age. *Early Human Development*, *87*(1), 31–35.
http://doi.org/10.1016/j.earlhumdev.2010.09.374

Barakat, L. P., Kazak, A. E., Meadows, A. T., Casey, R., Meeske, K., & Stuber, M. L.
(1997). Families Surviving Childhood Cancer: A Comparison of Posttraumatic
Stress Symptoms with Families of Healthy Children. *Journal of Pediatric
Psychology*, *22*(6), 843–859. http://doi.org/10.1093/jpepsy/22.6.843

Barbel, P., & Peterson, K. (2015). Recognizing subtle signs and symptoms of pediatric
cancer: *Nursing*, *45*(4), 30–37.
http://doi.org/10.1097/01.NURSE.0000461852.18315.b5

Barrera, M., Hancock, K., Rokeach, A., Cataudella, D., Atenafu, E., Johnston, D., …
Greenberg, C. (2014). External validity and reliability of the psychosocial
assessment tool (PAT) among Canadian parents of children newly diagnosed
with cancer. *Pediatric Blood & Cancer*, *61*(1), 165–170.
http://doi.org/10.1002/pbc.24774

Barsevick, A. M., Irwin, M. R., Hinds, P., Miller, A., Berger, A., Jacobsen, P., … Cella, D.

(2013). Recommendations for High-Priority Research on Cancer-Related Fatigue in Children and Adults. *Journal of the National Cancer Institute*, djt242. http://doi.org/10.1093/jnci/djt242

Belson, M., Kingsley, B., & Holmes, A. (2007). Risk Factors for Acute Leukemia in Children: A Review. *Environmental Health Perspectives*, *115*(1), 138–145. Retrieved from http://www.jstor.org/stable/4133080

Bennett, K. K., Weigel, D. J., & Martin, S. S. (2002). Children's acquisition of early literacy skills: examining family contributions. *Early Childhood Research Quarterly*, *17*(3), 295–317. http://doi.org/10.1016/S0885-2006(02)00166-7

Best, M., Streisand, R., Catania, L., & Kazak, A. E. (2001). Parental Distress During Pediatric Leukemia and Posttraumatic Stress Symptoms (PTSS) After Treatment Ends. *Journal of Pediatric Psychology*, *26*(5), 299–307. http://doi.org/10.1093/jpepsy/26.5.299

Block, J., & Kremen, A. M. (1996). IQ and ego-resiliency: Conceptual and empirical connections and separateness. *Journal of Personality and Social Psychology*, *70*(2), 349–361. http://doi.org/10.1037/0022-3514.70.2.349

Boman, K., Lindahl, A., & Björk, O. (2003). Disease-related Distress in Parents of Children with Cancer at Various Stages After the Time of Diagnosis. *Acta Oncologica*, *42*(2), 137–146. http://doi.org/10.1080/02841860310004995

Bona, K., Dussel, V., Orellana, L., Kang, T., Geyer, R., Feudtner, C., & Wolfe, J. (2014). Economic Impact of Advanced Pediatric Cancer on Families. *Journal of Pain and Symptom Management*, *47*(3), 594–603. http://doi.org/10.1016/j.jpainsymman.2013.04.003

Brannan, A. M., Manteuffel, B., Holden, E. W., & Heflinger, C. A. (2006). Use of the Family Resource Scale in Children's Mental Health: Reliability and Validity among Economically Diverse Samples. *Administration and Policy in Mental Health and Mental Health Services Research*, *33*(2), 182–197. http://doi.org/10.1007/s10488-006-0032-8

Braveman, P. A., Cubbin, C., Egerter, S., Williams, D. R., & Pamuk, E. (2010). Socioeconomic Disparities in Health in the United States: What the Patterns Tell Us. *American Journal of Public Health*, *100*(Suppl 1), S186–S196. http://doi.org/10.2105/AJPH.2009.166082

Brody, G. H., & Flor, D. L. (1998). Maternal Resources, Parenting Practices, and Child Competence in Rural, Single-Parent African American Families. *Child Development*, *69*(3), 803–816. http://doi.org/10.1111/j.1467-8624.1998.tb06244.x

Brown, R. T., Lambert, R., Devine, D., Baldwin, K., Casey, R., Doepke, K., … Eckman, J. (2000). Risk-resistance adaptation model for caregivers and their children with sickle cell syndromes. *Annals of Behavioral Medicine*, *22*(2), 158–169. http://doi.org/10.1007/BF02895780

Burrell, B., Thompson, B., & Sexton, D. (1994). Predicting child abuse potential across family types. *Child Abuse & Neglect*, *18*(12), 1039–1049. http://doi.org/10.1016/0145-2134(94)90130-9

Bustos, C., Aguinaga, A., Carmona-Torre, F., & Del Pozo, J. L. (2014). Long-term catheterization: current approaches in the diagnosis and treatment of port-related infections. *Infection and Drug Resistance*, *7*, 25–35. http://doi.org/10.2147/IDR.S37773

Candelaria, M. A., O'Connell, M. A., & Teti, D. M. (2006). Cumulative psychosocial and medical risk as predictors of early infant development and parenting stress in an African-American preterm sample. *Journal of Applied Developmental Psychology*, *27*(6), 588–597. http://doi.org/10.1016/j.appdev.2006.08.006

Cantrell, M. A., & Ruble, K. (2011). Multidisciplinary care in pediatric oncology. *Journal of Multidisciplinary Healthcare*, *4*, 171–181. http://doi.org/10.2147/JMDH.S7108

Castellino, S. M., Ullrich, N. J., Whelen, M. J., & Lange, B. J. (2014). Developing Interventions for Cancer-Related Cognitive Dysfunction in Childhood Cancer Survivors. *Journal of the National Cancer Institute*, *106*(8), dju186. http://doi.org/10.1093/jnci/dju186

Chan, K. W., & Jr, R. B. R. (2010). *Pediatric Oncology*. Springer Science & Business Media.

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of health and social behavior*, 385-396.

Compas, B. E., Desjardins, L., Vannatta, K., Young-Saleme, T., Rodriguez, E. M., Dunn, M., … Gerhardt, C. A. (2014). Children and adolescents coping with cancer: Self- and parent reports of coping and anxiety/depression. *Health Psychology*, *33*(8), 853–861. http://doi.org/10.1037/hea0000083

Corrigan, J. J., & Feig, S. A. (2004). Guidelines for pediatric cancer centers. *Pediatrics,* 113(6), 1833-1835.

Creswell, P. D., Wisk, L. E., Litzelman, K., Allchin, A., & Witt, W. P. (2013). Parental

depressive symptoms and childhood cancer: the importance of financial

difficulties. *Supportive Care in Cancer*, *22*(2), 503–511.

http://doi.org/10.1007/s00520-013-2003-4

Cure, M. B. (2014). Pediatric Cancer Survivors. *Pediatric Psycho-Oncology: A Quick*

Reference on the Psychosocial Dimensions of Cancer Symptom Management,

357.

Derogatis, L. R., & Spencer, P. M. (1993). *Brief symptom inventory: BSI*. Upper Saddle

River, NJ: Pearson.

Dinehart, L. H. B., Dice, J. L., Dobbins, D. R., Claussen, A. H., & Bono, K. E. (2006).

Proximal Variables in Families of Children Prenatally Exposed to Cocaine and

Enrolled in a Center- or Home-Based Intervention. *Journal of Early Intervention*,

29(1), 32–47. http://doi.org/10.1177/105381510602900103

Dockerty, J., Skegg, D., & Williams, S. (2003). Economic effects of childhood cancer on

families. *Journal of Paediatrics and Child Health*, *39*(4), 254–258.

http://doi.org/10.1046/j.1440-1754.2003.00138.x

Dunst, C. J., & Leet, H. E. (1987). Measuring the adequacy of resources in households

with young children. *Child: Care, Health and Development*, *13*(2), 111–125.

http://doi.org/10.1111/j.1365-2214.1987.tb00528.x

Dunst, C. J., Leet, H. E., & Trivette, C. M. (1988). Family Resources, Personal Well-

Being, and Early Intervention. *The Journal of Special Education*, *22*(1), 108–116.

http://doi.org/10.1177/002246698802200112

Dupuis, L. L., Boodhan, S., Holdsworth, M., Robinson, P. D., Hain, R., Portwine, C., …

Sung, L. (2013). Guideline for the prevention of acute nausea and vomiting due to antineoplastic medication in pediatric cancer patients. *Pediatric Blood & Cancer*, *60*(7), 1073–1082. http://doi.org/10.1002/pbc.24508

Eiser, C. (2004). *Children With Cancer: The Quality of Life*. Routledge.

Ellis, L. K., & Rothbart, M. K. (2001, April). Revision of the early adolescent temperament questionnaire. In *Poster presented at the 2001 biennial meeting of the society for research in child development,*

Enskär, K., & von Essen, L. (2007). Prevalence of aspects of distress, coping, support and care among adolescents and young adults undergoing and being off cancer treatment. *European Journal of Oncology Nursing*, *11*(5), 400–408. http://doi.org/10.1016/j.ejon.2007.01.003

Erickson, J. M., MacPherson, C. F., Ameringer, S., Baggott, C., Linder, L., & Stegenga, K. (2013). Symptoms and symptom clusters in adolescents receiving cancer treatment: A review of the literature. *International Journal of Nursing Studies*, *50*(6), 847–869. http://doi.org/10.1016/j.ijnurstu.2012.10.011

Eshbaugh, E. M., & Luze, G. J. (2007). Adolescent and adult low-income mothers: How do needs and resources differ? *Journal of Community Psychology*, *35*(8), 1037–1052. http://doi.org/10.1002/jcop.20210

Ewing-Cobbs, L., Prasad, M. R., Mendez, D., Barnes, M. A., & Swank, P. (2013). Social Interaction in Young Children with Inflicted and Accidental Traumatic Brain Injury: Relations with Family Resources and Social Outcomes. *Journal of the International Neuropsychological Society*, *19*(05), 497–507. http://doi.org/10.1017/S1355617713000210

Fedele, D. A., Hullmann, S. E., Chaffin, M., Kenner, C., Fisher, M. J., Kirk, K., … Mullins, L. L. (2013). Impact of a Parent-Based Interdisciplinary Intervention for Mothers on Adjustment in Children Newly Diagnosed With Cancer. *Journal of Pediatric Psychology*, jst010. http://doi.org/10.1093/jpepsy/jst010

Flury, M., Caflisch, U., Ullmann-Bremi, A., & Spichiger, E. (2011). Experiences of Parents With Caring for Their Child After a Cancer Diagnosis. *Journal of Pediatric Oncology Nursing*, *28*(3), 143–153. http://doi.org/10.1177/1043454210378015

Gage-Bouchard, E. A., Devine, K. A., & Heckler, C. E. (2013). The Relationship between Socio-demographic Characteristics, Family Environment, and Caregiver Coping in Families of Children with Cancer. *Journal of Clinical Psychology in Medical Settings*, *20*(4). http://doi.org/10.1007/s10880-013-9362-3

Ghasemi, A., & Zahediasl, S. (2012). Normality Tests for Statistical Analysis: A Guide for Non-Statisticians. *International Journal of Endocrinology and Metabolism*, *10*(2), 486–489. http://doi.org/10.5812/ijem.3505

Goldbeck, L. (2001). Parental coping with the diagnosis of childhood cancer: gender effects, dissimilarity within couples, and quality of life. *Psycho-Oncology*, *10*(4), 325–335. http://doi.org/10.1002/pon.530

Goldwin, M., Lee, S., Afzal, K., Drossos, T., & Karnik, N. (2014). The Relationship between Patient and Parent Posttraumatic Stress in Pediatric Oncology: A Theoretical Framework. *Children's Health Care*, *43*(1), 1–15. http://doi.org/10.1080/02739615.2014.850855

Grootenhuis, M. A., & Last, B. F. (1997). Adjustment and coping by parents of children

with cancer: a review of the literature. *Supportive Care in Cancer*, *5*(6), 466–484. http://doi.org/10.1007/s005200050116

Gupta, S., Wilejto, M., Pole, J. D., Guttmann, A., & Sung, L. (2014). Low Socioeconomic Status Is Associated with Worse Survival in Children with Cancer: A Systematic Review. *PLoS ONE*, *9*(2), e89482. http://doi.org/10.1371/journal.pone.0089482

Gurney, J. G., Krull, K. R., Kadan-Lottick, N., Nicholson, H. S., Nathan, P. C., Zebrack, B., … Ness, K. K. (2009). Social Outcomes in the Childhood Cancer Survivor Study Cohort. *Journal of Clinical Oncology*, *27*(14), 2390–2395. http://doi.org/10.1200/JCO.2008.21.1458

Haase, G. M., Mauer, A. M., & Reaman, G. H. (1998). Survivorship in childhood cancer. *Cancer*, *83*(4), 821–823. http://doi.org/10.1002/(SICI)1097-0142(19980815)83:4<821::AID-CNCR29>3.0.CO;2-T

Hain, R. (2004). Pain in Children with Cancer. In S. Kreitler and M. Weyl Ben Arush (Eds.) *Psychosocial aspects of pediatric oncology* (pp 71-80). West Sussex England: John Wiley and Sons.

Harper, F. W. K., Peterson, A. M., Uphold, H., Albrecht, T. L., Taub, J. W., Orom, H., … Penner, L. A. (2013). Longitudinal study of parent caregiving self-efficacy and parent stress reactions with pediatric cancer treatment procedures. *Psycho-Oncology*, *22*(7), 1658–1664. http://doi.org/10.1002/pon.3199

Hedström, M., Haglund, K., Skolin, I., & Essen, L. von. (2003). Distressing Events for Children and Adolescents With Cancer: Child, Parent, an Nurse Perceptions. *Journal of Pediatric Oncology Nursing*, *20*(3), 120–132. http://doi.org/10.1053/jpon.2003.76

Hematology/Oncology, S. on. (2004). Guidelines for Pediatric Cancer Centers. *Pediatrics*, *113*(6), 1833–1835.

Herman, S. E., & Marcenko, M. O. (1997). Perceptions of Services and Resources as Mediators of Depression Among Parents of Children With Developmental Disabilities. *Mental Retardation*, *35*(6), 458–467. http://doi.org/10.1352/0047-6765

Hildenbrand, A. K., Clawson, K. J., Alderfer, M. A., & Marsac, M. L. (2011). Coping With Pediatric Cancer Strategies Employed by Children and Their Parents to Manage Cancer-Related Stressors During Treatment. *Journal of Pediatric Oncology Nursing*, *28*(6), 344–354. http://doi.org/10.1177/1043454211430823

Hinds, P. S., Yang, J., Gattuso, J. S., Hockenberry, M., Jones, H., Zupanec, S., … Srivastava, D. K. (2010). Psychometric and Clinical Assessment of the 10-Item Reduced Version of the Fatigue Scale—Child Instrument. *Journal of Pain and Symptom Management*, *39*(3), 572–578. http://doi.org/10.1016/j.jpainsymman.2009.07.015

Hobbie, W. L., Ogle, S. K., Reilly, M., Ginsberg, J. P., Rourke, M., Ratcliffe, S., & Deatrick, J. A. (2010). Identifying the Educational Needs of Parents at the Completion of Their Child's Cancer Therapy. *Journal of Pediatric Oncology Nursing*, *27*(4), 190–195. http://doi.org/10.1177/1043454209360778

Hockenberry, M. J., McCarthy, K., Taylor, O., Scarberry, M., Franklin, Q., Louis, C. U., & Torres, L. (2011). Managing painful procedures in children with cancer. *Journal of pediatric hematology/oncology*, *33*(2), 119-127.

Hoekstra-Weebers, J. E. H. M., Jaspers, J. P. C., Kamps, W. A., & Klip, E. C. (1998).

Gender differences in psychological adaptation and coping in parents of pediatric cancer patients. *Psycho-Oncology*, *7*(1), 26–36. http://doi.org/10.1002/(SICI)1099-1611(199801/02)7:1<26::AID-PON315>3.0.CO;2-0

Hooper, L. M., Burnham, J. J., & Richey, R. (2009). Select Parent and Family System Correlates of Adolescent Current Weight Status: A Pilot Study. *The Family Journal*, *17*(1), 14–21. http://doi.org/10.1177/1066480708328460

Howlader, N., Noone, A. M., Krapcho, M., Garshell, J., Neyman, N., Altekruse, S. F., ... & Cronin, K. A. (2013). SEER Cancer Statistics Review, 1975-2010.[Based on the November 2012 SEER data submission, posted to the SEER web site, April 2013.]. *Bethesda, MD: National Cancer Institute*.

Hunger, S. P., Lu, X., Devidas, M., Camitta, B. M., Gaynon, P. S., Winick, N. J., … Carroll, W. L. (2012). Improved Survival for Children and Adolescents With Acute Lymphoblastic Leukemia Between 1990 and 2005: A Report From the Children's Oncology Group. *Journal of Clinical Oncology*, JCO.2011.37.8018. http://doi.org/10.1200/JCO.2011.37.8018

Izraeli, S., & Rechavi, G. (2004). Cancer in Children- an Introduction. In S. Kreitler and M. Weyl Ben Arush (Eds.) *Psychosocial aspects of pediatric oncology* (pp 1-8). West Sussex England: John Wiley and Sons.

Jacobsen, P. B., & Wagner, L. I. (2012). A New Quality Standard: The Integration of Psychosocial Care Into Routine Cancer Care. *Journal of Clinical Oncology*, *30*(11), 1154–1159. http://doi.org/10.1200/JCO.2011.39.5046

James, K., Keegan-Wells, D., Hinds, P. S., Kelly, K. P., Bond, D., Hall, B., … Speckhart,

B. (2002). The Care of My Child with Cancer: Parents' Perceptions of Caregiving

Demands. *Journal of Pediatric Oncology Nursing*, *19*(6), 218–228.

http://doi.org/10.1177/104345420201900606

Jones, B. L. (2012). The Challenge of Quality Care for Family Caregivers in Pediatric

Cancer Care. *Seminars in Oncology Nursing*, *28*(4), 213–220.

http://doi.org/10.1016/j.soncn.2012.09.003

Kamen, C., Tejani, M. A., Chandwani, K., Janelsins, M., Peoples, A. R., Roscoe, J. A.,

& Morrow, G. R. (2014). Anticipatory nausea and vomiting due to chemotherapy.

European Journal of Pharmacology, *722*, 172–179.

http://doi.org/10.1016/j.ejphar.2013.09.071

Kars, M. C., Duijnstee, M. S., Pool, A., Van Delden, J. J., & Grypdonck, M. H. (2008).

Being there: parenting the child with acute lymphoblastic leukaemia. *Journal of

Clinical Nursing*, *17*(12), 1553–1562. http://doi.org/10.1111/j.1365-

2702.2007.02235.x

Kazak, A. E., & Noll, R. B. (2004). Child Death From Pediatric Illness: Conceptualizing

Intervention From a Family/Systems and Public Health Perspective. *Professional

Psychology: Research and Practice*, *35*(3), 219–226. http://doi.org/10.1037/0735-

7028.35.3.219

Kazak, A. E., Barakat, L. P., Meeske, K., Christakis, D., Meadows, A. T., Casey, R., …

Stuber, M. L. (1997). Posttraumatic stress, family functioning, and social support

in survivors of childhood leukemia and their mothers and fathers. *Journal of

Consulting and Clinical Psychology*, *65*(1), 120–129. http://doi.org/10.1037/0022-

006X.65.1.120

Kazak, A. E., Brier, M., Alderfer, M. A., Reilly, A., Parker, S. F., Rogerwick, S., …

    Barakat, L. P. (2012). Screening for Psychosocial Risk in Pediatric Cancer.

    Pediatric Blood & Cancer, *59*(5), 822–827. http://doi.org/10.1002/pbc.24166

Kazak, A. E., Cant, M. C., Jensen, M. M., McSherry, M., Rourke, M. T., Hwang, W.-T.,

    … Lange, B. J. (2003). Identifying Psychosocial Risk Indicative of Subsequent

    Resource Use in Families of Newly Diagnosed Pediatric Oncology Patients.

    Journal of Clinical Oncology, *21*(17), 3220–3225.

    http://doi.org/10.1200/JCO.2003.12.156

Kazak, A. E., & Noll, R. B. (2015a). The integration of psychology in pediatric oncology

    research and practice: Collaboration to improve care and outcomes for children

    and families. *American Psychologist*, *70*(2), 146–158.

    http://doi.org/10.1037/a0035695

Kazak, A. E., Rourke, M. T., Alderfer, M. A., Pai, A., Reilly, A. F., & Meadows, A. T.

    (2007). Evidence-based Assessment, Intervention and Psychosocial Care in

    Pediatric Oncology: A Blueprint for Comprehensive Services Across Treatment.

    Journal of Pediatric Psychology, *32*(9), 1099–1110.

    http://doi.org/10.1093/jpepsy/jsm031

Kazak, A. E., Barakat, L. P., Ditaranto, S., Biros, D., Hwang, W. T., Beele, D., ... &

    Reilly, A. (2011). Screening for psychosocial risk at pediatric cancer diagnosis:

    the psychosocial assessment tool. *Journal of Pediatric Hematology/oncology*,

    33(4), 289-294.

Kazak, A. E., Schneider, S., Didonato, S., & Pai, A. L. H. (2015b). Family psychosocial

    risk screening guided by the Pediatric Psychosocial Preventative Health Model

(PPPHM) using the Psychosocial Assessment Tool (PAT). *Acta Oncologica*, 1–7. http://doi.org/10.3109/0284186X.2014.995774

Kelley, S. J., Whitley, D. M., & Campos, P. E. (2011). Behavior problems in children raised by grandmothers: The role of caregiver distress, family resources, and the home environment. *Children and Youth Services Review*, *33*(11), 2138–2145. http://doi.org/10.1016/j.childyouth.2011.06.021

Kelley, S. J., Whitley, D., Sipe, T. A., & Crofts Yorker, B. (2000). Psychological distress in grandmother kinship care providers: the role of resources, social support, and physical health. *Child Abuse & Neglect*, *24*(3), 311–321. http://doi.org/10.1016/S0145-2134(99)00146-5

Kelly, K. P., Wells, D. K., Chen, L., Reeves, E., Mass, E., Camitta, B., & Hinds, P. S. (2014). Caregiving Demands and Well-being in Parents of Children Treated With Outpatient or Inpatient Methotrexate Infusion: A Report From the Children's Oncology Group. *Journal of Pediatric Hematology/Oncology*, *36*(6), 495–500. http://doi.org/10.1097/MPH.0b013e31828b0947

Klassen, A., Klaassen, R. J., Dix, D., Pritchard, S., Yanofsky, R., & Sung, L. (2010). Caregiving Demands in Parents of Children With Cancer: Psychometric Validation of the Care of My Child With Cancer Questionnaire. *Journal of Pediatric Nursing*, *25*(4), 258–263. http://doi.org/10.1016/j.pedn.2009.01.002

Kurtz, B. P., & Abrams, A. N. (2011). Psychiatric Aspects of Pediatric Cancer. *Pediatric Clinics of North America*, *58*(4), 1003–1023. http://doi.org/10.1016/j.pcl.2011.06.009

Landier, W., & Tse, A. M. (2010). Use of Complementary and Alternative Medical

Interventions for the Management of Procedure-Related Pain, Anxiety, and Distress in Pediatric Oncology: An Integrative Review. *Journal of Pediatric Nursing*, *25*(6), 566–579. http://doi.org/10.1016/j.pedn.2010.01.009

Lavee, Y. (2005). Correlates of Change in Marital Relationships Under Stress: The Case of Childhood Cancer. *Families in Society: The Journal of Contemporary Social Services*, *86*(1), 112–120. http://doi.org/10.1606/1044-3894.1883

Letvak, S. (2002). The importance of social support for rural mental health. *Issues in Mental Health Nursing*, *23*(3), 249–261. http://doi.org/10.1080/016128402753542992

Lindahl Norberg, A., & Boman, K. K. (2008). Parent distress in childhood cancer: A comparative evaluation of posttraumatic stress symptoms, depression and anxiety. *Acta Oncologica*, *47*(2), 267–274. http://doi.org/10.1080/02841860701558773

Long, K. A., & Marsland, A. L. (2011). Family Adjustment to Childhood Cancer: A Systematic Review. *Clinical Child and Family Psychology Review*, *14*(1), 57–88. http://doi.org/10.1007/s10567-010-0082-z

Macias, M. M., Saylor, C. F., & Spratt, E. G. (2007). Assessing parenting stress in multiple samples of children with special needs (CSN). *Families, Systems & Health*, *25*(4), 435+. Retrieved from http://go.galegroup.com/ps/i.do?id=GALE%7CA173463356&v=2.1&u=lom_wayn esu&it=r&p=ITOF&sw=w&asid=a6abb4348a57e57b025dde4df58987a8

Mahoney, L., Ayers, S., & Seddon, P. (2010). The Association Between Parent's and Healthcare Professional's Behavior and Children's Coping and Distress During

Venepuncture. *Journal of Pediatric Psychology*, jsq009.

http://doi.org/10.1093/jpepsy/jsq009

Marsland, A. L., Long, K. A., Howe, C., Thompson, A. L., Tersak, J., & Ewing, L. J. (2013). A Pilot Trial of a Stress Management Intervention for Primary Caregivers of Children Newly Diagnosed With Cancer: Preliminary Evidence That Perceived Social Support Moderates the Psychosocial Benefit of Intervention. *Journal of Pediatric Psychology*, *38*(4), 449–461. Retrieved from

http://jpepsy.oxfordjournals.org.proxy.lib.wayne.edu/content/38/4/449

Maupin, A. N., Brophy-Herb, H. E., Schiffman, R. F., & Bocknek, E. L. (2010). Low-Income Parental Profiles of Coping, Resource Adequacy, and Public Assistance Receipt: Links to Parenting. *Family Relations*, *59*(2), 180–194.

http://doi.org/10.1111/j.1741-3729.2010.00594.x

McCarthy, M. C., Ashley, D. M., Lee, K. J., & Anderson, V. A. (2012). Predictors of Acute and Posttraumatic Stress Symptoms in Parents Following Their Child's Cancer Diagnosis. *Journal of Traumatic Stress*, *25*(5), 558–566.

http://doi.org/10.1002/jts.21745

McCarthy, M. C., Clarke, N. E., Vance, A., Ashley, D. M., Heath, J. A., & Anderson, V. A. (2009). Measuring psychosocial risk in families caring for a child with cancer: The psychosocial assessment tool (PAT2.0). *Pediatric Blood & Cancer*, *53*(1), 78–83. http://doi.org/10.1002/pbc.22007

McGrath, M. M., & Sullivan, M. C. (1999). Medical and ecological factors in estimating motor outcomes of preschool children. *Research in Nursing & Health*, *22*(2), 155–167.

McGrath, P., & Phillips, E. (2008). "It Is Very Hard": Treatment for Childhood Lymphoma from the Parents' Perspective. *Issues in Comprehensive Pediatric Nursing*, *31*(1), 37–54. http://doi.org/10.1080/01460860701877209

McGregor, L. M., Metzger, M. L., Sanders, R., & Santana, V. M. (2007). Pediatric cancers in the new millennium: dramatic progress, new challenges. *Oncology*, *21*(7), 809-820.

McNeil, D. E., Coté, T. R., Clegg, L., & Mauer, A. (2002). SEER update of incidence and trends in pediatric malignancies: Acute lymphoblastic leukemia. *Medical and Pediatric Oncology*, *39*(6), 554–557. http://doi.org/10.1002/mpo.10161

Meitar, D. (2004). The Family of the Child with Cancer. In S. Kreitler & M. W. B. Arush (Eds.), *Psychosocial Aspects of Pediatric Oncology* (pp. 229–246). John Wiley & Sons, Ltd. Retrieved from http://onlinelibrary.wiley.com/doi/10.1002/0470020776.ch9/summary

Miller, K. S., Vannatta, K., Compas, B. E., Vasey, M., McGoron, K. D., Salley, C. G., & Gerhardt, C. A. (2009). The Role of Coping and Temperament in the Adjustment of Children with Cancer. *Journal of Pediatric Psychology*, *34*(10), 1135–1143. http://doi.org/10.1093/jpepsy/jsp037

Misra, D. P., O'Campo, P., & Strobino, D. (2001). Testing a sociomedical model for preterm delivery. *Paediatric and Perinatal Epidemiology*, *15*(2), 110–122. http://doi.org/10.1046/j.1365-3016.2001.00333.x

Moore, J. B., Kaffenberger, C., Goldberg, P., Oh, K. M., & Hudspeth, R. (2009). School Reentry for Children With Cancer: Perceptions of Nurses, School Personnel, and Parents. *Journal of Pediatric Oncology Nursing*.

http://doi.org/10.1177/1043454208328765

Myers, R. M., Balsamo, L., Lu, X., Devidas, M., Hunger, S. P., Carroll, W. L., … Kadan-Lottick, N. S. (2014). A prospective study of anxiety, depression, and behavioral changes in the first year after a diagnosis of childhood acute lymphoblastic leukemia. *Cancer*, *120*(9), 1417–1425. http://doi.org/10.1002/cncr.28578

Natarajan, G., Shankaran, S., Pappas, A., Bann, C., Tyson, J. E., McDonald, S., … the Extended Hypothermia Subcommittee of the Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network. (2014). Functional status at 18 months of age as a predictor of childhood disability after neonatal hypoxic-ischemic encephalopathy. *Developmental Medicine & Child Neurology*, *56*(11), 1052–1058. http://doi.org/10.1111/dmcn.12512

Noll, R. B., MachLean, W. E., Whitt, J. K., Kaleita, T. a, Stehbens, J. A., Waskerwitz, M. J., … Hammond, G. D. (1997). Behavioral Adjustment and Social Functioning of Long-Term, Survivors of Childhood Leukemia: Parent and Teacher Reports. *Journal of Pediatric Psychology*, *22*(6), 827–841. Retrieved from http://jpepsy.oxfordjournals.org.proxy.lib.wayne.edu/content/22/6/827

Oeffinger, K. C., Nathan, P. C., & Kremer, L. C. M. (2008). Challenges After Curative Treatment for Childhood Cancer and Long-Term Follow up of Survivors. *Pediatric Clinics of North America*, *55*(1), 251–273. http://doi.org/10.1016/j.pcl.2007.10.009

Ompad, D. C., Nandi, V., Cerdá, M., Crawford, N., Galea, S., & Vlahov, D. (2012). Beyond income: Material resources among drug users in economically-disadvantaged New York City neighborhoods. *Drug and alcohol dependence,*

120(1), 127-134.

Pai, A. L. H., Patiño-Fernández, A. M., McSherry, M., Beele, D., Alderfer, M. A., Reilly, A. T., … Kazak, A. E. (2008). The Psychosocial Assessment Tool (PAT2.0): Psychometric Properties of a Screener for Psychosocial Distress in Families of Children Newly Diagnosed with Cancer. *Journal of Pediatric Psychology*, *33*(1), 50. http://doi.org/10.1093/jpepsy/jsm053

Pai, A. L. H., Tackett, A., Hente, E. A., Ernst, M. M., Denson, L. A., & Hommel, K. A. (2014). Assessing Psychosocial Risk in Pediatric Inflammatory Bowel Disease: Validation of the Psychosocial Assessment Tool 2.0_General. *Journal of Pediatric Gastroenterology and Nutrition*, *58*(1). http://doi.org/10.1097/MPG.0b013e3182a938b7

Patenaude, A. F., & Kupst, M. J. (2005). Psychosocial Functioning in Pediatric Cancer. *Journal of Pediatric Psychology*, *30*(1), 9–27. http://doi.org/10.1093/jpepsy/jsi012

Patiño-Fernández, A. M., Pai, A. L. H., Alderfer, M., Hwang, W.-T., Reilly, A., & Kazak, A. E. (2008). Acute stress in parents of children newly diagnosed with cancer. *Pediatric Blood & Cancer*, *50*(2), 289–292. Retrieved from http://onlinelibrary.wiley.com/doi/10.1002/pbc.21262/abstract

Pearson, H. A. (2002). History of Pediatric Hematology Oncology. *Pediatric Research*, *52*(6), 979–992. http://doi.org/10.1203/00006450-200212000-00026

Peterson, A. M., Harper, F. W. K., Albrecht, T. L., Taub, J. W., Orom, H., Phipps, S., & Penner, L. A. (2014). Parent Caregiver Self-Efficacy and Child Reactions to Pediatric Cancer Treatment Procedures. *Journal of Pediatric Oncology Nursing*, *31*(1), 18–27. http://doi.org/10.1177/1043454213514792

Pui, C.-H., Mullighan, C. G., Evans, W. E., & Relling, M. V. (2012). Pediatric acute lymphoblastic leukemia: where are we going and how do we get there? *Blood*, *120*(6), 1165–1174. http://doi.org/10.1182/blood-2012-05-378943

Raikes, H. A., & Thompson, R. A. (2005). Efficacy and social support as predictors of parenting stress among families in poverty. *Infant Mental Health Journal*, *26*(3), 177–190. http://doi.org/10.1002/imhj.20044

Redd, W. H., Montgomery, G. H., & DuHamel, K. N. (2001). Behavioral Intervention for Cancer Treatment Side Effects. *Journal of the National Cancer Institute*, *93*(11), 810–823. http://doi.org/10.1093/jnci/93.11.810

Reindl, T. K., Geilen, W., Hartmann, R., Wiebelitz, K. R., Kan, G., Wilhelm, I., … Driever, P. H. (2005). Acupuncture against chemotherapy-induced nausea and vomiting in pediatric oncology. *Supportive Care in Cancer*, *14*(2), 172–176. http://doi.org/10.1007/s00520-005-0846-z

Rhodes, A., Sciberras, E., Oberklaid, F., South, M., Davies, S., & Efron, D. (2012). Unmet Developmental, Behavioral, and Psychosocial Needs in Children Attending Pediatric Outpatient Clinics: *Journal of Developmental & Behavioral Pediatrics*, *33*(6), 469–478. http://doi.org/10.1097/DBP.0b013e31825a70e6

Riggio, R. E., & Carney, D. (1989). Manual for the social skills inventory. *Research ed. Consulting Psychologists. Pr., Palo Alto, CA.*

Robinson, K. E., Gerhardt, C. A., Vannatta, K., & Noll, R. B. (2007). Parent and Family Factors Associated with Child Adjustment to Pediatric Cancer. *Journal of Pediatric Psychology*, *32*(4), 400–410. http://doi.org/10.1093/jpepsy/jsl038

Robison, L. L., & Hudson, M. M. (2014). Survivors of childhood and adolescent cancer: life-long risks and responsibilities. *Nature Reviews Cancer*, *14*(1), 61–70. http://doi.org/10.1038/nrc3634

Rodriguez, E. M., Dunn, M. J., Zuckerman, T., Vannatta, K., Gerhardt, C. A., & Compas, B. E. (2011). Cancer-Related Sources of Stress for Children With Cancer and Their Parents. *Journal of Pediatric Psychology*, jsr054. http://doi.org/10.1093/jpepsy/jsr054

Rosenberg, A. R., Baker, K. S., Syrjala, K. L., Back, A. L., & Wolfe, J. (2013). Promoting Resilience among Parents and Caregivers of Children with Cancer. *Journal of Palliative Medicine*, *16*(6), 645–652. http://doi.org/10.1089/jpm.2012.0494

Rothbart, M. K., Ahadi, S. A., Hershey, K. L., & Fisher, P. (2001). Investigations of Temperament at Three to Seven Years: The Children's Behavior Questionnaire. *Child Development*, *72*(5), 1394–1408. http://doi.org/10.1111/1467-8624.00355

Rytting, M., & Choroszy, M. (2010) Acute Leukemia. In K. W. Chan, & R. Raney, Jr (Eds.) *Pediatric Oncology* (pp 1-15). Springer Science & Business Media.

Schwartz, R. M., Bruno, D. M., Augenbraun, M. A., Hogben, M., Joseph, M. A., Liddon, N., … Wilson, T. E. (2011). Perceived Financial Need and Sexual Risk Behavior Among Urban, Minority Patients Following Sexually Transmitted Infection Diagnosis: *Sexually Transmitted Diseases*, *38*(3), 230–234. http://doi.org/10.1097/OLQ.0b013e3181f41b81

Siegel, R. L., Miller, K. D., & Jemal, A. (2015). Cancer statistics, 2015. *CA: A Cancer Journal for Clinicians*, *65*(1), 5–29. http://doi.org/10.3322/caac.21254

Silovsky, J. F., Bard, D., Chaffin, M., Hecht, D., Burris, L., Owora, A., … Lutzker, J.

(2011). Prevention of child maltreatment in high-risk rural families: A randomized

clinical trial with child welfare outcomes. *Children and Youth Services Review*,

33(8), 1435–1444. http://doi.org/10.1016/j.childyouth.2011.04.023

Simonds, J., & Rothbart, M. K. (2004). The Temperament in Middle Childhood

Questionnaire (TMCQ): A computerized self-report instrument for ages 7–10. In

Poster Sess Present Occas Temperament Conf Athens, GA.

Slaughter-Acey, J. C., Caldwell, C. H., & Misra, D. P. (2013). The Influence of Personal

and Group Racism on Entry Into Prenatal Care Among-African American

Women. *Women's Health Issues*, *23*(6), e381–e387.

http://doi.org/10.1016/j.whi.2013.08.001

Sloper, P. (1996). Needs and responses of parents following the diagnosis of childhood

cancer. *Child: Care, Health and Development*, *22*(3), 187–202.

http://doi.org/10.1046/j.1365-2214.1996.788788.x

Smith, M. A., Seibel, N. L., Altekruse, S. F., Ries, L. A. G., Melbert, D. L., O'Leary, M.,

… Reaman, G. H. (2010). Outcomes for Children and Adolescents With Cancer:

Challenges for the Twenty-First Century. *Journal of Clinical Oncology*, *28*(15),

2625–2634. http://doi.org/10.1200/JCO.2009.27.0421

Smith, M., & Hare, M. L. (2004). An Overview of Progress in Childhood Cancer Survival.

Journal of Pediatric Oncology Nursing, *21*(3), 160–164.

http://doi.org/10.1177/1043454204264407

Spielberger, C.D. (1977). *State-Trait Anxiety Inventory for Adults.* Redwood, CA: Mind

Garden, Inc.

Streiner, D. L. (2003). Starting at the Beginning: An Introduction to Coefficient Alpha

and Internal Consistency. Journal of Personality Assessment, 80(1), 99–103.

http://doi.org/10.1207/S15327752JPA8001_18

Streisand, R., Kazak, A., & Tercyak, K. (2003). Pediatric-specific parenting stress and

family functioning in parents of children treated for cancer. *Children's Health

Care*, *32*(4), 245–256. Retrieved from

http://proxy.lib.wayne.edu/login?url=http://search.ebscohost.com/login.aspx?direc

t=true&db=ccm&AN=2004039471&site=ehost-live&scope=site

Sulkers, E., Tissing, W. J. E., Brinksma, A., Roodbol, P. F., Kamps, W. A., Stewart, R.

E., … Fleer, J. (2015). Providing care to a child with cancer: a longitudinal study

on the course, predictors, and impact of caregiving stress during the first year

after diagnosis. *Psycho-Oncology*, *24*(3), 318–324.

http://doi.org/10.1002/pon.3652

Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., &

Wang, M. (2005). Conceptualizing and measuring family quality of life. *Journal of

Intellectual Disability Research*, *49*(10), 777–783. http://doi.org/10.1111/j.1365-

2788.2005.00751.x

Syse, A., Loge, J. H., & Lyngstad, T. H. (2010). Does Childhood Cancer Affect Parental

Divorce Rates? A Population-Based Study. *Journal of Clinical Oncology*, *28*(5),

872–877. http://doi.org/10.1200/JCO.2009.24.0556

Tai, E., Buchanan, N., Townsend, J., Fairley, T., Moore, A., & Richardson, L. C. (2012).

Health status of adolescent and young adult cancer survivors. *Cancer*, *118*(19),

4884–4891. http://doi.org/10.1002/cncr.27445

Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International

Journal of Medical Education, *2*, 53–55. http://doi.org/10.5116/ijme.4dfb.8dfd

Tomlinson, D., Hinds, P. S., Ethier, M.-C., Ness, K. K., Zupanec, S., & Sung, L. (2013).

Psychometric Properties of Instruments Used to Measure Fatigue in Children and

Adolescents With Cancer: A Systematic Review. *Journal of Pain and Symptom*

Management, *45*(1), 83–91. http://doi.org/10.1016/j.jpainsymman.2012.02.010

Trask, P. C., Paterson, A. G., Trask, C. L., Bares, C. B., Birt, J., & Maan, C. (2003).

Parent and Adolescent Adjustment to Pediatric Cancer: Associations with

Coping, Social Support, and Family Function. *Journal of Pediatric Oncology*

Nursing, *20*(1), 36–47. http://doi.org/10.1053/jpon.2003.5

Trivette, C. M., Dunst, C. J., & Hamby, D. W. (2010). Influences of Family-Systems

Intervention Practices on Parent-Child Interactions and Child Development.

Topics in Early Childhood Special Education, *30*(1), 3–19.

http://doi.org/10.1177/0271121410364250

Tsimicalis, A., Stevens, B., Ungar, W. J., McKeever, P., & Greenberg, M. (2011). The

cost of childhood cancer from the family's perspective: A critical review. *Pediatric*

Blood & Cancer, *56*(5), 707–717. http://doi.org/10.1002/pbc.22685

Tyc, V. L., Mulhern, R. K., Barclay, D. R., Smith, B. F., & Bieberich, A. A. (1997).

Variables Assoicated with Anticiplatory Nausea and Vomiting in Pediatric Cancer

Patients Receiving Ondansetron Antiemetic Theraphy. *Journal of Pediatric*

Psychology, *22*(1), 45–58. http://doi.org/10.1093/jpepsy/22.1.45

Van Horn, M. L., Bellis, J. M., & Snyder, S. W. (2001). Family Resource Scale-Revised:

Psychometrics and Validation of a Measure of Family Resources in a Sample of

Low-Income Families. *Journal of Psychoeducational Assessment*, *19*(1), 54–68.

http://doi.org/10.1177/073428290101900104

Vannatta, K., & Gerhardt, C. A. (2003). Pediatric Oncology: Psychosocial Outcomes for

Children and Families. In *Handbook of pediatric psychology (3rd ed.)* (pp. 342–

357). New York, NY, US: Guilford Press.

Varni, J., Quiggins, D., & Ayala, G. (2000). Development of the Pediatric

Hematology/Oncology Parent Satisfaction Survey. *Children's Health Care*, *29*(4),

243–255. Retrieved from

http://proxy.lib.wayne.edu/login?url=http://search.ebscohost.com/login.aspx?direc

t=true&db=ccm&AN=2001023742&site=ehost-live&scope=site

Vrijmoet-Wiersma, C. M. J., Klink, J. M. M. van, Kolk, A. M., Koopman, H. M., Ball, L.

M., & Egeler, R. M. (2008). Assessment of Parental Psychological Stress in

Pediatric Cancer: A Review. *Journal of Pediatric Psychology*, *33*(7), 694–706.

Retrieved from http://jpepsy.oxfordjournals.org/content/33/7/694

Wakefield, C. E., McLoone, J. K., Butow, P., Lenthen, K., & Cohn, R. J. (2011). Parental

adjustment to the completion of their child's cancer treatment. *Pediatric Blood &*

Cancer, *56*(4), 524–531. http://doi.org/10.1002/pbc.22725

Ward, E., DeSantis, C., Robbins, A., Kohler, B., & Jemal, A. (2014). Childhood and

adolescent cancer statistics, 2014. *CA: A Cancer Journal for Clinicians*, *64*(2),

83–103. http://doi.org/10.3322/caac.21219

Warner, E. L., Kirchhoff, A. C., Nam, G. E., & Fluchel, M. (2014). Financial Burden of

Pediatric Cancer for Patients and Their Families. *Journal of Oncology Practice*,

JOP-2014.

Wdlff, J. A. (1991). History of Pediatric Oncology. *Pediatric Hematology-Oncology*, *8*(2),

89–91. http://doi.org/10.3109/08880019109033436

Weiss, D. S., & Marmar, C. R. (1997). The Impact of Event Scale—Revised.

Whittaker, J. E. V., Harden, B. J., See, H. M., Meisch, A. D., & Westbrook, T. R. (2011). Family risks and protective factors: Pathways to Early Head Start toddlers' social–emotional functioning. *Early Childhood Research Quarterly*, *26*(1), 74–86. http://doi.org/10.1016/j.ecresq.2010.04.007

Wiemels, J. (2012). Perspectives on the causes of childhood leukemia. *Chemico-Biological Interactions*, *196*(3), 59–67. http://doi.org/10.1016/j.cbi.2012.01.007

Williams, P. D., Williams, K. A., & Williams, A. R. (2013). Parental caregiving of children with cancer and family impact, economic burden: nursing perspectives. *Issues in Comprehensive Pediatric Nursing*, *37*(1), 39–60. http://doi.org/10.3109/01460862.2013.855843

Wong, D. L., & Baker, C. M. (1988). Pain in children: comparison of assessment scales. *Pediatr Nurs*, *14*(1), 9-17.

Wu, L.-M., Sheen, J.-M., Shu, H.-L., Chang, S.-C., & Hsiao, C.-C. (2013). Predictors of anxiety and resilience in adolescents undergoing cancer treatment. *Journal of Advanced Nursing*, *69*(1), 158–166. http://doi.org/10.1111/j.1365-2648.2012.06003.x

Zebrack, B. J., Gurney, J. G., Oeffinger, K., Whitton, J., Packer, R. J., Mertens, A., … Zeltzer, L. K. (2004). Psychological Outcomes in Long-Term Survivors of Childhood Brain Cancer: A Report From the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, *22*(6), 999–1006. http://doi.org/10.1200/JCO.2004.06.148

Zebrack, B. J., & Zeltzer, L. K. (2003). Quality of life issues and cancer survivorship.

Current Problems in Cancer, *27*(4), 198–211.

ABSTRACT

**EXAMINING THE PSYCHOMETRIC PROPERTIES OF THE
FAMILY RESOURCE SCALE-REVISED**

by

HEATHERLUN S. UPHOLD

May 2016

Advisor: Dr. Shlomo Sawilowsky

Major: Evaluation and Research

Degree: Doctor of Philosophy

Introduction: Over 10,000 children under the age of 15 will be diagnosed with cancer in the year 2015 (Siegel, 2015). The five year survival rate across all cancer types is roughly 80%, and there are over 330,000 survivors of pediatric cancers (Ward, 2014; Cure, 2014). Pediatric cancer poses psychological and physical stress to the child and the entire family (Compas, 2014). Several professional organizations have recommended that patients and their families be screened for psychosocial stress (AAP, 2012; Rosenberg, 2013). It is important to have accurate data collection tools. The purpose of this study was to examine the psychometric properties of the Family Resource Scale-revised in urban pediatric cancer populations.

Methods: Data from one hundred and forty four families from two urban pediatric cancer centers were examined. Descriptive statistics were computed for demographic variables and scale and subscale scores. Internal consistency of the scale was analyzed using Cronbach's alpha. Correlations were assessed between demographic variables, individual items from the scale, subscales, and total scale scores. Principal

Components Analysis was conducted to further examine the internal structure of the scale.

Results: The demographic variable of income positively correlated with the total scale score and the subscales of basic needs and money. Parent's level of education positively correlated with the subscale money. Cronbach's alpha was 0.927 for the entire scale, and Spearman-Brown Prophecy coefficients for all four subscales ranged from 0.944 to 0.981. Principal Components Analysis resulted in a three factor, 16 item model explaining 64.782% of the variance and a 17 item four factor model where 70.915% variance was explained. A 12 item, five factor model was also computed that explained 83.708% of the variance.

Conclusion: Significant relationships between scale and demographic variables note that the higher the level of household income the more adequate the families levels of money and coverage of basic needs. Also the higher the parent's level of education the more adequately they reported their levels of money to be. Cronbach's alpha and Spearman-Brown Prophecy coefficients emphasize the high level of internal consistency and reliabilities of the scale and its subscales. These results confirm that the *Family Resource Scale-revised* is a reasonably valid measure for estimating the level of resources families of children in treatment for pediatric cancer. Further examination of this scale with pediatric cancer populations in other geographical settings would be recommended. Also, having parents complete the scale at various times during diagnosis and treatment as well as during survivorship would be helpful information because of the possibility that levels of resources may change over time.

The relationships between the adequacy of resources and parent and child levels of

distress and anxiety should also be examined.

AUTOBIOGRAPHICAL STATEMENT

Heatherlun S. Uphold

Professional Preparation

B.S.	Business Administration	Ferris State University	2000
M.S.A.	Administration-Leadership	Central Michigan University	2001

Professional Appointments

2009-Present   Research Assistant, Wayne State University/Karmanos Cancer Institute

Publications

1. **Uphold, H.,** Foster, T., Peterson, A., Elliott, J., Hagiwara, N., Harper, F., Taub, J., Penner, L., & Albrecht, T. (2011). General anesthesia, or Conscious sedation: Better for the parent or better for the child. Annals of Behavioral Medicine, 40: s196.
2. Harper, F. W. K., *Peterson, A., **Uphold, H.,** Albrecht, T. L., Taub, J., & Penner, L. A. (2012). Longitudinal study of parent caregiver self-efficacy and parent stress reactions to pediatric cancer treatment procedures. Psycho-Oncology. doi: 10.1002/pon.3199
3. Harper, F.W.K., Peterson, A., **Uphold, H.,** Albrecht, T.L., Taub, J., & Penner, L.A. (2012). Longitudinal study of parent caregiver self-efficacy and parent stress reactions to pediatric cancer treatment procedures. Psycho-Oncology, doi 10.1002/pon.3199.
4. Harper, F. W., Peterson, A. M., **Uphold, H.,** Albrecht, T. L., Taub, J. W., Orom, H., ... & Penner, L. A. (2013). Longitudinal study of parent caregiving self-efficacy and parent stress reactions with pediatric cancer treatment procedures. *Psycho-Oncology*, 22(7), 1658-1664.
5. Harper, F. W. K., *Peterson, A., **Uphold, H**., Albrecht, T. L., Taub, J., Phipps, S., & Penner, L. A. (2013). Brief Report: Post-traumatic stress symptoms in parents of pediatric cancer patients: A mediational analysis. Health Psychology, under review.